

**INACCESSIBLE ACCESSIBILITY:
AN ETHNOGRAPHIC ACCOUNT OF DISABILITY AND GLOBALIZATION IN
CONTEMPORARY RUSSIA**

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A dissertation submitted to the faculty at the University of North Carolina at Chapel Hill in partial fulfillment of the requirements for the degree of Doctor of Philosophy in the Department of Anthropology.

**Chapel Hill
2015**

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ABSTRACT

Cassandra Hartblay: Inaccessible Accessibility:
An Ethnographic Account Of Disability And Globalization In Contemporary Russia
(Under the Direction of Michele Rivkin-Fish)

Based on over twelve months of fieldwork in Russia, this dissertation explores what an ethnographic approach offers disability studies as a global, interdisciplinary, justice-oriented field. Focused on the personal, embodied narratives and experiences of five adults with mobility impairments in the regional capital city of Petrozavodsk, the dissertation draws on methods including participant observation, ethnographic interviews, performance ethnography, and analysis of public documents and popular media to trace the ways in which the category of disability is reproduced, stigmatized, and made meaningful in a contemporary postsoviet urban context.

In tracing the ways in which concepts of *disability* and *accessibility* move transnational and transculturally as part of global expert cultures, I argue that Russian adults with disabilities expertly negotiate multiple modes of understanding disability, including historically and culturally rooted social stigma; psychosocial, therapeutic, or medicalized approaches; and democratic minority group citizenship. Considering the array of colloquial Russian terms that my interlocutors used to discuss issues of access and inaccess in informal settings, and their cultural antecedents, I suggest that the postsoviet infrastructural milieu is frequently posited as always opposed to development and European modernity. I draw on personal history narratives to relate how people with disabilities experienced the shifting discourses of human rights, democracy, and strategies of integration during the postsoviet transition of the 1990s through Putin's

reconsolidation in the 2010s. The final section of the dissertation relates how adults with mobility impairments who came of age during the postsoviet transition years enact Russian citizenship and assert social worth in the context of an art therapy group, through online social networks, and in kinship and gender relations.

This work contributes to cultural and medical anthropology, to the ethnography of postsocialism and NGO culture, and to the establishment of a robust anthropology of disability.

ACKNOWLEDGEMENTS

The research for this work was funded by a National Science Foundation Graduate Research Fellowship. I also received funding from the Program in Sexuality Studies at the University of North Carolina at Chapel Hill.

My stay in Petrozavodsk was facilitated through visa sponsorship for Youth Exchange through the Center for Initiatives, and for Cultural and Scientific Ties through the Karelian Center for Gender Research. I am grateful to Larissa Dmitrievna Boichenko of the Karelian Center for Gender Research and the Law School of Petrozavodsk State University for her unwavering support in securing my visa status and championing citizen exchange at a moment when our countries began to lean once again toward antagonism. I am also grateful to other scholars in the city of Petrozavodsk, especially Alexey Volkov and Vitaly Nilov. My ties to Petrozavodsk (as well as my Russian language skills) are entirely due to the enduring influence of Jude Wobst, who established and continues to support the exchange program between Amherst Regional High School in Massachusetts and School Number 17 in Petrozavodsk.

This project would not have been possible without the support of the Russian disability and gender studies community, including Svetlana Driakhlitsina Affolter, Marianna Muravyeva, Elena Iarskaia-Smirnova and the late Pavel Romanov. I especially am grateful to Valeriya Markina, whose own forthcoming ethnography on disability theater in Moscow I am eagerly anticipating, and who is one of the few people in the world with whom it is possible to have the conversation, “how should we translate ‘the politics of staring’ into Russian?” My research also included extensive participation in a social theater project not discussed in this work, for which I

am thankful to all of the members and supporters of the *Dobry Den' Theater*, especially Oleg Lipovetsky and Lidia Pobedinskaia.

I am grateful to the many professionals in Russian NGOs and government agencies who took the time to talk with me and either provide interviews or direct me toward further resources. Those colleagues at international non-profits who have taken an interest in elements of this project and supported me over the years deserve recognition. I am especially indebted to my colleagues at CEC ArtsLink and the Open World program, who brought me deeper into Russia, and to Kate Lapham at OSI, who took a chance on a young scholar. Ethnography is not possible without the participation of a great number of people, both those who participate formally, and those who buoyed me through my time in Russia with friendship and comradery. Thank you to those who participated in this research project. And thank you to my many friends in Petrozavodsk and across Russia. *Spasibo*.

Preliminary findings and components of this work were presented at several academic conferences and workshops, and I am grateful to co-panelists, discussants, and audience members in those settings for their helpful feedback. In this vein, I am especially glad to have found interlocutors in Anastasia Kayiatos, Stevie Peace Larson, Louise Hickman, Marina Bazelevych, Amanda Cachia, Sara Hendren, Aimi Hamraie, and the participants and organizers of the Crippling Development Conference in Prague in the fall of 2013, especially Katerina Kolarova, Robert McRuer, and Chris Chapman. You all changed me.

This work and project came into being thanks to the unwavering faith and support of my committee members at UNC-Chapel Hill Michele Rivkin-Fish, Jocelyn Lim Chua, Arturo Escobar, Sue Estroff, and the late William S. Lachicotte. I am also grateful to the members of the Moral Economies of Medicine working group, including Peter Redfield and Barry Saunders, and

the Social Movements working group, especially Michal Osterweil, Jean Dennison, and Dottie Holland. The performance ethnography crowd, including Marie Garlock, Renee Alexander Craft, and Joseph Megel have made elements of this work possible that could not have existed otherwise. My intellectual trajectory and sheer capacity to keep writing and “make it work” would not have been possible without friends and comrades, including Diana Gomez-Correal, Amelia Fiske, Sara Juengst, Mike Dimpfl, Adam Leeds, Lindsey Wallace, the 2013-2014 and 2014-2015 UNITAS community, and many more. And Katie Herzog: as the song goes, “stories don’t mean anything if you have no one to tell them to.” Thanks for being the one I gather stories for. Finally, embarking on this project and completing this dissertation would not have happened were it not for the support of my family: thank you.

TABLE OF CONTENTS

LIST OF TABLES, FIGURES, AND ILLUSTRATIONS.....	xiii
LIST OF ABBREVIATIONS.....	xv
LIST OF GEOGRAPHIC AND GEOPOLITICAL TERMS	xvi
A NOTE ON DISABILITY AND TERMINOLOGY	xix
A NOTE ON LANGUAGE AND RUSSIAN TRANSLATION AND TRANSLITERATION	xxi
PART I: DISABILITY AS A GLOBAL CATEGORY	1
CHAPTER I: INTRODUCTION	1
Situating this work.....	13
Major themes: Personhood and Citizenship, Infrastructure and Performance	16
Methodology	23
Arriving at a topic for Engaged Ethnography.....	26
Plan of the present work.....	40
CHAPTER II: TOWARD AN ANTHROPOLOGY OF DISABILITY IN AN AGE OF GLOBAL INTERCONNECTION.....	45
Cross-cultural approaches to disability.....	48
Disability as a conceptual category	49
Enacting Disability	53
Models of Disability in Euroamerican Disability Studies.....	56
Tracing disability stigma in Russia History	65

Talking about Disability in Russian	68
Conclusion	81
CHAPTER III: GLOBAL BODIES: DEFINITION & DEMOGRAPHY OF DISABILITY IN INTERNATIONAL CONTEXT	83
Demography of Disability: techniques of measurement.....	89
Defining Disability.....	93
Measuring Disability Rates in Russia.....	103
Finding Demographic Data about Russia.....	103
Working with Household Survey Data to arrive at Disability Prevalence Estimates for the Russian Federation	108
Writing Disability Rights	112
Defining Disability in Global Friction.....	116
Conclusion	121
PART II: Materializing <i>Invalidnost'</i>	124
CODA I: THE VALAAM MYTHOS	124
CHAPTER IV: PLACE, SPACE AND DISABILITY IN PETROZAVODSK	130
Petrozavodsk: Territory and Place	132
Postsoviet Karelian Imaginaries	143
Disabling Postsoviet Karelia.....	146
Locating Post-Soviet Public Space.....	147
CHAPTER V: "LIFE IN FOUR WALLS": POST-SOVIET APARTMENT COMPLEXES AS MATERIAL AND SOCIAL BARRIERS	150
Home Alone.....	155
The Cultural History of the Soviet Apartment Building.....	158

Strategies for Obtaining Living Quarters	167
Inaccessible Ins and Outs.....	173
Safe Spaces: Four walls as comfort.....	177
CHAPTER VI: "IT'S JUST FOR THE CHECK MARK": MINIMUM REQUIREMENTS, GLOBAL FRICTION, AND INACCESSIBLE ACCESSIBILITY RAMPS.....	
Access in the Russian Built Environment	187
A Sociocultural Approach to Disability	188
The Physics of Friction: The Ramp in global motion	189
Checklists as smooth passage	192
Friction in Function and Form.....	194
Friction Two: minimum requirements and the logic of checklists	198
"Lots of lists - really a lot!": Building professionalism	201
Conclusion: the ramp as modernity	206
CHAPTER VII: <i>KAKAIA VLAST', TAKIE I DOROGI</i>: RUSSIAN TALK AND TERRITORIES OF IN/ACCESS.....	
Locating <i>Accessible Public Space</i> in Global Discourse	216
The origins of <i>access</i> as a disability justice concept.....	217
Pothole Talk: Infrastructures of In/access for nondisabled residents of Petrozavodsk	222
Talk, Complaint, and the Russian Nation	225
Infrastructure and Governance	229
Infrastructure, Access, and Transnational Development.....	232
Talking about Access.....	234
Access and Infrastructure.....	240

Part III: Performing <i>Invalidnost'</i>	247
CHAPTER VIII: "WE HAVE ALWAYS BEEN GUINEA PIGS": BECOMING <i>INVALIDI</i> IN POSTSOVIET PETROZAVODSK.....	247
Act One	247
Act Two: Guinea Pigs.....	251
Act Three: The organizational infrastructure	257
Conclusion	262
CHAPTER IX: "TOO MUCH PUSHKIN, AND NOT ENOUGH OF US": THE AUTUMN CONCERT, OR, PERFORMING DISABLED CITIZENSHIP	266
The Autumn Concert.....	267
Pushkin in Russian Culture	270
Pushkin and <i>kulturnost'</i>	274
Therapy and the Good Citizen.....	281
The Capable Independence/Minority-in-Democracy Model.....	289
Rehearsal: Cultivating Moral Personhood.....	293
Performing Disabled Citizenship.....	305
Conclusion	311
CHAPTER X: SERGEICHBURG: IDENTITY AND MEDIA REPRESENTATIONS OFDISABILITY	314
Publics, Strangers, and the Comedy of Recognition	319
Crip Masculinity: From Social Problem to Therapeutic Citizen	326
Conclusion	329
CHAPTER XI: "I TURN ON MY COMPUTER AND THE DAY BEGINS": CRIP TIME, VIRTUAL SOCIALITY, AND PIXELIZATION ON RUNET	333
"I turn on the computer and the day begins"	334

Digital Performance.....	337
RuNet.....	341
Networked Publics.....	343
Digital access: mobility as an object of desire.....	344
Talking Through Walls: Digital Space.....	346
Online All of the Time.....	350
Disability, Digital Mobility and Isolation.....	356
Pixelization/Conclusion.....	357
CHAPTER XII: CRIP ENGAGEMENTS?: INTERDEPENDENCE, KINSHIP AND SEXUALITY.....	358
Crip Futurity: Kinship, Disability, Feminist and Sexuality Studies.....	362
Russian Kinship Patterns: Obfuscated matrilocality.....	364
Kinship and In(ter)dependence.....	366
Tracing Disability & Kinship Relations: Family, Residence, and Future in Petrozavodsk.....	368
Conclusion.....	379
CODA II: <i>KHEPPI ENDINKS</i> AND OTHER FUTURES.....	381
CHAPTER XIII: CONCLUSION: ENACTING <i>INVALIDNOST</i> , DISABILITY THROUGH GLOBAL CONNECTIONS, AND THE COMMODIFICATION OF ACCESS.....	383
APPENDIX 1: DESCRIPTION OF RESEARCH.....	389
APPENDIX 2: A NOTE ON COMPLIMENTARY TEXTS & MEDIA.....	390
WORKS CITED.....	392

LIST OF TABLES, FIGURES, AND ILLUSTRATIONS

Figure 1: Map of Russia with Petrozavodsk Marked	xxii
Figure 2: A Russian Lexicon for Talking about Disability	78
Figure 3: Global Disability Prevalence Rates.....	95
Figure 4: Variation in estimates of Disability in Canada	99
Figure 5: Survey Instruments to Measure Self-Reported Disability and Impairment	100
Figure 6: Sample questions to elicit prevalence of disability according to a functional model.....	102
Figure 7: Photo: Household Survey Data Processing	108
Figure 8: Excerpt from the RMLS Adult Questionnaire.....	110
Figure 9: Table: Estimates of rates of disability in Russia.....	113
Figure 10: Map of Russia's Climactic Zones	133
Figure 11: Map of the Natural Resources of Russia.....	133
Figure 12: Map of Ethnic Groups of the USSR.....	134
Figure 13: Map of Karelian Border Region	136
Figure 14: Graphic: Shifting Borders of Finland.....	137
Figure 15: Photo: Petrozavodsk Train Station.....	140
Figure 16: Photo: Petrozavodsk neighborhoods	140
Figure 17: Photo: View of Petrozavodsk from across the Lake	141
Figure 18: Film Still: Images of replicating Soviet Apartment Buildings.....	160
Figure 19: Film Still: Opening Sequence from The Irony of Fate.....	161
Figure 20: Photo: Exterior view of typical housing in the Drevlyanka region of Petrozavodsk.....	164

Figure 21: Photo: A typical apartment building staircase in Petrozavodsk	174
Figure 22: Photo: A typical entrance doorway in the Drevlyanka region of Petrozavodsk.....	176
Figure 23: Meme Analytics.....	181
Figure 24: Photo: Neighborhod Ramp in Petrozavodsk	185
Figure 25: Photo:“Don't Park here, 8am-8pm!”\	200
Figure 26: Dictionary definitions of the word accessible in English.....	211
Figure 27: Table: Russian Words for Access	237
Figure 28: Table: Theoretical and Colloquial notions of Access	239
Figure 29: Photo of Nevskii Prospekt in Petrozavodsk	244
Figure 30: Photo of Petrozavodsk neighborhood roadways	244
Figure 31: Photo: Pothole in Central Petrozavodsk.....	245
Figure 32: Photo of a driveway in springtime, speckled with potholes	245
Figure 33: Photo of a snow-covered ramp.....	246
Figure 34: Photo of Alina at the computer	347

LIST OF ABBREVIATIONS

- ADL** Activities of Daily Living (an abbreviation used in US disability adjudication, e.g. whether or not an impairment results in limited functioning in ADL can be a factor in determining disability status for Social Security purposes; the term is also used in international disability definitions)
- CP** Cerebral Palsy; used occasionally in rotation with the roughly equivalent Russian diagnosis, DTsP, *detskii tserebralnyi paralich*.
- HRW** Human Rights Watch
- ICF** International Classification of Functioning (the most widely cited system of defining and/or determining disability status that has been proposed for international use; like the DSM, now in several forms)
- IMF** International Monetary Fund
- PWD** People with Disabilities (as a category used in public health and int'l aid contexts)
- RF** The Russian Federation, 1991-present. Currently the world's largest nation state by land area. Rooted in a national mythology of ancient Russian ethnic heritage stretching back to early medieval Kievan Rus'.
- RSSR** Russian Soviet Socialist Republic; territorial/ethnic corollary to the present day Russian Federation during the Soviet era
- TBI** Traumatic Brain Injury
- UN** United Nations
- US** The United States, or, of or pertaining to policies and social dynamics of The United States of America
- USSR** Union of Soviet Socialist Republics (The Soviet Union); Following the 1917 Revolution, officially recognized globally from 1922-1991. The region of Russian Karelia, with varying borders and under shifting administrative designations, was a part of the USSR from its inception.

LIST OF GEOGRAPHIC AND GEOPOLITICAL TERMS

- Eurasia** The world's largest landmass, Eurasia encompasses Western Europe, Northern Europe, Russia, Central Asia, China and Mongolia, and Southeast Asia. The Russian Federation is the political unit occupying the largest territory. The history of Eurocentrism holds a strange sway over Russia, which tends to identify as part of Europe, even as it is orientalized by Westerners as mysterious and impenetrable.
- Helsinki** The capital of Finland. A historic city surrounded by water on the southern shore of the Finnish peninsula. An eight-to-ten hour drive by car or shuttle bus from Petrozavodsk.
- Karelia, or, The Karelian Republic** An administrative unit of the Russian Federation similar to a state in the US federal system. However, in the political system of the RF, a republic, unlike an Oblast', has certain unique properties based in a history of being recognized as a territory belonging to a particular ethnic group, in this case, the Karelians, a people historically and linguistically linked to eastern Finns. Today, the population of the Karelian Republic is ethnically majority Russian, mainly due to centrally orchestrated migration during the Soviet era. Today, Russian is the main language of public life in the region, and thanks to the systematic assertion of the Russian language over the Karelian language in education and commerce throughout the Soviet era, very few families continue speak Karelian at home. Aside from folk songs sung on holidays or at festivals, it is very rare to hear Karelian in the city (although one might hear tourists speaking Finnish or migrant workers speaking Uzbek or Kyrgyz). Southern Karelia is also home to an indigenous group known as the Veps people. Borders Finland to the West, Murmansk Oblast' to the North; the White Sea and Arkhangelsk Oblast' to the east; and Vologda Oblast' and Leningrad Oblast' to the south.
- Moscow** The capital of the Russian Federation and the seat of the federal government. The largest city in Russia and a center of global commerce. Russia's main diplomatic center and the main point of international air traffic into and out of Russia.
- North America** Here I mean the US and Canada (although Mexico is sometimes included in this group, by invoking North America in places in this dissertation, I mean to reference specifically Anglophone states of the global North)
- Petrozavodsk** The capital city of the Karelian Republic.
- The Post-Soviet Period and postsoviet society** As an abstract phrase, this refers to the social, cultural, and political configuration of daily life in the two decades immediately following the collapse of the Soviet Union, e.g. 1991 roughly to 2008. As of the writing of this dissertation in 2014, journalists, scholars, and analysts in business and government generally agree that a new era of US-Russia relations, and a new stage of Russian social realities, have begun. I identify 2008

as the end of the Post-Soviet Period, and the start of a new period of Russian history. "The New Russia" or "Putin's New Russia" has often been used to refer to the subsequent years since 2008, but terminology continues to evolve, and in many cases, including in this dissertation, "post-Soviet" is intended to mean, "anything that happened after the dissolution of the Soviet Union in 1991." In critical scholarship, postsoviet or postsocialist is sometimes used as a single word, to denote not a period of time, but a cultural configuration, following similar moves amongst postcolonial scholars (e.g. Chari and Verdery 2008). Nancy Fraser (1997) has argued that with the collapse of the Soviet Union, so too collapse a global left that considered communism and socialism as a viable political solution; she characterizes this post-1991 horizon of political imaginary as a global postsocialism. As such, I have used post-Soviet when I intend to refer to a period of political history, and postsoviet when I intend to refer to a cultural configuration.

The Russian Federation, or, Russia A political state stretching from Kamchatka and shared seas with Japan in the East, to the North Sea, sharing borders with China, Mongolia, and Kazakhstan to the South, and Central European and Baltic States to the East. The Russian Federation is a Constitutional Democracy. However, since the current Constitution was adopted in 1993, under Putin, systems of regional rule have shifted from electoral selection of regional administration to federal appointment. Vladimir Putin served as President for two terms 2000-2008, then as Prime Minister during the presidency of Dmitry Medvedev (the candidate of Putin's party, United Russia) 2008-2012, and again from 2012 to the present. In the spring of 2014, the Russian Federation annexed Crimea, a region of Ukraine, an country that was also a former Soviet Republic. At the time of this writing, militarized warfare over Donetsk and Luhansk provinces of Ukraine was ongoing (see [BBC Ukraine Crisis in Maps](#) for an overview).

Saint Petersburg One of the historic capitals of the Russian Empire and the site of the Russian Revolution, still considered to be a capital of cultural life. Formerly known as Leningrad and Petrograd. Six hours from Petrozavodsk by train, slightly less by car.

Sortavala A small city on the Russian side of the Karelian Russian-Finnish border. Known to residents of Petrozavodsk as the seat of various grey and black market exchanges and social distress related to its status as a border town.

Soviet Society As an abstract phrase, this refers to the social, cultural, and political configuration of daily life during the Soviet Union, e.g. after the establishment of the Soviet Union (1917) and prior to the collapse of the USSR (1991).

The Soviet Union, or, the USSR The Union of Soviet Socialist Republics, a major political unit following the Russian Revolution of 1917 and the establishment of the Soviet Union, comprised of Russia as well as numerous other socialist republics in Eurasia, 1922-1991. Established as a socialist regime, the intention of the

revolutionary founders was to work to build a system democratic communism, in which the state would eventually fade away, capitalism would be overthrown, and a worldwide workers union would prevail. State violence, brutal political repression, and chronic shortages of foodstuffs and consumer goods have come to characterize the memory of the USSR. During the second half of the twentieth century, following World War II, the Cold War stand-off pitted the USSR as the political enemy of the United States, not only in the nuclear arms race, but in terms of ideological systems and the capacity of a state to provision its people. The end of the Soviet Union, came abruptly for Russian citizens and was marked by hardship and a period of uncertainty.

A NOTE ON DISABILITY AND TERMINOLOGY

In this dissertation I have employed several conventions of disability studies in discussing and describing embodiment. As in any field, especially those concerned with a liberatory consciousness, the question of language is both paramount and hotly debated.

Wherever possible, I have used the unmarked category, nondisabled, to designate normative embodiments. This serves as a way of decentering a status quo in which disability is always a deviant or marked identity. Just as critical race theory describes whiteness, gender studies describes masculinity, and queer theory observes the habits and assumptions of a straight majority, disability studies seeks to define and interrogate the boundaries and stability of the category of able-bodiedness or nondisabled identity. By understanding the dominant group as equally socially and culturally constructed as the oppressed group, this move to name the unmarked category is an important political and theoretical move. In disability studies, some scholars call this group "able-bodied" while others, seeking to center disability experience, call it "nondisabled." I use both phrases at different points in the manuscript.

As with other identity-based critical theory, disability studies names the system of oppression that works to maintain a status quo in which people with disabilities are reproduced as an oppressed and stigmatized minority group. *Ableism* describes the complex social and cultural system that works at interpersonal, institutional, and cultural-political levels of society to discriminate against people with disabilities, and deny access to resources and prevent full social participation solely on the perceived or purported membership in the group that is called or defined as "disabled". I refer to ableism in this text sometimes as a universal system. However, as with sexism, racism, and heterosexism, a global approach to ableism requires a recognition that different cultural and historical contexts produce and reproduce distinct patterns or systems of ableism, that is, a global disability studies investigates and compares *ableisms*. This dissertation can only claim to describe the specific ableism at work in Petrozavodsk in 2012-2013.

Scholars of Disability Studies have, over the past twenty years, suggested and named a variety of models of disability. A key concept that all readers should be aware of is the way that disability studies distinguishes between *disability* and *impairment*. According to the *social model* of disability, impairment describes a particular body and its capabilities, especially a diagnosis or biological state; disability describes a socially and culturally stigmatized perception of an impairment (e.g. Linton 1998). As with the sex/gender distinction in gender studies, scholars disagree about this model. In particular, there is debate about the degree to which impairment can ever exist outside of culture, or whether there are some impairments that regardless of accommodations and social mores, will always be disabling. The *environmental model* of disability assumes that a social model must consider the surrounding inanimate world, as well as social and cultural factors, to understand the degree to which someone's impairment might be disabling (e.g. Shakespeare 2006); this is the predominant model in use in transnational disability rights (e.g. Mont 2007). A further mode of conceptualizing disability as *relational* or *transactional* observes that circumstances, culture, human interactions, and environments are never static but changing, fluid, and in motion, and then for disability depends on a body's occupation and physical and social positioning at a given moment in relation to other people and

the environment; *relational* is currently used in critical humanities and social sciences (e.g. Kafer 2013:6), while a *transactional approach* is a current in critical applied fields such as occupational science and education (e.g. Cutchin and Dickie 2013:98).

There is also an ongoing disagreement in disability studies regarding preferences for people-first language (e.g. person with a disability, person living with autism) or descriptive adjectives (e.g. disabled person, autistic person). This debate is partially a disagreement between British and American disability activism, in which Americans tend to prefer people first language, and Brits tend to prefer a short descriptor (Phillips 2011); however the neurodiversity movement in the US, as well as *crip sensibilities*, have in recent years asserted a preference for descriptive adjectives in American English as well. I personally do not come down on either side of this question, and I have used both types of language. This is partly a reflection of the diversity of Russophone terms that I am representing, and partly a desire for a varied vocabulary in a long document. I hope colleagues and activists will perceive my intention to dismantle ableism. Similarly, I have done my best to avoid ableist language ("blind to the problem," "crippled with doubt," etc), or language that assumes limitations/suffering rather than capabilities (e.g. I write "wheelchair-user" rather than "confined to a wheelchair").

When it comes to diagnostic terminology related to disability, I have frequently used Anglophone words to discuss specific impairments or conditions. However, as is the convention of medical anthropology, I do not assume that the semantic locations of various diagnostic translations are equivalent in English and Russian. For that reason, where applicable, I have included the Russian phrase in question in parentheses or a footnote. Because a great deal of this work concerns the semantic notion of what constitutes disability, or *invalidnost'* in Russian, I have frequently used the Russian word *invalidnost'* rather than *disability* when I am describing specific situations and discursive events on the ground in Russia. Alternatively, because the lexicon of disability in Russian is rich and varied (as I discuss in Chapter IV), and people frequently refer to a concept of disability or impairment using some other phrase, when quoting one of my Russian interlocutors, I have usually included the exact term they used in transliterated Russian in brackets. For example, "... person with disabilities [*chelovek s invalidnostu*]..." You will see as you read this work that a wide variety of phrases are used.

A NOTE ON LANGUAGE AND RUSSIAN TRANSLATION AND TRANSLITERATION

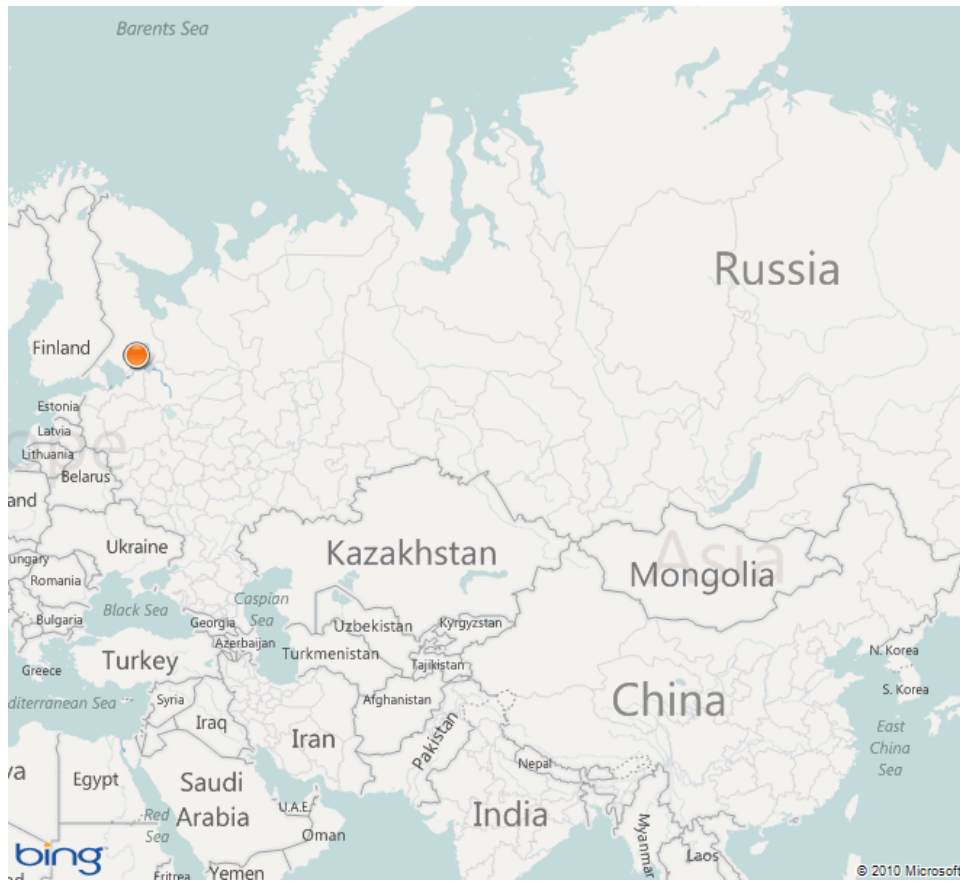
Although I am not a native speaker of Russian, I have received an unusual amount of Russian language instruction for an American of my generation. I began to study Russian in a high school Russian program in the ninth grade. I first travelled to Russia on a month-long high school exchange program in 2002; therefore, by the time I began fieldwork, I had been studying Russian for over ten years. I had placed as an advanced speaker by my first year in College in the US, and continued my immersion as a study abroad student in Russia. I subsequently continued to develop my Russian skills in a professional capacity as a program coordinator and Russian-to-English translator working for the Open World cultural exchange program with CEC ArtsLink (a role which also immersed me in contemporary Russian culture, hosting and presenting the work of Russian writers and cultural figures including Zakhar Prilepin and Elena Fanailova in New York City from 2007-2009). I am fluent in conversational Russian, although I speak with an accent and the grammatical and lexical oddities of a non-native speaker; however, most Russians could not tell based on my accent alone what my native language might be (guesses included German, Polish, and Latvian as well as English).

Given this level of fluency, I was able to participate fully in social exchange, understand and respond, ask questions, and be understood without a translator, interpreter, or research assistant, though I would occasionally consult friends for proofreading purposes when preparing a document in Russian (usually the type of documents, such as CVs or official letters, that would warrant a friend's proofreading in English as well). I was also able to conduct independent in-depth fieldwork immediately upon arriving in the field, whereas many anthropology PhD students spend the first months of their fieldwork mastering the language. That said, I am not a linguist or a slavist by training, and I do not claim to have the command of Russian that some of my more literary and linguistically-oriented colleagues have in terms of nuance and tone, particularly in my ability to perfectly replicate the variety of native Russian registers of speech, especially in translation from English to Russian. However, I am quite comfortable operating in Russian and I am quite adept at translating Russian into English (a process that, especially in writing, I enjoy).

All translations from the Russian are my own.

When using Russian words in transliteration I have followed the Library of Congress system for latinization of the Cyrillic alphabet, sans diacritics. In certain cases, as is customary, I have used conventional or accepted Americanizations of Russian proper nouns which may not adhere to this system (e.g. *Anya*, rather than *Ania*).

Figure 1: Map of Russia with Petrozavodsk Marked



**PART I
DISABILITY AS A GLOBAL CATEGORY**

**CHAPTER I
INTRODUCTION**

“Ability and disability are not so much a matter of the capacities and limitations of bodies as about what we expect from a body at a particular moment and place”

– Rosemarie Garland-Thompson (2005: 83)

“The creation of conceptual boundaries between civil society, the state, and the market–enacted in legal and administrative practices – permits the democratic claim of universal inclusion in public activity, especially in politics, while accomplishing the exclusion of various categories of person.”

– Susan Gal (1997:34)

The building was somewhere over near the bus station, I saw on my Yandex Navigator app. A social worker I met had invited me to come and meet some of the adults with disabilities in the community; she was facilitating an art therapy program that afternoon. She knew that I wanted to invite new people to participate in my ethnographic project. She also thought that this group would be entertained to meet an American who spoke Russian, as she was herself.

How did anyone ever do ethnography before iPhones?, I wondered, as I trudged across the bridge over the railroad, and down the makeshift path to the bus station, past the old woman, bundled in layers and layers of clothes, who was always asking for change in that spot. If you pressed a few coins in her hand, she would give you a blessing, calling after you as you walked on in a deep, throaty, and surprisingly heart-felt voice. There was a light snow falling, and a light dusting was beginning to accumulate, although it was still early fall. Snowflakes gathered on the top of my hat and the shoulders of my wool coat. Fighting a cold, I slurped a cough drop and tightened my scarf as I made my way downhill.

In the bus station yard, diesel exhaust billowing and 1980s-issue buses lined up at their gates, I could see that the building I was supposed to go to was just beyond the rear fence, a large brick multiuse building with a Sberbank sign on the side. Cutting through the central terminal, past merchants selling tchotchkes and people smoking next to duffel bags and plaid plastic totes, I walked to that end of the bus yard, only to find that exit on that side was blocked by a chain link fence. I had to circle back to the main entrance and exit onto Chapaev street, and loop around. Worried now that I would be late, I hurried past teenagers and unemployed men clustered at the *mashrutka* stop, careful not to slip on the thin layer of snow on asphalt.

I was anxious about making a good impression on a group of people that I hoped to get to know. Somehow this anxiety manifested into a sense of urgency and incompetence. I managed to walk in circles around the building several times, not knowing which entrance to use, before phoning the group's facilitator, and asking her where to go. She told me which entrance to use, and came down to meet me at the door. Climbing the stairs, speckled linoleum underfoot, she said that my timing was good, they had just finished one segment of the afternoon's activities, and there would be time to introduce me before the photography lesson began.

The meeting was in a photography studio, which the owner had donated to the group for the afternoon, along with a pro bono lesson. Ordinarily, the studio, shared by two professional photographers, offered private lessons to teenagers and adults in the area, as well as a space for the photographers to do their portrait work. It was a fairly small room, but with high ceilings, and the shades were drawn on the windows that lined one wall. When I entered, a group of people was seated in a semi-circle facing a still life tableau with various lighting and photographic equipment aimed at it, but spotlights were out, and the room was lit by overhead fluorescents reminiscent of a public school building. The group was composed of people who all looked to be

about my age. One woman with dark hair sat in a wheelchair, on the edge of the semi-circle closest to the door, and the rest were perched on an assortment of folding chairs and stools. There didn't seem to be much talking going on - more like waiting.

"You guys," the facilitator announced, speaking in Russian, using an announcement voice, "this is Kah-sahn-DRAH. She is *American*. She will join our group today. Please, introduce yourselves."

"Sveta."

"Max."

A shy, larger woman with dyed red hair whispered, "Sasha."

A man with a boyish face and neatly combed blond hair grinned. It was his turn, but he didn't want to talk. A silver point-and-shoot camera was on a strap around his neck, and he held it in one hand, poised to click.

"That's Vakas," said the facilitator, matter-of-factly. "Volodya, why don't you say your name!?"

"Hello." Said Volodya-Vakas, mischievously mimicking the social worker's matter-of-fact tone.

"Sergei?" asked the facilitator, looking at the next person in the misshapen semi-circle.

"I'm Sergei!" He announced, redundantly, holding up his hands and shrugging his shoulders.

"Alina," said the woman in the wheelchair, looking me in the eye.

"Today we're going to take a photography lesson," the facilitator explained to me. "We're just waiting for the photographer to come. Vakas likes photography, right, Vakas?" she asked.

Vakas grinned and snapped a photo, his lens aimed in our direction.

"And poetry. Vakas has also written a book of poetry."

She looked at him. Vakas looked at me and nodded.

"I like poetry," I said.

Sasha nodded good-naturedly. Max and Sveta looked bored. Alina was watching me with interest.

"And Sergei is a very good musician and singer," the facilitator said, gesturing to Sergei. Sergei looked embarrassed, but pleased, and blushed a little.

"I also like to sing," announced Alina.

I blinked, not sure what to do. I felt my cough coming on, and reached into my pocket for a cough drop.

"Take your coat off, get comfortable!" said Alina. A fuss ensued while another chair was produced. I took the pause to pop the cough drop into my mouth. I took a swig of water from the small water bottle I had in my bag, and hoped that I wouldn't have a coughing fit.

The chair landed in front of me, and I was instructed to put my coat on it and sit down. I did so, hanging my shoulder bag over the back as well.

"So, Cassandra, tell us about yourself," instructed the facilitator.

"Yes, tell us," said Alina.

I took a deep breath. I began to explain that I was from a university in a state called North Carolina, that I had studied Russian since I was in high school, that I was interested in writing a book about -- and here the tickle in my throat intensified, and tears sprung to my eyes -- people with disabilities in Petrozavodsk. I swallowed. They were still listening and waiting.

"I'd really like to ask all of you," I continued, "if any of you would like to participate in my project. I'd like to get to know, and to conduct some interviews about your lives --" I managed. And then I began to cough.

And I kept coughing.

And coughing. And my eyes were watering, they felt like they were bulging out, and I just couldn't stop. It was the deep, dry kind of cough, coming from far down in my aggrieved bronchi. I blinked and tried to swallow, and there were more coughs coming. I was mortified that the whole group had to watch me in such a state of utter collapse, of inability to take command over my body. But there was nothing that I could do. I kept coughing, trying not to spit the coughdrop out and send it flying across the room.

"Excuse me, I can't stop coughing - I've been sick!" I said, grabbing my shoulder bag and heading into the hall through the studio's open door.

After another thirty seconds of noisy and painful aggression, the cough subsided, and I sipped some water. They could all hear me coughing. I took a tissue from my bag, and blotted my eyes. I took a few deep breaths. Another mini cough welled up, and I briefly indulged it, before taking another swig of water, regaining control, and returning to the room.

"I'm sorry, please excuse me," I said, "I'm a little sick. I didn't know a person could cough so much."

"It's okay," Alina said, earnestly. "People cough."

I looked at her, and saw that she meant it. People *do* cough, I thought. Sometimes our bodies take over, and participating in social life means going along anyway, vulnerabilities, peccadillos, and all.

In a way, it was fitting that this was my first introduction to the group of adults with disabilities who would become some of my closest collaborators in the coming months. After all, I had come to Petrozavodsk to think about disability, about what happens to people when their bodies don't fit into a situation or into broad social expectations. Of course, there are people whose bodies don't "fit" in any location. So why did I chose Petrozavodsk?

I had become curious about Russian and post-Soviet understandings of disability. According to disability theorists, disability, like gender or race, is a culturally constructed category that depends on social, political, medical, and legal norms to make sense. If this was the case, then disability, or at least experiences of disability would be different across cultural settings. In writing about the oppression and discrimination against people with disabilities in contemporary society, disability studies scholars often point to capitalism as a core cause or root problem that leads to the devaluing of people with disabilities. Yet, people with disabilities were also oppressed - frequently incarcerated in institutions or hidden from public view by family members - in conditions of socialism as they existed in the Soviet Union (Phillips 2009). So in this sense, the political configuration of disability stigma produced in Soviet socialism might be different from that in capitalism. And the changing cultural circumstances of in Russia since the collapse of the Soviet Union has led to changes in daily life; yet disability stigma continues to exist. What does it mean to have a disability in postsoviet Russia?

A few of the characters from this group of adults with disabilities would later become the core of my ethnographic study. Alina, Sergei, and Vakas - more than anyone else in Petrozavodsk, opened up their life stories to me, often amused and bemused by my foreign attitudes and mannerisms, but interested in the novelty of having an American of their own over

for tea, and invested in the project of telling the story of coming of age with a disability in Petrozavodsk.

I don't know if my vulnerability in that moment of introduction had anything at all to do with this troika's decision to trust me. In fact, they were quite used to strangers - foreigners and locals alike, mostly nondisabled - appearing out of nowhere and proposing "collaborative" projects. So in a way, my announcement that I was interested in writing a book with and about them was part of a long chain of well-intentioned outsiders showing up with the intention of doing something "for" or "with" young people with disabilities.

Alina, Vakas, and Sergei - along with a few other characters who will appear later on - all grew up in the city of Petrozavodsk during the 1980s and 1990s, and came into adulthood in the early 2000s. From the outside, in international discourse, the 1990s are commonly thought of as the "transition" years, the time when the Russian Federation, following the collapse of the Soviet Union in 1991, was the object of immense economic, political, and social upheaval, as the economy shifted from a centrally planned system in which all goods and services were provisioned by the state, to a market capitalism model, in which the state was still responsible for some social benefits and entitlements, but commerce depended on business and entrepreneurship. According to the ideological orientation of the time, international organizations - from aid agencies sponsored by foreign governments (like USAid and its equivalent organizations from Finland, Sweden, Germany, and Switzerland) to non-governmental organizations (like the Soros Foundation and ACTE) set out to promote cross-cultural exchange and facilitate democratization by fostering civil society in the many small cities across Russia's vast territory. According to the logic of liberal democracy, in order for the new economic system

to fully succeed, a new civil sphere would need to emerge that would offer a basis from which entrepreneurship and commerce could emerge.

In this schema, the Russian third sector, or non-profit, non-governmental organizations - those "voluntary associations" that support social interests and are said to make up the stuff of a civil society - were there target of a great deal of foreign aid.

Just as organizations proposing projects to fund support of the homeless (Hojestrand), of the elderly (Caldwell), of women's organization (Hemment), so too parents of children with disabilities, and other organizations supporting the needs of people with disabilities found foreign funders and organizations eager to provide support and models for intervention. As was the case with women's organizations, this new arena of potential paychecks and resources became an important organizing factor in the professional lives of the generation of Russians who were already adults in the 1990s. This was an era when the basic supports of the Russian state receded: salaries for state employees were often backlogged for months at a time, state-run social services ceased to function in the absence of funding. Getting by meant finding other sources of income, tracing new routes of professionalization as non-profit workers (Hemment; Phillips). However, this shift towards foreign funding did not mean that the generation who were adults in the 1990s - roughly speaking the parent generation of the group at the center of this study - left behind the Russian state as a potential provider of resources. Rather, the state came to be seen as variable and unreliable, subpar in functional capacity to foreign governments in Europe and the US, but in some ways more stable than foreign funders. If a foreign organization would fund projects that kept an organization afloat for three or five or even ten years, the best chance that that organization had for longterm survival was still to seek affiliation with the Russian government.

Or, as Meri Kulmala has shown in her study of non-profit organizations in the neighboring Karelian city of Sortavala, the savviest mode of negotiating this shifting landscape was to keep one foot in Russian state funding and one foot in independent non-profits. The normative model of State/Civic/Private spheres is a manner of understanding the source of funding, and the character of and relative attributes, strengths, and weaknesses of a given opportunity, but to an organizers trying to create resources for herself, her family, and community members with shared interests, this heuristic was besides the point. Organizations frequently sought funding from both foreign and domestic state sources, and professionals often wore multiple hats, working during business hours for a state institution - an afterschool cultural program, for instance - and on weekends and in the summer as an organizers for a small non-profit.

In this climate, a network of small non-profit organizations serving children with disabilities and their families emerged during the 1990s as a way for parents to cope with the responsibilities of raising children with medical and social needs that surpassed those of their peers. What started out as a one-room organization for parents in the early 1990s later became a resource center and lobbying network; some parents branched off to form a research organization that conducted academic policy studies on the needs of children with disabilities and their families; another became a social and occupational therapy driven weekend meeting site. Some parents, fed up with the constant politicking that was required to maintain the collaborative ties and variable donors necessary to keep such organizations running withdrew from the scene, preferring to make do on their own. Some made their own living in this way for a time, then stepped back after funding setbacks or disagreements with co-organizer peers. A few eventually leveraged the expertise they had developed over the years of working with foreign funders and

supporters into professional roles in a reconsolidating state system of social services that was beginning to emerge from about 2008 and onward.

For the children growing up and coming of age in this environment, this meant that new projects and opportunities to engage with new people and new methodologies might pop up at any time. By the time I showed up at the meeting of the art therapy group in 2012, Sergei, Alina, and Vakas had already participated in a wide variety of "projects" [*proekti*]. As age mates who were often included in a social grouping in terms of the character of their disabilities - significant physical impairments and high intelligence. At the same time that they recognized one another as part of a shared cohort, they were not close friends, per se. Outside of projects, they rarely sought out one another's company, or even spent much time talking with one another online. Yet they were a cohort in the sense that they had a long history of shared experiences and some shared interests, particularly projects having to do with arts and culture. Over the course of the time that I spent with them and the other members of the art therapy group, this troika tended to back each other up and side with one another while more or less ignoring or avoiding extended interactions with other participants (whom they mostly perceived as either having lower intelligence, or being of a different age cohort).

In some ways I was different from other visitors who had proposed projects in the past. For one thing, this troika accepted me as a peer. Being of roughly the same age, and interested in arts and culture, I was a worthy conversationalist. At the same time, I fit this familiar mold. The troika had been part of an array of projects in the past with the similar goal of offering a platform for youth with disabilities to tell their own stories: they had launched, with the help of Fridrikh, a vocational educator at a local afterschool program who took on computer literacy classes when a group of visitors from Vermont donated several computers in the early 2000s, an online

magazine, for which they all created the content (and which prompted another member of their loose cohort, Aaina, to pursue a career in journalism). Vakas, when I met him was already the author of one chapbook of poetry, and subsequently published a second book of poetry and an additional book of memoir-type writing.

I also approached this group as a peer. Unlike the nondisabled social workers and psychologists - also our agemates - who were charged with organizing and facilitating the art therapy group (and who were paid in an official capacity to do so), I had no official status. Of course, I did have an official visa status: first through the local Center for Initiatives under the category of Youth Exchange, and subsequently through the regional Center for Gender Studies under the category of Cultural and Scientific Ties. But these were loose affiliations, and my project was independent. They knew that my stay in Russia was funded by a grant from the US government to research a book, but the fact that I made no pretense toward and "rehabilitative" goal set me and my project apart.

Which is not to say that I didn't arrive with my own agendas. My identity back home as a scholar of anthropology and feminist disability studies at once melted away without a frame of reference that made those concepts make sense, and created moments of absurdity and ridicule when I brought up ideas or categories that were contextually foreign. This strangeness in a way made me a novel interlocutor. At times, I found that I was asking questions or steering conversation in such a way that led my interlocutors to have to reckon with my categories and understanding of the world, rather than opening myself to their emic categories and insider perspective on living with a disability in Russia. On the other hand, sometimes my blunders or absent-minded adherence to my own categories also created opportunities for interlocutors to explain why I had it wrong.

In any case, what ultimately convinced this troika to accept me as their own remains unclear to me, and perhaps also ultimately to them. After that first meeting, I made a habit of attending the weekly meetings of the art therapy group each Wednesday. Following the photography lesson, the group met in a different location, and studying drawing, then theatrical diction; the program concluded with the presentation of a performance of Pushkin poetry for friends and family.

I didn't set out to study any particular type of disability. Instead, I was interested in disability as a category. The art therapy group included people with mobility impairments as well as adults with learning disabilities. In my preparation for this research, I had worked long and hard to consider the special challenges of doing research among people with intellectual disabilities or cognitive differences. I had reviewed literature, considered methodologies, and devised strategies. However, as an accident of fieldwork circumstance, the group of people whom I became most closely acquainted with were all identified by the Russian medical-rehabilitative category *oporniki* - people with disorders of the muscular-skeletal system. This had to do with the shape of social networks: once I had come to know Vakas and Alina and Sergei, knowing them helped me to demonstrate insider status to others who had grown up attending similar programs and schools. Although I did meet and interview adults with learning disabilities, and some deaf adults, there were disability cultures in the city that I never explored. I heard a lot about the advocacy and activity network for blind people in the city, but never came to know any members of that group. Following my Masters research with parents of children with disabilities, I was kept abreast of major developments in educational settings.

Situating this work

In this dissertation, I start from a question about how to understand *disability* as a social status and identity in Russia today. I investigate the globalization of *disability* as a category, and offer theoretical observations about how disability, as a status of the welfare state and the global human rights apparatus, attenuates personhood and social identity. I draw on my interlocutor's narratives to describe their own social worlds. I find that their experiences of social exclusion and in/access illuminate the ways in which disability is configured by transnational social, political, and legal dynamics. Their personal histories offer an account of education and social programming that sought to facilitate inclusion in the context of the rapidly changing social and political milieu of the immediate postsoviet years, contributing an as yet unexplored perspective on the development discourses more frequently called "transition" or "democratization" in Russia since the fall of the Soviet Union. Global discourses about disability access and social inclusion take on specific meanings in Russian society, which has particular configurations of material culture and the physical world. The combination of personal accounts also contributes to scholarly questions about how people with disabilities understand themselves and their social roles, and about the liberatory consciousness that prompts some people with disabilities to become activists.

This dissertation combines ethnographic approaches with theoretical insights from critical medical anthropology, disability studies, and the anthropology of infrastructure and development to understand disability as an enacted identity in contemporary Russia. A core goal of this work is to document and theorize the ways that the social exclusion of people with disabilities is reproduced in a changing local context. Russian moral personhood, performative modes of expressing collective belonging, and norms of social behavior mean that the cultural

patterns which reproduce disability stigma or combat it are not configured in the same way that they are elsewhere.

I argue that in order to understand the challenges facing people with disabilities in the city of Petrozavodsk, scholarship must attend to the ways that the semantic location of disability and stigma are produced in locally specific ways, attending to the specificities of the material world and social practices of the former Soviet Union. I find that disability issues dovetail with barriers to civic participation for all citizens in contemporary Russia in a manner that is not immediately obvious to a Western observer.

An array of factors reproduces and normalizes the social exclusion and impoverishment of people with disabilities in Russia. These include social stigma, a history of segregation in education and labor, and infrastructural barriers¹. Many development and democratization projects in the immediate post-Soviet era took on the issue of social inclusion for people with disabilities. Seeking to apply Western frameworks of access and inclusion to the Russian context, these organizations built a patchwork system of social supports for people with disabilities; but, concepts of personal independence and minority rights did not translate easily to the Russian context. Now, Putin's reconsolidation of power under federal jurisdiction and disincentives for non-profits to seek foreign funding since 2008 have left many of those organizations defunct, while federally-funded municipal social work agencies reestablish primacy in the provision of social services. This dissertation relates this history through the

¹ Human Rights Watch. 2013. *Barriers Everywhere: Lack of Accessibility for People with Disabilities in Russia*. Romanov, P. V, and Elena Iarskaia-Smirnova. 2006. *Politika invalidnosti: sotsial'noe grazhdanstvo invalidov v sovremennoi Rossii*. Saratov: Nauchnaia kniga.
Phillips, Sarah. 2011. *Disability and Mobile Citizenship in Postsocialist Ukraine*. Bloomington: Indiana University Press.

personal accounts of my interlocutors, adults with disabilities like the troika of Alina, Sergei, and Vakas, who, now in their 30s, came of age during this era of shifting civic resources and changing concepts of what constitutes social accessibility and participation.

In choosing this approach to the subject, I argue that ethnography is particularly suited to elucidate insider perspectives that shed light on minority identity and civil society in Russia. Building on a tradition of feminist ethnography of the body, feminist and queer theory of minority political participation, and ethnographic accounts of NGO culture in the postsoviet arena², my work contributes to a transnational social science approach to disability studies. I have found Anna Tsing's concept of friction in global connection particularly useful in thinking through the ways that objects - like ramps and family apartments - and ideas - like *disability* and *access* - that are part of universalizing projects, are actually changed and recreated in local contexts.

In many ways, this is a document that attempts to tell the story of a particular community. At the same time, I offer it as a contribution to anthropological and disability studies scholarship. In particular, I seek to contribute to the development of a robust critical anthropology of disability as a subfield of our discipline. I also aim to contribute new insights to ongoing conversations in disability studies about how disability theory and disability advocacy can be globalized without participating in ideological colonialism that always privileges a Euroamerican perspective. In an applied or engaged sense, through this work I hope to address practitioners,

² Essig, Laurie. 1999. *Queer in Russia: A Story of Sex, Self, and the Other*. Durham: Duke University Press.
Hemment, Julie. 2007. *Empowering Women in Russia: Activism, Aid, and NGOs*. Bloomington: Indiana University.
Rivkin-Fish, Michele. 2005. *Women's Health in Post-Soviet Russia: The Politics of Intervention*. Bloomington: Indiana.

theorists, and activists working to create and foster programming and policies that contribute to more just and inclusive societies for people with disabilities cross-culturally.

In addition to traditional scholarship, as part of my ethnographic methodology, I use multimedia methods including photography and social theater projects to create ethnographic outputs that are accessible and valuable to collaborators in the field as well as to scholars and international disability advocates. I urge the reader to explore some of these complimentary works that are based in the same research.

Major themes: Personhood and Citizenship, Infrastructure and Performance

My first impressions of Vakas, Sergei, and Alina during our initial introduction at the photographers studio would grow and take on shades of meaning as I got to know them over the next several months, and subsequently, stayed in touch online after my return to the United States. Their respective personalities, life circumstances, family relationships, and personal histories took shape through our shared experience of participating in the art therapy project, in interviews and visits in their homes and mine, through stories shared with mutual acquaintances, and other meetings around the city. While this depth of perspective and the friendships that we formed is not unusual as an ethnographic encounter, my intention to represent each of them as a unique person, on their own terms, runs counter to so much conversation about "disability" which foregrounds the aggregate or locates "people with disabilities" as a uniform group with shared interests and needs.

I remember saying to a mutual acquaintance, after having first met Alina, that she is much more assertive and sure of herself than is frequently expected of women with significant physical disabilities. It is often assumed - in the US as well as Russia - that a woman with a significant physical disability would be shy or have what Russian-speakers refer to as

"complexes," a sort of psychological barrier to social life. Particularly in Russia, where adult women are relied upon to run the home space, as well as to be conventionally attractive to men in order to be worthy of social respect, and therefore self-esteem, to be a woman with a disability compromised Alina's capacity to participate in some of the expectations of womanhood [see Phillips 2012]. But Alina suffered no crisis of self-respect. Over the course of my fieldwork, I often observed Alina working to shrug off the perceptions of others who, through their actions or ways of relating to her, implied that she ought to have low self-esteem.

Shortly after my first encounter with the group at the photographer's studio, I recorded the following entry in my field notes journal:

As we watched the woman demonstrate the different manners in which to light a still life for photography - front on, from the side, from the rear, and the varying levels of contrast, shadow that ensue from hard or soft lighting - everyone sat transfixed, now and then shifting in their seats to take a better look at how the change in light had changed the visual. Here, just before them was literally a lesson in how to shift perception via manipulation of material surroundings. We all wanted to control the light. When it came time for the teacher to show how to light a portrait - grey background, soft fore light, shaded side lamp, opposite light - Alina readily volunteered to be the model.

"I am always the one who closes my eyes in pictures," she had said, and joked that she would be the perfect subject for those photographers who for artistic reasons prefer to shoot only in natural light.

She slowly moved to undo the brakes on her wheelchair, and then asked the facilitator - who was across the room - to help her move into place. Alina's malomobilnost' then translated interestingly, for once she was set, she was more or less in place. She moved her head and hands with ease, but to reposition the lighting, the photographer moved the actual lamp bases, rather than asking Alina to shift her chair again.

Perhaps to Alina's disappointment, the flash with all this equipment was even brighter and more shocking than a regular flash, and she visibly jumped at the first one. "It takes people awhile to get used to the flash, but most people eventually adjust," the photographer said to the group, as she made adjustments. "Am I right, that you haven't had your photo taken this way before?" she asked. Alina, who nodded, and seemed lost in thought as if trying to work out what she should do with herself in this position as subject. There was only time for about two minutes worth of shots, and the photographer eventually directed Alina to first look at the softbox, then to look at the lens, and to smile. Smiling, Alina has dimples. These images were the best that were captured. The group was surprised to learn that usually for a really good shoot the subject sits for 1-2 hours. "You can see why," the photographer said.

In this exchange, Alina readily and gamely took on the role of model, volunteering herself and her extraordinary body for the literal spotlight. She was at once at ease and happy with the opportunity to have a new experience, and aware of herself and her composure, working to

display appropriate conduct for an unfamiliar role, but a role that she had seen portrayed time and again and in the media, but rarely by a bearer of a disabled body.

As I came to know Alina better, I struggled to understand her point of view. She remains the most difficult of my interlocutors to describe in writing, perhaps because her sense of self and other people's perception of her are so divergent. Unlike Vakas and Sergei, she resists internalized oppression. But, unemployed and very poor, she does not situate herself in the community as an activist or public figure, and her family seems at first, from a Western perspective, to have very little cultural capital. As I came to better understand the ways that competing logics of moral personhood - Soviet, liberal democratic, therapeutic, and New Russian - circulated and intertwined in Petrozavodsk, I came to see Alina as a savvy cultural actor, adept at moving between competing frames of reference. I found that it was impossible to describe the complexity of how Russians with disabilities narrated and performed their social roles without contextualizing broader global dynamics and the history of the postsoviet era.

Medical anthropology frequently uses the notion of *personhood* as a way to consider how individual people might be perceived by others around them as social actors. In this paradigm, *full personhood* is a term that anthropologists use to denote the characteristic of some people to be perceived as not only human, but as social equals and actors. Meanwhile, *compromised personhood* is a way that anthropologists describe situations in which particular groups of people who have been racialized, medicalized, or in some other way cast as deviant or separate from a social whole. In these accounts, personhood is often related to *citizenship*, or the ways in which a person might be considered by others to be privy to and participate in the rights and responsibilities of a member of a political state. When personhood is compromised, so too is citizenship.

Disability stigma - a social phenomenon in Russia and elsewhere - casts people with disabilities as somehow outside of or situated in opposition to an imagined norm. Stigma, as described by Irving Goffman, is the mode by which some people are produced as and treated as *deviant*. According to Goffman a broad array of categories deemed socially undesirable in a given culture might be cast as deviant; in his description of the US in the mid-twentieth century, this included racialized subjects, as well as those deemed sexually deviant, felons or the otherwise incarcerated or formerly incarcerated, immigrants, and the chronically ill and disabled. Subsequently, Lennard Davis has described the ways in which the very idea of deviance relies on a logic of mathematical statistics. Davis, a disability theorist, argues that the invention of statistics in fact created the linguistic possibility in Euroamerican discourse to conceptualize a *norm* and, in turn, a *normal person*. That is, before the advent of statistics in the mid-1800s, or population level thinking (which James C. Scott also describes), the possibility of conceptualizing normal did not yet exist.

In this way, disability studies has worked through the problem of understand how it is that particular groups of people come to be defined as abnormal or deviant somewhat differently than medical anthropology. Where medical anthropology has observed the ways in which social personhood of an individual or a group of people might be compromised, disability studies has worked to describe the production of the unmarked category of the nondisabled normal body. Rosemarie Garland-Thomson builds on Goffman's idea of deviance to imagine that person who is unmarked by difference in anyway. In Goffman's era, this was imagined as the white, male, heterosexual, sexually active, middle class professional college graduate, married American-born citizen. Garland-Thomson calls this figure the *normate*. Drawing connections between queer theory and disability theory, Robert McRuer suggests that thinking with the idea of the normate

in relation to what queer theorists name compulsory heterosexuality suggests that in order to access the full rights and possibilities of citizenship and social personhood, a person must be or present socially as both able-bodied and straight. The normal body, he argues, does not exist without the disabled body; disability as a category in part shores up the stance of the nondisabled as part of the dominant and privileged group. Moreover, McRuer argues, the midcentury American mode of heterosexuality has subsequently become more flexible. Where once one was heterosexual unless proven otherwise, contemporary Euroamerican cultural configurations often require a straight person to "come out as straight" and to associate with and configure oneself in relation to, rather than in stark opposition to homosexuality.

Where personhood and citizenship have been developed by anthropologists as theoretical tools that might be configured and applied differently across cultures, the work of disability theory has largely focused on the Euroamerican context. In this sense, transnational or intercultural explorations of disability stigma require attending to the ways in which the normate is differently constituted in different cultural contexts, and that compulsory able-bodiedness and compulsory heterosexuality operate in different modes. How do they function in contemporary Russia?

In Russian, socially marginalized people often invoke a particular phrase to describe their situation: to be needed by nobody, or *ne komu ne nuzhni*. This is a phrase that I have occasionally heard disability advocates use to describe the attitude of dominant culture toward people with disabilities. It is a shorthand for describing marginalization and stigma. To be needed by nobody is explicitly about a sort of dislocation of a person from the social whole. In her book, which takes this phrase as its title, and describes the experiences of homeless populations in Russia in the 1990s and early 2000s, Hojstrand writes:

'human' and 'needed' are Russian articulations of what anthropologists usually call social personhood, which implies being a recognized co-actor, or agent-in-society, in a social whole of some sort. Like personhood, neededness is contextual, that is, construed in different but partially interconnected social settings, and may be bestowed upon someone in one context but not in another. (6)

In this way, I entered the field with the expectation that my interlocutors, living with disabilities, might frequently refer to this concept of attenuated personhood, or the sense of being needed by nobody. On the contrary, what I found both in in-person conversations, and subsequently in reviewing interview transcripts, was that while the social personhood of people with disabilities might be compromised by stigma, in fact, only some interlocutors talked about this explicitly. The people who were explicit in discussing this were almost always those who self-identified as activists or advocates, or whom I would perceive as having a liberatory consciousness about disability. Alina, Vakas, and Sergei, meanwhile, rarely talked about *disability*, rarely discussed stigma or marginalization, and tended instead to use colloquial anecdotes to dwell on moments or instances in which they *were* recognized as bearers of full personhood. That is, their self-narration, personal histories, and responses to interview questions often returned to instances in which they were socially embedded, needed, and treated as such by others. That is, if sociality is what gives our lives meaning, their accounts of their own lives as meaningful were more interested in moments of sociality than in moments of social rejection.

In this way, social personhood is produced through positive accounts in my interlocutors narratives.

In addition to themes of personhood, the reader will find that this dissertation takes on some current topics in anthropological theory, particularly, anthropology of design or anthropology of infrastructure, which I have here blended with insights and theoretical perspectives long present in Anglophone disability studies, especially conversations about accessible or universal design and geographies of disability. In many ways, these concepts are

related to older themes in anthropological theory, particularly the notion of material culture as always intimately linked with and co-constitutive of social life, and to an anthropology of the body.

Likewise, it would be somewhat impossible to write ethnography of disability experience without considering and overlapping with the significant work on stigma, diagnosis, and governmentality in medical anthropology. Like Joao Biehl's *VITA*, Matthew Kohrman's *Bodies of Difference*, or Karen Nakamura's investigation of Deaf culture in Japan, this ethnography puts the lived experience of people with disabilities first. This differs from the conventions of some medical anthropology in that it does not privilege the clinic or sites of medical knowledge making as the sole location of medicalization or pathologization of certain bodies. Given the deep theoretical resonance of disability theory with contemporary queer theory, and the rise of "crip theory" in US disability studies, I find that this work is in some ways more akin to ethnography of international queer communities, than to medical anthropology. Yet, I have been deeply influenced by medical anthropologists writing ethnography about people with disabilities, and at least in introductory chapters, I have taken the medical anthropological concern with diagnostics and definitions to bear on the question of disability as a category. Which is to say, the reader interested in theory will find that my references span all of these subgenres.

As for the reader who happens to be interested in disability in Russia, or in everyday life in contemporary Russia, this dissertation is in some ways laid out like a classical ethnography. First, I define the group of people that have become the central subjects of this study (as much by accident and through their own insistence as by any will of my own). Second, I will describe the geographical locale in which the action of the ethnography unfolds. Much like Evans-Pritchard or Malinowski, I will tell the reader about the public space of the town, and about the habits and

customary private dwellings. By doing so, I will demonstrate some of the social realities of life in the city. In this case, the focus will be on the material and social marginalization of people with disabilities. Third, I will tell the reader a bit about the educational systems, and how it is that people come to identify as part of the group in question. Fourth, I will talk about social performances, rituals, and public rites, as a way to understand group belonging and how these identities get reproduced. Finally, I will observe the systems of kinship and cultural reproduction within household units. Generally speaking, the section one of this dissertation introduces disability as a subject of study; section two takes a design or infrastructural approach to understanding the reproduction of disability stigma; and the third section has to do with the social performance of disability.

Methodology

The central argument of this dissertation is that *disability* - as a category of human social reality - is culturally contingent. And that the reproduction of stigma and marginalization of people with disabilities is coemergent with the material factors of a given place in culture, history, and infrastructure. In the first place, a consideration of what Russian-English dictionaries translate as "disability" - the Russian word *invalidnost'* - requires stepping back and reconstructing each element of how the category is reproduced as a socially meaningful idea. Secondly, if those concerned with justice for people with disabilities consider disability as an international or universal concept, an anthropological *material approach* can be a useful mode by which to consider the ongoing social marginalization of people with disabilities in a given context. That is - I will explore how *invalidnost'* is meaningful as a bureaucratic category to the Russian state, as a stigmatized and performed social identity in both live interactions and media representations, and how the material world and built environment of the city of Petrozavodsk,

Russia contributes to the reinscription of *invalidnost'* in people's everyday lives. In the language of contemporary disability studies debates, this offers a *relational model* of disability that accounts for performative as well as environmental modes of socially reproducing disability as a category.

The dissertation focuses not only on the people of a given place, but a subculture or subpopulation within a complex society - that is, residents of Petrozavodsk who have been disabled since childhood. The tactic of focusing on a particular subgroup is one that has been increasingly popular as ethnography has evolved as a genre, as it has become more popular to work in complex societies. Moreover, the role of ethnography in examining and attending to peripheral or subjugated groups within a society has been widely explored - in feminist and postcolonial ethnographies, and in applied anthropology.

And, in a sense, this dissertation has the most in common with those works of applied anthropology which take an activist stance; like feminist anthropology, an anthropology of disability poses questions about how the ongoing subjugation and domination of a particular category of people is reproduced and maintained not only in a single cultural context, but in myriad ways in different cultural configurations.

I seek to unpack the ways in which ableism, the systematic oppression of people with disabilities that is built into attitudes, structures, and institutions - both materially and socially, manifests and is reproduced in contemporary Russia. In doing so, I will argue that these ableist attitudes and systems of oppression are coemergent. While I am not the first to argue that attitudes and systems of oppression are coemergent, this position is distinct from some disability advocates, who argue that marginalization begets stigmatizing attitudes (Charlton 2010); and

from others, who argue that stigmatizing attitudes can be seen as the root of disability segregation.

This argument is particularly relevant in thinking about disability in postsoviet Russia. I say this because, as I have argued elsewhere, the dominant Anglophone perception of Russia is one based on a pseudo-colonial understanding of Russian culture as "less progressed" than Western society. That is, Russia is perpetually imagined to be "behind" the US and Britain on a teleological model of progress that imagines the modern nation state as always moving toward a better configuration of social life (Hartblay 2012). This bias is expressed in the binary models of popular representations of Russia versus the West (repressed/free, totalitarian/democratic, corrupt/non-corrupt, etc.), which, in fact are hardly defensible (Yurchak 2006; Klein 2007).

This dissertation takes issue with the idea, often projected by human rights discourse in particular, that ideals of *access* and *disability rights* - and even the concept of *disability* itself - can flow unhindered from centers of global expert culture to the multiplicity of local contexts. Instead, I will argue, following Tsing, that even in cases where ideas and forms seem to get taken up as universal, smoothly entering new contexts, they are actually operating in friction. Friction is not always bad; rather, as Tsing argues, the tensions and rough edges may produce productive results (and these results may in turn further mask the mismatch). That is, we will see in this dissertation that to talk about *disability* internationally, to write about *disability* in Petrozavodsk, is to unpack the productive friction inherent in the mismatch between universal definitions of disability and access, vernacular concepts of *invalidnost'*, and about the purposes and inherent value of political and social participation and movement through public space, arbitrated by complex puzzles of contrasting motivations and meanings.

It is with this set of precepts in mind that I pose the questions that are at the center of this dissertation:

- What does it mean to be disabled in Russia today?
- What does it mean to think about the *category of disability* as an idea that moves transnationally, cross-culturally, and is at once global and local?
- How do the specific social configurations, political configurations, and material configurations of Petrozavodsk create a particularly Russian or postsoviet meanings for *disability*? For *access* or *inclusion*?
- How does the social performance and reproduction of *disability* occur (e.g. that makes it a cultural artifact, passed down through culture, rather than a fixed medical condition located in a particular body); How are Russians *doing* disability? How does disability get *enacted*?

I should also mention that those readers interested in non-text-based media related to this topic will find an afterword which offers complimentary videos, artworks, and other projects - some of which were co-created or are the sold creative works of collaborators in the field. This dissertation is by no means the last word on disability experience in Petrozavodsk, and indeed, I anticipate that it is but one utterance in a long conversation.

Arriving at a topic for Engaged Ethnography

As ethnographers know well, the topics that we imagine to be relevant from our position in the University are frequently upended when we arrive in the field. If we seek to enact an engaged model of ethnographic scholarship that indeed seeks to center the knowledge and perspectives of those within a given cultural group, much of the work of listening and recording that we do becomes a reflexive process of shedding preconceptions and ego, of rebuilding research questions on the fly. As Julie Hemment has pointed out, sometimes the moment when a projected research topic breaks down is precisely the kernel deserving of ethnographic attention (2007). In many ways, this dissertation project has taken this strategy to heart, tracing moments of "failure" or realignment, as a way to understand global friction. In this section, I describe the

process of arriving at a locally-relevant ethnographic topic; the anthropologist's fieldwork narrative in turn becomes an ethnographic product, elucidating for the reader why and how this subject matter emerged as relevant.

When I conducted Master's Thesis research in Petrozavodsk in 2010, I was able to connect with a group of parent advocates who had worked with civil rights lawyers and an international network of disability rights organizations to successfully receive a court decision stating that children with disabilities must be allowed to attend any public school or preschool at the discretion of their parents. In practice, up to that point, according to the parent advocates, children with disabilities had been routinely denied access to public educational institutions in Petrozavodsk, aside from those institutions deemed "*internati*" or designated as serving special populations (there were several of these institutions - one for children with mobility impairments, one for children with intellectual disabilities but no physical or mobility impairments, and special departments within other schools for children with visual, auditory and behavioral needs, respectively). Many other children, still, were not attending school *per se*, but were receiving distance education. Meanwhile, the availability of open spaces in public preschools was insufficient for the population of the city overall; many parents of non-disabled children complained that there were long waiting lists for daycares and preschools, and that there were only a few private preschools which were prohibitively expensive for the majority of city residents.

Having won the first lawsuit regarding kindergarten programs in 2006, and the subsequent lawsuit regarding primary-secondary schools³ in 2008, parent advocates and their

³ The Russian educational system does not separate primary and secondary education as the American public school system does. Instead, pre-school kindergarten (*detskii sad*) serves children aged 5-7. Children begin first grade at

allies were eager to speak with me on this subject in 2010. They described the upcoming struggle to get their children enrolled in public schools. They described the remaining barriers as being primarily related to negotiating with school directors to assert the necessary renovations to make schools accessible for students with disabilities who wanted to be mainstreamed. Publicity materials stressed that integration would occur only at the behest of parents, as the constitution protects a parent's right to choose a child's school, and not be enforced as a required action.

Even by 2012, when I returned to the field for dissertation research, public opinion remained starkly against inclusive education. Public polling by a respected polling organization showed that the majority of Russians felt that including children with disabilities in "normal" [*obychnikh*] public school classrooms would result in a decreased quality of education for other students (FOM 2012)⁴.

When I returned to the field in July of 2012, I set about reconnecting with parent advocates, organizations - both independent nonprofits and municipal centers - serving families of children with disabilities. I quickly realized that one of the most active ally-advocates – Svetlana - a sociologist and social worker who had orchestrated much of the action, and herself written several academic works on the exclusion of young people with disabilities, was planning to move out of the city. At our first in person meeting after two years, she happily told me that

age seven, and usually continue in the same school from first through eleventh grades (cite). This means that one "school" serves children aged 7-17. There are a few exceptions or alternate pathways: some students apply to a specialized or prestigious high school (liceum) for the last four years of school. Others may leave school (*shkola*) to attend a trade or community college at age 16 (kolledzh), where they will study alongside students of a range of ages seeking an applied professional education in a particular field (music, mechanics, etc.). University is open and free (in terms of tuition, but not room and board - most live at home with parents, and only a minority who were raised far from the city of study in a student dorm) to those students finishing school (*shkola*) or liceum who have received a minimum score on an entrance exam (cite).

⁴ See the info-graphic report from the poll (in Russian) here: <http://fom.ru/obshchestvo/10588>.

she was engaged to her boyfriend in Europe, and now that her daughters were both in university, she would leave them in the family apartment, and move abroad to live with her fiancé. I congratulated her, and we chatted about her daughters. As I met with her and other advocates in the following weeks, I realized that her looming absence had quite seriously circumscribed the possibilities for future plans for the small but dedicated group of advocates in the city.

In the meantime, I had renewed my relationship with a municipal center serving families of young children with disabilities. Analogous to what would be deemed early intervention in the United States, the center housed a summer camp and kindergarten (with insufficient space to provide year-round services to all the families in need), as well as a dedicated group of child psychologists and social workers, and provided free professional rehabilitation in Russian disciplines similar to North American speech therapy [*logoped*] and occupational therapy [*defectologia*]⁵ to families. With the permission of the director, and help from one of the psychologists, I was allowed to conduct outreach recruitment to parents of children with disabilities utilizing the center's services. My colleague mentioned my project to document family's struggles to parents, and several of them agreed to an interview. We met in the center, usually at the end of the day, when parents were there to pick up their children. Some interviews were with only mothers, and some were with both mothers and fathers. However, I found these interviews to be exceedingly difficult, both ethically and methodologically. Having been recruited by a psychologist, many parents came to the interview with the impression that they were being asked to take a survey that would evaluate the degree of their psychological

⁵ *Logoped* is a professional designation quite aligned with western speech therapy. Occupational therapy, however is less formally linked to the work of the Russian *defectolog*. I would argue that a full article discussing the historical and current convergences and divergences of these professional designations would be of great use to the field, however, that is not the subject of the present work.

adjustment to having a special needs child. Many seemed determined to give the "right" answers, and were befuddled by the open-ended interviewing strategy in which I suggested that we have a conversation, and they tell me about themselves - they wanted to give short, correct answers to discrete questions, and this alternate format both seemed to place too much responsibility on them, and to be overly emotional. Additionally, of course, this recruitment methodology did not allow sufficient opportunities to establish rapport with the interviewees. They had agreed to the interviews, it seemed, largely out of trust and gratitude for my colleague, the psychologist, but we were often meeting for the first time at the time of our interviews. Very few of the parents agreed to a second interview, and none of them were interested in a third interview.

By the time I had been pursuing this strategy for six weeks, I realized that it was an unsustainable way to proceed. Unlike the parent advocates with whom I had already made acquaintance, these parents did not consider having a disabled child as a fundamental part of their identity, or, as many had young children, they had not yet proceeded through the work of integrating this new reality into their sense of self (see: Landsman 2009; Stockall 2000). Additionally, as an adult female who was often the same age or older than the women I was interviewing, I felt that my status as a (by choice) childless adult made it hard for the mothers to feel that they could relate to me. Maybe they felt that I was unable to understand the kinds of choices that mothers make (and indeed, I often tell my friends who are parents that I am awed but befuddled by the way they organize their lives as ongoing compromise); or maybe they were actually confused by my status as a 28-year-old who was both unmarried, uncoupled, and childless (certainly an anomaly in this regional capital city). My research strategy to conduct ethnographic research with a range of parents - not only parent advocates - was failing.

I redoubled my efforts by returning to the parent advocates who had been most eager to tell me their stories in 2010. What issues are you interested in now, I asked them. How could we do a project together that would be relevant to the problems that you are now facing? Based in part on Svetlana's completion of her own dissertation on the social issues facing young people with motor impairments in the Karelian region, the focus of the group of activists had changed. Svetlana had found in her research that the problems of transportation and inaccessible environments created such barriers that the problem of the built environment effectively prevented her research subjects from accessing all other elements of life she had hoped to study - school, employment, socialization (2009).

Using a strategy of dialogic engaged research (Madison 2013), I worked to reframe my research as centered around the needs of the parent advocate community. I also broadened my strategy. Considering the problem of pursuing research with parents as a non-parent, I sought to reach out to teenagers and young adults who themselves had had the experience of growing up with disabilities. I had already intended to make contact with this population, and the series of dead ends with parents led me to turn to this population. Maybe my age-mates with disabilities would be more interested in building relationships with me.

Especially given Sveta's planned departure, Katya, who was one of the parents at the center of the original civil legal suit, was open to developing a collaborative research-action project. Sveta, too, liked the idea of an action research model, and urged us to pursue this collaboration. As scholar who cares deeply about using her work to improve life circumstances for people with disabilities, she was also interested in the methodology. Noting that there is so little written on the subject of participatory or engaged research in Russian, she asked me to write a description of the methodology so that she might use it and disseminate it in the future.

I suggested several possible models of engaged scholarship. Katya and I considered a photovoice project at length. I liked the idea of people using their own photos to explain their daily lives or *byt'*. Katya, however, was skeptical: how would she find the time and energy to photograph her life? As a parent to a daughter with cerebral palsy, who, at 7 years old, used a wheelchair, and needed help with all of her daily activities, Katya quipped, "what am I supposed to take a picture of? How we brush her teeth? I need three hands already to brush her teeth! How am I supposed to hold the camera?" We thought about recruiting an outside photographer to take the photos, but decided that ultimately that would feel invasive.

I suggested returning to the topic of inclusive education - documenting the process of how parents made claims about including their children in mainstream public schools. But both Katya and her collaborators had already given up on this effort. The work of removing not only the physical barriers in schools, but also the social barriers in terms of the attitudes of administrators, teachers, and other students, had turned out to be insurmountable, they explained. Plus, because these families had children with cerebral palsy, they felt that their kids needed ongoing physical therapy to improve motor function and mobility. Getting their kids walking and talking remained an important goal, that, from their perspectives, took precedence over social integration.

That is, these mothers had reallocated their energies from inclusive education to other pursuits. One group had been pursuing another legal claim that people with disabilities are entitled to free living space; they felt that if they were able to prove their social right to have land distributed to them, they could build a home. Meanwhile, Katya had devoted her efforts to finding a sustainable model for children and young adults with more severe disabilities. Like

Sofia in my previous research (Hartblay 2006), she realized that even integration in public school would not ensure her daughter's future after high school.

Now that Polya was older, it seemed to Katya that she would most likely be a wheelchair-user with quite impaired verbal communication throughout her life. In my interactions with Polya, I have understood her to be a bright young girl with an impish sense of humor; however because her speech is quite labored, and she rarely uses more than 1-3 word phrases, often waiting for an interlocutor to ask her a yes or no question, I've also observed that her caretakers at school tend to consider her overall abilities limited. Of course this attitude is maddening for a parent who knows that her child communicates, and, overtime, leads to the child withdrawing inward and becoming less and less communicative as their communications are ignored (and, unfortunately, as is so often the case, caretakers speak about non-verbal people as if they are not present (or cannot hear or understand conversations)⁶. I suspect that Katya, having considered this, decided that she would have to create an alternate environment if she wanted Polya to thrive.

Eventually, we decided on a collaborative photo blog⁷ that would gather photos of accessible and inaccessible entryways in Petrozavodsk and the surround region. This seemed to dovetail well with the only activist event that I had witnessed in my first two months in the field, a "Day of Access" *aktsiia* organized by Sveta, based on her observation of how advocacy

⁶ I cannot describe the kind of frustration I felt when I happened to observe teachers at the specialized school talking about non-verbal students as if they were also cognitively unable to comprehend. I also observed that frequently such students were sedated (probably because they began to act out out of frustration). In this way, the "tyazholi" group at the specialized school becomes a sort of pre-institution track. Although the children participate in school holidays, music class, and art projects, they are overall considered to be unteachable. This attitude is not limited to Petrozavodsk, but can be found in special education settings the world over. I have seen analogues in the United States.

⁷ <http://ktokudakakkarelia.tumblr.com/>

regarding the built environment was happening in other cities. As a result of her organizing two local wheelchair users and allies invited press to come and watch as they did a disability audit of the main street of the town. At the same time, the question of doorways, thresholds, ramps, and material barriers resonated with previous work that I had done in Arturo Escobar's seminar on Anthropology of Design and in a presentation for the AAA to integrate critical anthropological theory with feminist disability studies and accessible design theory. And as all of this was unfolding in the field, I was simultaneously engaged in a lengthy online correspondence with artist and design theorist Sarah Hendren, who was in the midst of conceptualizing her new project *Slope:Intercept*⁸.

Given this new project of gathering images of accessible and inaccessible spaces, I decided to parlay this into an opportunity to engage local high school students. As a visiting American, I was invited to give a series of presentations to students enrolled in a high level English class. Talking with the teachers, I explained my project and my work, and they agreed that it would be useful for students to know how to talk about disability in such a way as to not offend foreigners⁹. The lessons that I conducted with those students ultimately served as focus groups, in the sense that the students - who were tracked within the school toward become doctors or civil servants (as opposed to a math and engineering track) - and their responses acted

⁸ Sarah Hendren's *Slope:Intercept* lives online [here](#). Her work to decouple the ramp from its role as a "disability thing," to consider it as part of an aesthetic of access more broadly, as a tool of vernacular architecture and a simple machine that gets deployed in myriad ways beyond the "access ramp" of codified design was very influential in the development of this dissertation. Subsequently, her work on the [Accessible Icon Project](#), an activist design intervention to remake the handicap symbol, gained a viral following and has become extremely well-known.

⁹ As students in one of two or three elite high schools in the city, it was presumed that these were the youngsters who in the future might have the responsibility of communicating on what Russians refer to as "the international level" - e.g. signifying that they are amongst the best that the country has to offer, and therefore worthy of representing Russia to foreigners. At the very least, they were more likely to go on to work for jobs that required English.

as a sort of thermometer of opinions and knowledge of disability things and places within the general population of the city. I conducted three lessons each with four groups of 12-20 students over eight weeks in the fall of 2012. I thought I might also recruit the students to work on the collaborative project; in fact, a few contributed photos to the [photo blog](#), but there wasn't sufficient interest to garner further student participation.

Working with Katya, we devised an online contest to solicit photo submissions to the blog online, but although we received a few photos, we did not receive many. Later, friends told me that it's hard to take pictures of barriers in the city, for the very reason that the city is difficult to get around. For able-bodied residents, barriers remain unnoticed, but for those who experienced the infrastructure as disabling, the assignment seemed a bit like an unintentional irony: how were people meant to go out and take pictures of things that make it hard for one to go out?

With the concept of pursuing a photo blog falling flat, I continued to search for potential collaborative projects, or manners in which my research might respond to concerns on the ground. When I told a local social worker about my photo blog effort, she mentioned that she was taking a group of young people with disabilities participating in a publically funded art therapy program to a photography studio. She offered to let me attend that group meeting, where I met the participants in the art therapy project. I introduced myself and explained my project, and together we took an hour long photography techniques class. As a result of that meeting, several of the young people with disabilities agreed to be interviewed for my project - which I explained as an effort to write a book about the experiences of people with disabilities in Petrozavodsk. And, given this response, the group as a whole unanimously voted to allow me to attend their group meetings each week.

For the rest of that fall, I spent one afternoon a week participating in the art therapy group. I became friends with several members of the group and friendly with others, and got to know the staff administering the programming. The second half of the course involved the creation of a performance, which, billed as an "Autumn Concert" was a sort of variety show showcasing the talents of the participants. Lidia, a local theater professional, worked with the group for several weeks in order to select a theme, suss out each performer's contribution, and develop a program for the performance.

As I came to know the group of young people, visiting them at home for interviews, working on their autumn concert, driving around the city each Wednesday with the program facilitators to pick up and drop off the participants - I realized the degree of their marginalization not only socially, but also physically. Aside from their weekly group, many of those young people hardly left their apartments due to the material barriers in their apartment buildings.

As an age-mate to the three members of the group who came to figure most prominently in this research - Sergei, Alina, and Vakas - it was easy to form social bonds. We chatted, messaged online, and looked forward to drinking tea and eating sweets together when I visited them at home (Sergei preferred to visit me in my apartment). In these meetings I came to know their family members, as we all chatted in the kitchen over tea and cookies. I was often called on to tell stories of my own family in the US, to offer an American interpretation of some international news item, or to compare American holiday traditions to Russian customs taking place that season. I learned each of their life histories, how they spent their days, their practical and emotional relationships with each of their family members, their opinions on marriage, children and family, and their personal experiences of schooling and trying to find work as an

adult with a disability. These three relationships became some of the most important in building this ethnographic account.

Having come to know this group, and realized that this cohort was far more interested in partnering with me on collaborative projects - the autumn performance, and the work of translating their personal histories into writing for an international audience - I went back to Sveta and Katya with the suggestion that I shift my project focus. Sveta immediately agreed to help me deepen and broaden my network. Katya herself had recently begun work to develop programming for similar populations, and frequently invited me to visit the organization where she was working: once the work & labor headquarters for people with disabilities in the city during the Soviet era, the "Center" had retained its name and titular identity, but Katya and her colleagues explained to me, for years had been neglected and allowed to languish under the leadership of a disinterested or corrupt leader. Seizing on an opportunity to work on her passion within a state-funded entity, Katya signed on to direct programming to re-launch and re-brand the Center. During the bulk of my fieldwork, she was engaged in building capacity, advocating for building repairs, and conducting surveys to find out what kinds of programming would be relevant to young people with disabilities. By the time I returned for a brief visit in the spring of 2014, the Center's programming was operational, and Katya was leading a group of young people with developmental disabilities on an outing to the library to learn a new crafting technique.

Sveta suggested that given the new focus on young adults and the built environment, I ought to meet Vladimir Rudak, a disability advocate and well-known local musician and filmmaker. It turned out that Rudak was the lead singer of a band in which a friend's husband played trumpet. So, before Sveta had gotten around to introducing us, I met Rudak for the first

time after the band's performance at a popular local rock club. After watching the show, our mutual friend introduced us, I explained my project, and Rudak invited me to visit him and record an interview later that week. I was impressed by Rudak's ability to draw together worlds that I rarely saw integrated in Petrozavodsk. In the audience at the club that night were a range of acquaintances: social workers and NGO workers, a group of friends who knew the trumpet player (none of whom were visibly disabled), and a two women - acquaintances with visible disabilities - whom I had met through my research. I had been to the rock club many times before, as an evening activity with friends, but never for "research." I had never seen anyone with a visible disability in the space before (Rudak was carried into the basement level club through a back staircase by his bandmates). Watching this audience come together through Rudak's music, I realized that we had much in common, and that we already shared an unusual cross-section of the social sphere.

Indeed, Rudak became a key collaborator, close advisor, and participant in the development of this research project. He offered a savvy activist viewpoint; unlike many of my collaborators up to this point he was both disabled and considered himself an activist. His work as a writer and documentary filmmaker, shared many of the activist goals about social justice behind my own impetus to take on this subject ethnographically, as well as many of the same logistical, ethical, and artistic concerns. Although his words appear in this dissertation as those of an interviewee, in fact, Rudak is more of a mentor and colleague to me. That is, he was not only a teacher to me in the way that any interlocutor teaches the ethnographer about the insider's cultural perspective; in fact he was also a role model and teacher of methodology, as an expert practitioner of creative documentary work with a disability justice intent (see links to his list of video documentaries in the end matter).

Rudak also introduced me to Anya. One afternoon while I was sitting at his house for an interview, he called her, and insisted that we set up a meeting, offering that I would go to her house so that she wouldn't have to meet me anywhere. Like Rudak, Anya straddled the disabled and nondisabled worlds in Petrozavodsk. A few years older than me, she had completed high school and attended university without ever going to a segregated school, in spite of a degenerative condition that had begun in childhood. When we met, Anya used a power wheelchair and relied on her mother to get to her two jobs as a psychologist for group work in social work agencies. Anya pulled together the perspective of someone who is herself disabled, and the perspective of social workers and psychologists; not only did she negotiate life with a logistically intensive impairment herself, in her work, she often administered programs or led group work for adults with disabilities.

Extremely intelligent, Anya was compassionate but harsh in describing how it was that so many of her clients - peers with disabilities - came to live "passive" lives, neither working nor participating in social life outside of their immediate families and disabled peers. As a fellow researcher/professional engaged in working to destigmatize disability and to support the adults with disabilities in living full lives, Anya and I had much to talk about. She recognized me nearly immediately as someone with whom she could share crip humor, blithely describing with biting sarcasm situations of inaccess and barriers that she or friends from an online forum she frequented had experienced. As someone who had written a Master's thesis on disability and psychology, she understood the academic nature of my work, and the idea of writing about disability in a scholarly way, in a way that few others in Petrozavodsk did. In this way, Anya's testimony became very important to this dissertation in that during our interviews, she herself was working as a cultural translator and disability theorist, narrating for me how a social model

of disability maps out in the context of Petrozavodsk. Although she appears in this dissertation as a participant and interlocutor, Anya, like Rudak, is very much a colleague, and we have intentions to coauthor future studies.

Although it is my scholarly hand and methodological and theoretical approach that are captured in this dissertation, the ideas, sentiments, and narratives presented here were produced in collaboration with this group people. The account that follows is very much the product of unfolding interactions with these core interlocutors. There are numerous stories of disability and advocacy in Petrozavodsk that are not told here: the stories of the aging advocates who worked for disability rights already as adults in the Soviet Union; those who are aging and acquiring disabilities with age; the stories of Blind and Deaf communities in the city, respectively; the stories of adults with intellectual disabilities; the stories of those families whose children and teenagers with disabilities are now attending mainstream schools; and especially, the stories of the many people with disabilities who are institutionalized in state-run longterm care facilities. And, as Svetlana's dissertation research demonstrates, the situation for those adults with mobility impairments living in villages and smaller cities in Karelia is quite different from the lives that the Petrozavodsk cohort lead (Driakhlitsina 2009b:21-22). Each of these topics would warrant significant further research.

Plan of the present work

The dissertation is arranged in three parts. In the first part, I introduce the topic. In chapter two, I unpack the particular language that is used to talk about disability in Russia. In chapter three, I extend this question about what counts as disability and why to the global level, to examine how demography of disability is conducted and what is at stake in measuring rates of disability in a given population. That is, in the first section as a whole, I frame the concern of the

dissertation with the question about how we say disability in Russian, and about how definitions of disability and the semantic domains of the disability category are contested and culturally configured. I argue that the category of disability, as an abstract idea or technology of the welfare state, travels in friction through chains of global connection. A discussion of how to talk about disability in Russian in 2012 is nearly impossible to write without considering the global context, and the ways that certain phrases move from global advocacy cultures into Russian lexicons.

In the second part of the document, I shift my focus to the spatial, material, and infrastructural specificities of Petrozavodsk. By describing the built environment and landscape, this section attempts to sketch some of the ways that place and the politics of space play a role in the reproduction of barriers to social participation for people with disabilities that is specific to the local context. In this section, I work to describe some of the specificities of the built environment in Petrozavodsk especially, but also in the former Soviet Bloc more generally, especially as they pertain to barriers for people with disabilities.

Chapter Four situates Petrozavodsk historically as a city in a border region; this status, and the city's proximity to Finland, has the effect of highlighting the ways in which the peculiarities of Russian governance and infrastructural configurations are not absolute. Chapter Five discusses the history of the (post-)Soviet apartment as a fact of postsocialist life, and the ways in which the ubiquitous nature of centrally-planned and chronically scarce housing complexes create particular kinds of marginalization for my interlocutors. Chapter Six moves to the public space of the city and the internet, to explore the ways that barriers in the built environment, particularly the phenomenon of the inaccessible accessibility ramp, get replicated and reproduced both online and in reality. Here, again, I use Anna Tsing's notion of friction to observe how ramps, as "disability things" or as an object/technology, have very different

meanings in for different stakeholders, from architectural professionals, to wheelchair users, to international disability advocates, to Russian government officials.

Chapter Seven builds on the discussion of barriers in the built environment to explore how my interlocutors with disabilities voice *complaints* about *inaccess* in ways that may at first sound to a Western listener to be complacent, but actually align with broader Russian discourses about infrastructure, development, and governance. In this way, complaints serve to align the speaker with a broader Russian citizenry, thereby situating disability access not as a specific problem of a minority group, but as a one component of the inaccessibility of Russian life in general.

Part Three of the dissertation moves the focus from infrastructure and material barriers to the performance and enactment of *invalidnost'* as a social identity. In Chapter Eight, I use Sergei's narration of his personal history moving through a variety of educational and non-profit institutions to observe the ways that this cohort has continually been the subject of "first attempts." As children their parents were in many ways the first generation (at least in their region and in their telling) to organize amongst themselves to support one another in keeping children whom doctors recommended be institutionalized; as children in the 90s, they were able to participate in numerous NGO programs sponsored by foreign aid organizations; then, as young adults, they had the opportunity to participate in foreign-funded pilot projects in secondary education and career-building; finally, I observe a more recent development, the end of the NGO era of postsoviet civil society, replaced by a reconsolidation of social services under a recentralized federal system since 2008.

In Chapter Nine, I describe the events that unfolded in the performance of "The Autumn Concert" as part of an art therapy group, and puzzle over the ways in which the participants are

at once asked to perform competent citizenship and to perform a need for "social rehabilitation." I suggest that rehabilitation produces disability as always and irreparably pathologized, and that this creates tensions and complexity in the social roles that members of the art therapy group enact. In Chapter Ten, I revisit a subject of some previous writing, the Russian comedian Sergeich, whose appearance on television as a person with a visible disability simultaneously played an important role for Alina's perception of what is possible to do as a person with Cerebral Palsy (*DTsP*), and reinscribed certain modes of normalcy, specifically compulsory heterosexuality and compulsory able-bodiedness. This chapter address two important concerns of disability studies - the representation of people with disabilities in the media, and the degree to which crip theory might be translatable to the Russian context.

Chapter Eleven picks up the question of digital worlds and online sociality, exploring it in particular through Vakas's description of his own days on and offline, seen in part through the lens of embodied temporality, or, what some theorists call *crip time*. In Chapter Thirteen, I directly address two elements that arise throughout the text: sexuality and independence. In part returning to the question of compulsory heterosexuality as a culmination of rehabilitation to personhood and citizenship, I situate the expectation of the formation of a reproductive family unit as part of the normal lifecourse in Russian kinship relations. I draw on examples from a variety of interlocutors to sketch the broad array of family arrangements in which adults with disabilities live in contemporary Petrozavodsk, with varying degrees of sexual and social independence from families of origin.

Finally, I link the three sections of the dissertation with a conclusion, in which I both review major themes throughout the work, and suggest directions for further scholarship. Between sections, I have also included short "codas" or snippets of lyrical writing which relate to

the overall themes but do not fit squarely within the logical argument of any given chapter. In the postscript, I list supplemental non-textocentric projects that I invite readers to explore.

CHAPTER II TOWARD AN ANTHROPOLOGY OF DISABILITY IN AN AGE OF GLOBAL INTERCONNECTION

In order to orient the reader to the conceptual location of the idea of *invalidnost'*, this chapter will make two moves. First, I will review the theoretical framework that has been used to approach *disability* as a concept in Anglophone scholarship, including (feminist/queer) disability studies, medical anthropology, and science and technology studies. Second, I will consider how the Russian concept of *invalidnost'* is located in historical and cultural contexts that in some ways distinguish it from Euroamerican disability.

This chapter therefore not only prepares the reader to consider the ethnographic material presented in this dissertation, but also makes a contribution to scholarship by examining cross-cultural notions of disability and theorizing how it is that an intercultural study of disability can be undertaken and located conceptually. In articulating this manner of approach to the broader research questions, I am also proposing a theoretical manner in which to conceptualize disability as a *contingent category* that is enacted and made real through lived performance in tension with structural elements of material environments, media representations, and expert discourses.

There are several reasons why a cross-cultural comparison of disability and *invalidnost'* offer important inroads for scholarship - both applied and theoretical. First, as I have argued elsewhere (Hartblay 2014), Anglophone critical disability studies scholarship frequently points to conditions of capitalism as a precipitant to the oppression and domination of people with disabilities; however, given the significant presence of ableism (the systematic domination of people with disabilities, including both individualized disability stigma and structural and

institutional barriers to participation of people with disabilities) in non-capitalist contexts, this claim may be unsubstantiated. Certainly, more investigation is needed to understand how ableism functions in socialist, purportedly socialist, and small-scale societies, as well as in the capitalist nation state.

Critical disability studies scholars have in recent years argued for a greater attention to the ways that universalizing frameworks that posit disability rights as human rights and call on nation states to enforce those rights. They argue that the well-intentioned export of disability rights frameworks may inadvertently have the effect of reinforcing the hegemony of the nation state over postcolonial populations and privilege a model of individual rights (Soldatic and Meekosha 2011). For instance, in contemporary indigenous Australian societies, many people understanding *disability* not as an inherent or natural way of describing people, but as *a category of colonizing states*. That is, because disablement is a political-bureaucratic concept (with medical determinants), the concept of disability is interpreted not as a helpful form of redistribution or entitlement to particular sets of rights, but rather as a way in which a colonizing state counts, surveils, medicalizes and pathologizes indigenous bodies (Meekosha 2011). In this light, cross-cultural studies of disability in global settings requires a careful attention to the ways that disability gets exported to local, non-western contexts. What Western activists, NGO or government workers may perceive as a path to justice - the implementation of federal social service and education programs for people with disabilities, may not be perceived as such by those receiving the services. Moreover, the meaning of disability, in that sense comes to be contested, and its political antecedents and results indicative of global systems of oppression.

In the Russian case, the history of Western European and American intervention in the region, and a longstanding Eurocentrism in Russian culture that prizes a European modernity as

the height of civilization, must be identified as the global context in which a disability rights agenda is introduced. The export of global human rights discourse from Europe and America to Russia, and Russian dominant culture resistance to these interventions, has been well documented recently in the case of LGBT rights in Russia; disability represents a similar case of minority identity, in that Western activists assume that the implementation of Western activism and agitation will benefit members of that group in Russia. Likewise, they assume that when such efforts fall short, it is because of a "backwardsness" or failure on the part of Russian society to "catch up" with Western disability rights measures (e.g. implementing inclusive education). In this way, global human rights discourse has become a way in which Eurocentrism is enforced and Western hegemony is expressed (Zigon 2013).

That is, a critical ethnographic approach to disability requires asking not only whether capitalism or Socialism is a better environment for inclusion, but recognizing the normative framework or cultural bias of the researcher's perspective. That is, an ethnography of disability in global context ought to examine how both (a) scholarly models and (b) vernacular semantic domains of disability differ, and what pathways of global connection operate between these categories. Even as I present here disability and *invalidnost'* as paired conceptual realms, counterparts in dictionary definitions, I maintain space for a recognition that ontological worlds may be incommensurable (Ries 2009). This chapter presents two genealogies: one of the definition and concept of disability in the Euroamerican Disability Studies tradition, and one of the colloquial Russian concept of *invalidnost'*. In the following chapter, I expand on the global context in which ideas move between and operate in relation to both of these realms of meaning-making.

Cross-cultural approaches to disability

Given that this dissertation and this chapter propose a tactic of describing *invalidnost'* or disability in a specific geographically and temporally bounded context, with the implicit goal of offering this for comparison with other historical and cultural moments and places, we might ask: What is the utility of studying disability as a cross-cultural phenomenon? What assumptions do we make about the category of disability and about culture when we compare disabilities across culture? What intellectual and theoretical precedents exist for such an endeavor? On the one hand, we might take an extreme culturally relativist approach argue that categories of bodily difference, stigma, and productivity cannot translate across cultures. Or, we might take a utilitarian policy approach, and argue that, as much as possible, disability ought to be considered as a standardized category across place and time, in order to devise reasonable policy implications for how states and societies ought to respond to calls for rights and entitlements for people with disabilities.

This dissertation takes a third route, informed by the ways in which critical disability studies has taken cues from feminist and queer theory. Specifically, critical race theorists, feminist anthropologists and subsequently queer theory has argued that bodies are not in themselves inherently deserving of or bound to a particular kind of behavior or treatment. This opens the opportunity for scholars to document the variety and array of gender roles, behaviors, performances, expressions, and sexualities that are normalized within a given cultural context. Feminist anthropologists in the 1970s called for an anthropology of gender that would look at gender roles across cultures specifically with the goal of seeking out egalitarian modes of gender relation (Lewin 2006; Reiter 1975; Rubin 1975; Rosaldo, Lamphere, and Bamberger 1974; Ortner 1996 and 1974). We must do the same with disability. By paying attention to the ways in

which categories of bodily difference related to health, sensory experience, and productivity are enacted across cultures, ethnographers can contribute to a key goal of disability studies - specifically, documenting the ways in which what counts as "normal" varies across cultural contexts (McRuer 2006; Davis 2006; Garland Thomson 1997), and unpacking how oppression and marginalization - or egalitarianism - plays out in different cultural contexts. That is, a performative and interactional approach to understanding what it is that we call disability is important (Sandahl and Auslander 2005).

Disability as a conceptual category

At the heart of this inquiry is a question about classification (Bowker and Star 1999). What kind of category *is* disability? It seems to bleed between different systems of classification: is it medical, legal, social? Immutable and tangible, or relational and shifting? Given these incommensurable kinds of ways of thinking of disability, how do we enact identities and categories?

In order to address this question, it is important to step back and consider how it is that scholars have conceptualized the work of categorization, or classification, as a mode of human thought. Bowker and Star argue in their volume, *Sorting Things Out: Classification and Its Consequences* that sorting things, matter, people, and ideas into categories is fundamental to human cognition. From the system for placing cups on one shelf and plates on another in my kitchen cabinet, to the periodic table of elements, to the difference between a driver's license, a state ID, and a passport, human thinking is a system of taxonomic classifications. This insight is not new to anthropology: as Bowker and Star note, anthropologists and social scientists - from Weber to Levi-Strauss and onward - have paid a great deal of attention to systems of classification as a way to learn about human cultures. Observing how a group of people

conceptualizes the world, breaks things down into categories, helps outsiders to conceptualize a native perspective. That is, a foreign ontology - while as a whole incomprehensible - might be better understood by an outside through the social scientific work of identifying the discrete practices of categorization; attending to taxonomies allows the social scientist to isolate and illustrate different ways of knowing.

Indeed, as a young ethnographer in training, I was introduced to the Spradley method of ethnographic interviewing (Spradley 1972), spending a great deal of time and energy breaking down the taxonomies of thought hidden in the colloquial speech of my "informants." In order to breakdown and then rebuild an insider's perspective on a particular lifeworld or cultural way of knowing, Spradley urges ethnographers to abandon assumptions that we know what words mean, or how objects or ideas are related to one another in the folk logics of a given subculture.

Moreover, this activity of classification is a kind of "work" - that is, a great deal of human activity, energy, and technological know-how goes into creating, systematizing, revising and reinforcing our systems of classification. Bowker and Star argue that the "how" of classification is actually a moral and ethical issue, because, by enacting any one system of classification, a society "valorizes some point of view and silences another. This is not inherently a bad thing -- indeed it is inescapable. But it *is* an ethical choice, and as such it is dangerous -- not bad, but dangerous" (1999:5-6). In the case of disability, and the standards and systems of classifications used to define it, the process of putting people into categories can be particularly dangerous: on the one hand, the structural violence perpetrated against those perceived by others to be disabled makes it dangerous to be perceived as disabled; on the other hand, definitions of disability may not always fit the kinds of bodies and minds that prevent people from caring for themselves, and so there is a danger of not "counting" as disabled in the eyes of the state that

might otherwise provide disability benefits (Estroff et al 1997). But this does not mean that bearers of extraordinary bodies themselves have no control over disability as an identity.

As Ian Hacking argues in his essay titled, cleverly, "Making Up People" social identities are at once "made up" through the institution of bureaucratic categories, and then made real and made meaningful through people's willingness (or reluctance) to enact such categories (1984). That is, drawing on Foucault's discussion of the constitution of subjects, Hacking observes that categories are simultaneously enacted and prescribed, always social. This helps us to understand a core anthropological concern about identity, specifically, how to reckon the problem of structure and agency in the formation of disabled identity. That is, social structures - including categories of identity - are created, maintained, and transformed through the habits and enacted or performed actions of agentive subjects (Bourdieu 2008; 1984). In this way, disability - as a medico-legal category - becomes a meaningful social category because people use it in social practice (Edwards and Imrie 2003). The distinctions that expert cultures make about what kinds of people exist in the world may or may not have cache for use in colloquial social worlds; moreover, the usefulness and uses of a category like disability may be very different for different social actors (Holland et al 2008).¹⁰

My own conceptual understanding of the variable meanings and definitions of disability at work simultaneously were shaped by my experiences as a young paralegal working at the Legal Aid Society in Queens, New York. Plopped down in an office with access to the (then

¹⁰ This paragraph reflects several years of conversation and readings on this subject with Bill Lachicotte, who always pushed me to consider the question of disability identity in relation to structure and agency. Dr. Lachicotte died in 2014, never having published a work on this specific topic. Based on our discussions, however, I think the chapter in the *Identity and Agency in Cultural Worlds* volume that describes the case of Roger, mental health diagnoses, and identity, is fairly representative of Dr. Lachicotte's much more extensive theorizing of this question (Holland et al 1998:192-213).

newly) online editions of the DSM-IV and the manual of regulations of the Social Security Administration, I was tasked with determining whether or not potential clients might make a case for qualifying for legal status as "disabled" according to the terms of the SSA. Most of my clients had already been rejected twice via a remote application system, and now were seeking legal counsel to appeal these decisions in front of a judge (or, in the parlance of the field, an *ALJ* - administrative law judge). I was surprised to find that in the world of legal disability status, the definition of disability - bureaucratic, medico-legal system - depended on whether a given person (an individual, regardless of family status) met the *standards* of the legal code, which was intended to determine whether or not that person might be physically and mentally capable of holding down a paid job (any paid job!). This concept of disability - related to productivity and the responsibilities of a welfare state to its citizens - was greatly at odds with the symbolic concepts of stigma and normal or abnormal embodiments that I had read about in my undergraduate introduction to disability studies course. Yet, I felt, both *kinds* of disability were at work in the marginalization of the clients who came to us at Legal Aid.

How could this be? Two utterly different manners of understanding disability could co-exist side by side in a single complex society. And, as a person who was thinking deeply about social justice and disability, I found that both models applied.

Annemarie Mol, in her 2002 book *The Body Multiple* argues that very often words have incommensurable meanings not only across folkworlds, but within functioning social systems. This is not, she submits, an epistemological question - e.g. competing ideas about the nature of reality, and about which system of classification or way of knowing best represents or interprets an actually existing truth (vii). Rather, this is an issue of a "complicated crowd" of multiple

ontologies (6), or ways of enacting, recognizing, or relating to a particular classification about human bodies - in the case of Mol's research, atherosclerosis of the legs (a vascular condition).

I bring this up to gesture to the ways that there may be multiple definitions of disability circulating and being enacted within a single system. Another mode of understanding this question of manifold but intertwined ontological worlds in contemporary ethnographic theory is Anna Tsing's concept of friction, the productive mismatch that occurs when chains of commerce or meaning interact across difference. Globalized communities make use of multiple kinds of knowing; "universals" like human rights - or, the concepts of "disability" and "access" - travel across, through, and with different cultural realms, gathering distinct meanings and values in each.

Disability studies and medical anthropology take a similar tack in investigating both the information infrastructures of the welfare state (what is a definition of disability for? For whom is it working?), and the built environment of a given place (For whom does the city inhibit transportation? Who can move around easily?). That is, frequently, these questions of built-in-bias in both information and spatial systems are justice issues.

Enacting Disability

Ethnographers have long been concerned with sussing out folk categories as a manner of coming to understand a point of view. At the same time, information scientists, bureaucrats, and specialists in various fields are continuously concerned with the creation of expert categories.

On the one hand, disability is a medico-legal concept, defined by experts, diagnosed or granted through state systems (Stone 1984). It is also a folk category, an "I know it when I see it" form of bodily or sensory difference (Linton 1998; Garland-Thomson 1997). How, then, ought we understand the ongoing negotiation between disability as a category defined by experts

(lawyers, doctors, states), and by people in the thrownness of daily life? On the one hand, formal classification systems - knowable and known only to specialist or laypersons with extraordinary patience - are designed to reflect and interface with folk concepts, yet are elaborated more formally and are therefore more delineated.

Medical anthropologists have asked related questions about diagnostic systems of classification. When comparing cross-cultural systems of medicine and health, or ways of understanding the human body, medical anthropologists have observed that not only are the nosologies (or types of disease) different, but the bodily systems, parts, and symptoms that medical practitioners identify are also at odds (Good 2006). The question then becomes not so much whether or not there is one "correct" nosology (frequently assumed in mainstream US discourse to be Western or allopathic medicine, the only option that qualifies as "science"), but rather, how local systems of classifying the body and disease or difference play out in daily life. That is, a medical anthropological perspective insists that Chinese medicine (Farquhar 1994), Indian definitions of Alzheimer's disease (Cohen 1998), or Zande causes of disease (Evans-Pritchard 1976) are not invalidated by the recognition that they are cultural contingent; rather, they are *real* in that they are enacted as truth in ways that make them matter for people's lives.

Moreover, not only are localized systems of classification real, and enacted, they are naturalized and taken for granted. This becomes obvious in the ethnographic record, for example, in ethnographer's descriptions of the difficulty of finding a suitable informant: not every practitioner of a cultural system is able or willing to achieve the intellectual distance to describe their modes of action to an outsider (e.g., Shostak 2000 (1981)). The problem of unpacking local categories and domains of meaning is precisely the task of ethnographic research and analysis (Spradley 1973).

When categories are arranged into formal arrays produced by expert culture, the task becomes more difficult still, because speakers often assume scientific or formal knowledge to be "correct." This is a reasonable assumption: when a system of categorization - like diagnoses for an array of bodily impairments - has been invented and put into use, that indicates to a user that it is intended to convey standardized meanings across different contexts. In this way, when talking with interlocutors in transnational contexts, ethnographers may find that speakers tend to start out using formal or standardized categories because they assume that they will be easier to understand than more idiosyncratic or informal language. This makes the task of conceptualizing how to discern the colloquial locations and ontological meanings of formal arrays of categories particularly difficult.

These systems of formal categories can be described as *information infrastructures*. Bowker and Star offer two modes of defining and classifying diagnostic categories - the DSM (Diagnostic and Statistical Manual) and the ICD (International Classification of Disease) - as examples of information infrastructures. Read at face value, the ICD appears to be a natural and obvious representation of kinds of diseases in the world. However, when examined by attempting to trace how the existing information infrastructure was created, the categories are revealed to be undergirded by social circumstance and "the practical politics of classifying and standardizing." That is, "whatever appears as universal or indeed standard, is the result of negotiations, organizational processes, and conflict:" someone, somewhere had to make choices about what to include, what to exclude, and what to collapse into a single category (Bowker and Star 2000:44). Medical anthropology has long observed the many ways in which these nosologies of diseases, which are presumed to be universal by western medicine, in fact change over time and are difficult to apply cross-culturally. In these analyses, disability is usually

considered as an umbrella term describing certain diagnoses or certain severities of impairment. Yet, little attention has been paid to how *the category of disability is itself* is part of an information infrastructure. Disability must be understood as a knowledge infrastructure that emerges and is continually remade in lived contexts.

That is, in order to understand the concept of *invalidnost'* as embedded in enacted relations in contemporary Petrozavodsk, we need to understand how concepts of disability and *invalidnost'* have emerged and circulate locally, nationally and internationally, as well as historically. We need to excavate the classificatory systems of interlocking but heterogeneous parts that make up *invalidnost'* as a performed social identity, bureaucratic and medical category, reason for exclusion from the labor force and inclusion in the welfare state, and emerging or appearing/disappearing in given material and virtual worlds.

Models of Disability in Euroamerican Disability Studies

At the core of disability studies as a discipline is a critique of the *medical model* of disability. The medical model is the mode by which medical science views difference or abnormality as pathology (Linton 1998; Dreger 2007; Scully 2008). Under the medical model, disabilities are considered as related to illness, as needing to be cured, and as being the purview of medical expertise. People who are themselves the bearers of unusual bodies are assumed to be less knowledgeable about their conditions than medical professionals, which has the effect of devaluing and silencing the needs and perspectives of people with disabilities to speak for themselves about their own bodies. Medical authority becomes a form of violence.

This model of disability is conceptually akin to a range of work in medical anthropology, which, building on Foucault, considers *medicalization* as a form of violence that produces inequities of power/knowledge through the creation of expert cultures (Rivkin-Fish 2005). The

medical model and medicalization both imply that social problems are individualized, or adhere to the body of one person. In the medical model, for instance, this means that it is a *social phenomenon* of a social environment that presumes sighted users that is disabling for a blind user, who is otherwise perfectly capable. Medicine and diagnosis are therefore said to be individualizing discourses, in that individuals are defined as pathological. Disability in this view is totalizing or overdetermined (Garland Thomson 1997), so that in social settings, the many characteristics of a person fade in relation to the stigma of a disability or pathology (where feminists say, "my eyes are up here!" in response to sexualization, disability activists say "see me, not my disability!" in response to the pathologizing gaze). Disability Studies sought from its inception to flip this discourse, and figure ways that social contexts, rather than individual bodies, created disabling conditions for a diversity of human embodiments.

Disability studies has elaborated this critique by observing that the identifying a body as abnormal relies on the existence of a shared, cultural imaginary about a purported normal body. Lennard Davis, drawing on Canguilhem and Queletet, writes that the logical construct of ab/normal or deviant in European thought is tied to the invention of statistics as a science in the 1800s (2006). An imagined *normate* exists as a cultural construct in popular imagination, as someone who needs not be defined by an identity that deviates from an abstraction of what counts as normal in terms of race, age, class, appearance, sexuality, body, mind, and so on (Garland-Thomson). This theme of the normate will return repeatedly throughout this dissertation, as one important question that we might raise in thinking about disability in Russia is to define the unmarked category: what are the characteristics of a normate body in Russia today?

In place of the medical model, Euroamerican disability studies proposed a *social model* of disability, which posits that social and cultural attitudes and assumptions, not bodies, are at core of disability. The social model suggests a distinction between inherent characteristics of a given body - *impairment* - and the social and cultural responses and representations of the abnormal body - *disability*. It is this dyadic split that allowed disability studies to posit disability as socially and culturally constructed. The stigmatization of bodies as the result of medical pathologization, disabled scholars argued, was what was actually disabling, not any inherent characteristic of their individual bodies (Linton 1998). This social model relates to the argument of medical anthropology that diagnosis, nosology, and habits of the body are historically and culturally contingent. Similarly, medical anthropologists have argued that the reproduction of disability stigma has the affect of worsening or reproducing circumstances in which impairments and symptoms worsen (Biehl and Eskarod 2005; Barrett 2005).

Subsequent arguments from disability studies have complicated the notion of a social model, particularly the binary assumptions of the impairment/disability construct. As Tom Shakespeare has put it, the social model "risks implying that impairment is not a problem" (2006:200). There is no "barrier-free utopia" Shakespeare points out - although "barrier-free enclaves" or pockets of access in an inaccessible world are possible. "But disabled people face both discrimination and intrinsic limitations" (202). Others have challenged the implication that impairment, in the impairment/disability dyad is somehow outside of culture. Rather, impairment can also be understood as socially constructed (or at least the manner in which humans understand and name impairments). For instance, Shelley Tremain argues that the social model assumes impairment and disability to be opposed and mutually exclusive (2006:186-188). This leaves the concept of impairment under-theorized, as activist-scholar attention is focused on the

individualizing force of the medical model, and demonstrating the disadvantages that social orders create for the disabled based on their (objectively) impaired bodies. This dichotomy, like the notion of socially-constructed gender and "natural" sex in second-wave feminist theory, results in particular ways of categorizing and understanding the body and assumes some universal objective perspective from which impairment might be discerned (188). Tremain, similar to Davis who asserts that the conceptual possibility of abnormal bodies arose with population-level thinking, argues that because it is the result of the pathologization of an individual body, impairment ought to be understood as "an historical artifact of the regime of 'bio-power.'" She argues that the particular constellation of European liberalism described in Foucault's discussion of bio-power was a necessary cultural setting for the notion of impairment to arise.

Others, like Garland-Thompson, have further argued that impairment, like disability, depends on the cultural and material environment as well as on historical contexts. Drawing connections between gender theory and disability theory, feminist disability scholars suggest that how bodies are perceived and stigmatized is always changing: meanwhile, the impairment/disability dyad might imply a continuous or static relationship between bodies and stigma. Instead, disability is fluid and changing; bodies are never static, nor are social responses.

The question of what to do with the medical model has received a great deal of scholarly attention in disability studies. Additional titles and configurations have been suggested. The *environmental model* of disability assumes that a social model must consider the surrounding inanimate world, as well as social and cultural factors, to understand the degree to which someone's impairment might be disabling (e.g. Shakespeare 2006); this is the predominant model in use in transnational disability rights (e.g. Mont 2007). A further mode of conceptualizing

disability as *relational* or *transactional* observes that circumstances, culture, human interactions, and environments are never static but changing, fluid, and in motion, and then for disability depends on a body's occupation and physical and social positioning at a given moment in relation to other people and the environment; *relational* is currently used in critical humanities and social sciences (e.g. Kafer 2013:6), while a *transactional approach* is a current in critical applied fields such as occupational science and education (e.g. Cutchin and Dickie 2013:98).

Meanwhile, a separate thread of analysis has worked to describe the ways in which disability is related to notions of citizenship, to the nation state as a political entity, and to legal categories. Some might call this a political model of disability. According to the medical anthropological understanding of citizenship, disability is a transaction between citizen and state. Tracing the way that the category of disability was invented as a tool of the welfare state, Deborah Stone calls disability a medical-legal concept (1984). In my view, history of biopolitics and makes it difficult to separate medicalization from politics and the management of populations. At the same time, given that Biopolitics describes a very particular genealogy and historical-cultural configuration, it is important not to assume that the politics of disability are always the same: the cultural practices of medical authority and legal bureaucracy in a given nation state or particular subculture might produce very different modes of medicalization and ableism.

Anthropologist Sarah Phillips has argued that in the case of postsocialist Ukraine in the early 2000s, the configurations of citizenship and disability were multiple. She writes that individuals moved between competing but equally viable models of citizenship, choosing to mobilize logics of Soviet state provisioning and neoliberal individual responsibility in quick transition, as best benefitted their objective in the moment. Similarly, Adriana Petryna shows that

the value of a disability diagnosis depends on one's subject position, citizenship, and the particular political configuration of welfare apparatuses; she observes that Ukrainian citizens in the 1990s worked to use the medical system to maximize the best personal outcomes in negotiating the role of Chernobyl survivors.

In this way, the political model of disability is important for what it might assume about what counts as a strategy for justice. In Euroamerican contexts, as discussed above, a rights-based model of justice, which relies on the existence and functioning of a liberal nation state, dominates claims for disability justice. But research shows that strategies for disability justice are multiple and varied.

Rights-based justice strategies include the Americans with Disabilities Act (ADA), which uses a civil rights framework to shape legislative regulations about how public spaces and services ought to be configured to prevent discrimination. The ADA, in order to function, requires that the regulations in the written law be implemented in reality; this relies on a great deal of work and self-advocacy on the part of citizens to assert that the law exists and ask their neighbors to implement its policies (or, to sue those who refuse to do so).

Civil rights also presume a particular kind of understanding about the role of minority interest groups in a population. That is, they presume a condition of democratic rule of law that values pluralism. Civil Rights also often do not apply equally to a population; for instance, incarcerated people are frequently denied rights routinely; the very poor or officially homeless are also often unable to recognize civil rights or pursue justice if their rights are violated. That is, Civil Rights rely on judicial procedure, self-advocacy, and the continued existence of the guaranteeing body, the nation state. Drawing on Nancy Fraser's distinction between rights-based and redistribution-based struggles for justice, Tom Shakespeare has called for a recognition

within disability studies of the important role that redistribution, or financial provisioning, plays for many people with disabilities.

The ADA also relies on an additional logic that has often been presumed to be universal, the question of access to public space. In this mode of thinking, physical or material barriers in the built environment that prevent people with disabilities from moving freely through public space prevent full participation in social and civic worlds. Barriers to access, in the logic of the ADA, can be removed in order to create a more equitable and just society. Some disability advocates have criticized this model as relying too heavily on material or literal barriers, when often, barriers to participation are about social attitudes rather than material structures. Others argue that as a law, the ADA seeks to remove ambiguity about what counts as a barrier, and attempts to address social as well as physical barriers to access. In part, the logic of the ADA relies on a genealogy of the idea of universal design, inclusive design, or a barrier-free environment (Zola 1989; Imrie 2004). Emerging from the disability advocacy movement, the notion of inclusive design proposes that by designing an ideal built environment and social norms, society could remove the barriers to participation for a person with a disability. That is, harkening back to the social model, inclusive design involves the intentional creation of a social environment in which impairments need not be disabling. In some ways, the logic of inclusive design is inherently related to what Lefebvre calls the politics of space, or the ways that structures and tools are always created with particular bodies and activities in mind, and in so doing, implicitly privilege some users over others. That is, spatial relations are always power relations. Design thinking, as a particular technology of modernity, seeks to solve human problems through engineering. Socially-minded design, the logic goes, can minimize the power imbalances by design more egalitarian spaces and tools (Papanek 2000). Design thinking

continues to attract utopian aspirations and pragmatic problem-solving, both in relation to disability and more broadly (Escobar 2012; Hendren 2013).

Another core precept or organizing principle of Euroamerican disability studies is the language and representation matter for justice. These principles are related to broader understandings of systems of minority oppression. That is, like sexism, racism, and heterosexism, ableism silences the voices of the oppressed minority. When majority culture does not hear from people with disabilities on their own terms, this allows stereotypes to proliferate (e.g. people with Downs Syndrome can't read or care for themselves; members of racial minorities are always poor; lesbians are women with short hair; wheelchair-users need help to get around, etc). Like other minority groups, disability justice advocates in Europe and North America have pursued strategies of self-representation. This includes the idea that a person or group of people has the opportunity to chose what they want to be called (e.g. Deaf not deaf; First Nations not Native American; etc). It also suggests that seeking representation of one's own group in the media and entertainment can be an important strategy for building self-esteem among youth, raising awareness, and breaking down stereotypes and prejudice (e.g. many would argue that the proliferation of television shows with LGBTQ characters in the late 1990s and early 2000s was an important component in the shifting opinions of straight Americans toward the idea of same sex marriage). Yet, while these cultural models for combatting oppression, reclaiming identity, and raising visibility of a minority group's concerns are readily accessible in Euroamerican culture, they may not be as available in other regions or cultural settings.

Euroamerican disability studies and the anthropology of disability have contributed to this project of centering the voices of people with disabilities in the struggle for representation. Ethnographic works like *Making It Crazy* (Estroff 1981), *Making Life Work* (Levinson 2010),

and *VITA* (Biehl and Eskarod 2005) have very self-consciously situated themselves as amplifying subjugated voices, and telling the stories of people with disabilities. Meanwhile, disability literature and performance have sought similar tactics, locating disabled bodies onstage as performers (e.g.), and centering narratives of people with disabilities in stories, poetry, memoir, and novels (e.g. Nussbaum 2013; Finger 2009).

Like other Euroamerican social movements, disability advocacy has encountered the problem of differentiating assimilationist and radical strategies. For instance, queer theory has posited that while same sex marriage represents an assimilationist strategy by which some lesbian and gay people seek to become "just like" the straight majority, other queer-identified activists in fact continue to critique the institution of marriage as an inherently unequal patriarchal system of state-sanctioned class-based property distribution (Warner 1999). Even as assimilationist members of a group seek to become more like the majority, others maintain a radical critique that the previously subjugated position made obvious. In the case of disability justice, one term for the radical position might be *crip*. Taking a reclaimed word from the history of subjugation, crip advocacy might continue to resist some of the privileges of assimilation into mainstream culture. For instance, while some assimilationist disability advocates might proudly bring home a paycheck, asserting that thanks to minority rights movements and laws that combat discrimination, people with disabilities can earn a living and provide for themselves; meanwhile, a crip advocate or theorist might ask, should one's social worth and bodily comfort really be dependent on one's productive labor or earning power? Crip theory - as a distinct lineage of disability theory - takes this charge seriously, in particular, using a joining of queer and disability theory to unpack majority culture assumptions about what is good, right, and natural (McRuer 2006). That is, the crip perspective does not aspire to the norm, but seeks to trouble the norm.

In this sense, Civil Rights as a strategy for justice relies on the citizen organizer and the grassroots social movement to bring issues of injustice to public attention and to the judiciary. From deinstitutionalization, to the Independent Living Movement in California in the 1970s, to inclusive education movements, to the contemporary Neurodiversity movement unfolding online, a disability history of the US shows that gains in disability justice in the twentieth and twenty-first centuries all came about as the result of citizen organizing. This organizing relied on the willpower, education, and access to communication and resources of the subjugated group. In this sense, the disability movement must be understood as a social movement engaged in the act of knowledge production (Escobar 2008:24). By creating new ways of thinking about disability that challenge the dominant perspectives (e.g. naming the medical model), disability justice advocates worked to shift the ways in which bodies and difference are understood. This required use of mass media, interpersonal organizing, and any other means of distributing information and sharing knowledge. This view also situates disability studies, as an interdisciplinary genre of academic thought, as a direct result of the knowledge production organizing of the Euroamerican disability justice movement.

Tracing disability stigma in Russia History

In pre-Revolutionary Russia (19th century and before), feudal systems located the majority of the population as agricultural serfs. The concept of difference was mediated by orthodox Christianity, and concepts of neediness as an organizing category; in this way, widows, orphans, the very ill, and the war-wounded and others somehow unable to care for themselves were grouped together as needy (Lindemeyer 1996). The rapid industrialization of labor following the revolution, and the creation of a welfare state with a workers' needs at its core instituted a category of disablement for adult workers and soldiers, regardless of gender (given

the radical ambitions of the early soviets to eradicate domestic slavery through the mobilization of women as laborers outside the home) (Madison 1968).

In the early twentieth century, a Soviet concept of childhood development rooted in Marxism was developed by Vygotsky (incidentally now en vogue in American psychology and educational scholarship). The hypotheses inherent in this approach located the fault for a child's development in his or her social circumstances. This often had the unintended effect of locating blame for a child's non-normative development in some action of the home environment (McCagg 1989). Most frequently, given the failure of the new gender order to live up to its claims, this meant that a child's abnormal development was the fault of some failing of the child's mother (Iarskaia-Smirnova 1999). Monetary benefits for families with children born with disabilities were not established until 1968 (Dixon and Macarov 1992: 197-199). This may have been, in part, because mothers were encouraged to institutionalize special needs children.

The popular representation of disablement in the second half of the twentieth century was one of denial and absence – although there was some popular discussion of the plight of the honorable injured veteran following the second world war (Krylova 2001), while Soviet realist style in visual and literary art glorified the working body, it erased the non-normative body. Sarah Phillips has observed the pervasive degree to which Soviet ideology linked physical, cognitive, and mental otherness with low moral worth, and literally denied the existence of people with disabilities in the population (2011). Because Soviet citizenship valued labor contribution to the collective as the measure of a good life, those who were unable to work due to disablement were faced with not only a bodily condition, but also with this specter of attendant moral failure. In their own words, disabled Soviet citizens observed that they were invariably cast as social pariahs, even, “social parasites” (the ultimate Soviet condemnation of

character) (Dunn 1989:218). Similarly, what we know about the conditions of life for people with disabilities in institutions or living as social pariahs in family homes, is bleak (Phillips 2011, McCagg 1989). There seems to have been a quite literal effort to incarcerate or otherwise hide bodies that were unable to contribute to labor practices in the normative way; there was even a colloquial refrain that because disablement was the product of social ills, disabled people existed in conditions of capitalism, but not in the Soviet Union.

Yet, as early as the 1980s, a federal disabled person's organization had member groups in various cities to support the lives of adults with mobility impairments (Personal Interviews).

With the dissolution of the Soviet Union, a period of social upheaval and lack of certainty about the day-to-day reproduction of life rendered political action difficult: many were struggling simply to maintain a semblance of their former way of life in the face of rolling wave of resource depletion. Moves toward democratic reform during the perestroika era became muddled with economic disarray. Categories of citizenship and belonging, of nationhood and moral frameworks of social good were all thrown into question as the Soviet system was abruptly juxtaposed in new and "shocking" ways with neoliberal capitalism.

In a climate of uncertainty, local solutions and organizing became critical for survival. Diverse strategies for claiming disability justice, especially alternatives to institutionalization, developed. Personal predilections, local politics, and available economic and intellectual resources all contributed to diverse strategies for disability lobbying across postsoviet territories. These local strategies often constitute unique hybrids of rights-based and social support-based pathways to disability justice. The community-based organization has served as an important locus of action, drawing on diverse vocabularies change (Hemment 2007; Henderson 2003; Kay

2000; Kuehnast and Nechimias 2004). The vibrant NGO culture of the 1990s and early 2000s became an important structure for disability justice.

Talking about Disability in Russian

In seeking to understand *invalidnost'* as a social category, I have been very curious about how Russians talk about disability. What words and phrases do people with disabilities use? Are these words and phrases different from the words that journalists use? That parents use? That the general population uses? What registers of language are implied by different phrases? Which words and ideas seem to be indigenous, or are considered native to their users? Which seem foreign? And, finally, when people with disabilities talk about themselves or others with disabilities, what words do they use?

In my research, I found that there were three overlapping formal lexicons for disability: medical, legal/official/social services, and journalistic. One could potentially argue for several additional sub-lexicons that exists within professional specialties: (1) architectural/infrastructural, (2) pedagogical, e.g. used by educators, (3) academic, e.g. used by sociologists who read foreign research. These lexicons remain quite specialized, in the sense that it is unlikely that anyone besides professionals in question would use them.

The medical lexicon in Russian behaves quite similarly to the English lexicon for disability, in that it privileges diagnostic terminology, which, although recognizable, remains impenetrable in terms of meaning to those without a medical degree. Also, the words for types of disability - diagnoses - can be used either as descriptive terms to talk about one's own or another person's specific impairment, or they can be manipulated to be used as an insult against an able-

bodied person¹¹. The language around disability and illness in Russian is somewhat more medicalizing than contemporary English usage. For instance, if a person with Cerebral Palsy (but no health problems) were describing an unknown person to me, she might use the word *zdorovy*, literally, *healthy*, to designate that person as nondisabled. A possible synonym in this circumstance would be to explain, "*on normal'nyi - v smisle, ne invalid*" that is, "he is normal, as in, not disabled." This is partly an artifact of the absence of a ubiquitous disability rights movement that has suggested naming the normative category; e.g. there is no equivalent neologism like the English *nondisabled*. The effect of this, however, is to produce *invalidnost'* as a category as occupying a semantic domain that is always opposed to health.

The legal or official lexicon of disability in Russian is interesting. In terms of the vocabulary of the welfare state, the word *invalid*¹² in this context means quite exactly "person who has been determined by the state to have a disability, based on a medical/psychiatric diagnosis, and therefore is entitled to a monthly pension among other benefits." The word *invalidnost'*, then, the abstract quality of being an *invalid* is quite similar to the concept of disability as a category of medico-legal status. This is quite precisely what is meant by disability in the eyes of the social security administration in the United States. In both cases, disability status is established based on a determination about the severity of impairment or illness,

¹¹ For example, a recent demonstration in Moscow used a Downs Syndrome slur to antagonize Ukrainian nationalists.

¹² I should say that I avoid using the Russian word *invalid* in English, and I do not translate it as the English *invalid*. This is because the word entered both Russian and English from the German in the 17th or 18th century, so genealogically, although they share a common root, the Russian *invalid* became the word used to describe social benefits, while in English this has, since the advent of Social Security in the 1930s, always been *disability*. In this sense *disability* is the proper translation for *invalid*. Moreover, I find it misleading to suggest that Russians "still" call the disabled "invalids" for two reasons - first, that the course of linguistic change over two centuries should not be expected to follow identical paths, and second, that in Russian the word *invalid* carries none of the connotations of "in-valid" or lacking worth that it does in English, since those root words are illegible to Russian speakers. In this sense, a Russian speaker might observe that the English word for dis-ability is quite derogatory. See Hartblay 2006 for a further discussion.

principally in regard to ability to work for adults and to severity of psycho-social-motor delays for children based on age and established medical norms for development. The disability determination process differs in that the Russian system recognizes three levels of disablement, each with a corresponding level of pension and benefits, while in the US, aside from Veterans benefits, state disability status is determined as a binary qualification. Additionally, in the Russian system, determination is made by appearing before a panel of medical experts in person, with one's medical records (while the US social security system involves an escalating process of application and appeal, with a single trained professional (not a doctor) making the determination at each stage).

Newer legal lexicons for disability have come into play since the 1990s, in the context of legal provisions regarding disability and access. These terms, by and large, have yet to make it into the general lexicon of the Russian language, although they are used by and familiar to some disability advocates who are familiar with the laws out of necessity. These sets of terminology tend to translated approximations of transnational accessibility regulations, such as the type found in the ADA.

Similarly, journalists, since the early 2000s, have used a range of translated terms that seek to speak of disability using less stigmatized language. These phrases tend to be euphemisms for disability that will be familiar to English speakers as related genealogically to those politically correct terminologies that circulated for a time in the 1990s, but now are generally considered overwrought: person with limited abilities, person with special needs, etc. [see chart, below]. Even so, the disability advocacy organization Perspektiva has released a set of linguistic guidelines that suggest a middle ground: to use the word *invalid*, but to modify it as a translation of "people with disabilities." This phrase *lyudi s invalidnostu* was the one that I tended to use

myself, because I found it easier to say and less euphemistic than the other alternatives, while still flagging an attention to word choice. Interlocutors, in interviews, tended to repeat that phrase back to me if they were speaking directly in response to a question; however, in most other cases, they simply use the word *invalid* or *invalidi* to talk about themselves or others. Journalism, for the most part, seems to have already established a set of standards that has institutionalized the longer phrases, especially in print. Television news is more likely than print journalism to use the word *invalidi*, or to use the phrases interchangeably.

Finally, there is yet another lexicon of official or state language for disability. This is language that appears in government documents, such as statements prepared by the ministry of health, or in official educational settings, or in the naming or description of government agencies or social work and by extension some NGO projects. Where until as recently most of these projects used the word *invalid* to describe projects, facilities, events, pockets of funding, or other programming aimed at people with disabilities, the most recent government documents use the phrase people (or children) with limited abilities¹³. This phrase has the quality of taking up a lot of space in print, and of taking a long time to say out loud, which suits Russian official style. To me, the phrase also implies translation from transnational models, in that I imagine that at some point a government official felt that this phrase was more politically correct and had more cache in international conversations. But it seems that the proliferation of the phrase in daily use by people in daily life has come from its appearance in government documents, and so it has the quality for provincial Russians of being simply an official way of saying *invalid*. For example, a friend insisted on using this phrase in her description of a volunteer children's theater project that

¹³ I thank Michael Rasell for corresponding with me about his take on the move to incorporate the longer phrase into Russian official documents.

we were planning, explaining that it was the most official phrase, and therefore the one that we ought to use to make our project sound professional.

Meanwhile, current usage amongst people with disabilities themselves has not, to my knowledge, turned to these longer phrases. When my interlocutors with disabilities intended to describe themselves or a friend as disabled, they used the word *invalid*. For instance, Anya (the psychologist and wheelchair user) once quipped when I asked her about this subject:

I don't see anything bad about the word "invalid". It's fine with me - short and clear. It's really good.¹⁴

In contrast, she pointed to the absurdity of the more effusive language.

I don't think the word [*invalid*] is bad and I and I can't remember why etiquette... it's a moral thing for people with *invalidnost'*. So, I wouldn't go around correcting people who say *invalid* because some people are offended by it. I personally don't understand why they're offended by this word. I think it's a totally normal word. For example, a clerk in a store doesn't get offended if you call him a clerk, does he? And it's just the same here: so, an *invalid*... yes - an *invalid*. What else are you supposed to call it? A person with limited abilities [*s ogranichennymi vozmozhnostyami*]? But what kind of abilities are limited?

I remember this one time, we were at a seminar on inclusive education. So everyone there was saying "*lyudi s ogranichennymi vozmozhnostyami*" And there was this one older guy there, and he's also a psychologist and a really good person. So he all of a sudden says, "it occurs to me that I myself can say that I am a person with limited abilities, because I can't go to space, and I can't go down into the mines... I'm a person with limited abilities."¹⁵

In this statement, Anya sets up a joke about the phrase "limited abilities." She does so partially as a way of gesturing to the absurdity of politically correct language, and her own disdain for what she perceives as a lot of fuss over nothing. At the same time, she uses the joke to flip the

¹⁴ This statement - that *invalid* - a useful, short word - and therefore worthy of hanging on to in spite of the proliferation of longer, more politically correct terms - seems to have something in common with sentiments expressed by Euroamerican disability activists or crip activists about the word "cripple." For example, in an essay in which she reclaims the word *cripple*, Nancy Mairs writes, "'Cripple' seems to me a clean word, straightforward and precise" (1986). I thank Sue Estroff for recalling this Mairs quote.

Я не вижу ничего плохого в слове «инвалид». Мне оно нравится – коротко и ясно. Очень хорошо.

¹⁵ Помню, мы были на семинаре по инклюзивному образованию. Так там все говорили «Люди с ограниченными возможностями.» Так там один дяденька – он тоже у нас психолог и очень хороший человек. Встал и говорит: «Я сейчас встал и могу сказать, что я – человек с ограниченными возможностями, потому что я не могу полететь в космос и не могу спуститься в шахту... Я – человек с ограниченными возможностями.»

meaning of the phrase "limited abilities," and points out that ability is relative anyway. In her description of the context, she clearly elucidates the reason for which the phrase "limited abilities" had been used: she was at a seminar on inclusive education. This means that the official lexicon of educational rhetoric was in use, and therefore, educators and psychologists were expected to use the official phrase. At the start of the quotation, Anya repeats the phrase *people with disabilities* back to me, but then shortly switches back to *invalid* to make her point.

At the same time, Anya was sometimes critical of other people with disabilities. She would herself use the word *invalid* as a way to designate someone who was dependent on the help of others, or in the case of Rudak, contrast his independence as atypical for a person with a disability. For example in one case she said:

So, what is *invalidnost'*? I for one can say.... that for a person who is physically healthy, but doesn't want to do anything. I can say that he in a way is an *invalid*. And so in this way... at the same time, I can't say the same about a person with physical impairments...

Like, for example, my friend [Rudak] - I wouldn't say about this person that he is an *invalid*, because he has a highly developed personality (*on vysoko razvitaya lichnost'*). You can't call him *invalid*. You could call him *a person with physical impairments* (*s fizicheskimi narusheniyami*), to say that his body [lit., biological form, *organism*] isn't totally ordinary. But at the same time you wouldn't call him...

In this way, Anya identified the stigma associated with *invalidnost'* as being intrinsically related to some abstract quality of a person's personal development and ability to self-actualize. In a sense, her assertion that Rudak is not an *invalid* is a way of saying that he does not allow himself to be disabled by social barriers, in spite of his physical impairments. This off-handed theorizing holds some relationship to the social model of disability, in that she locates disability outside of an individual body, and in social relations. On the other hand, Anya, trained as a psychologist, offers a model is more of a psychosocial than a social model; she ascribes Rudak's independence to his psychological development. In another segment of the same interview, she talks at length about how a child's mother can chose to raise her disabled child as an *invalid* or as a normal

person. In this way, she stresses *development* as a process of socialization or moral education [*vospytaniye*] by which someone might achieve or fail to achieve the skills for self-realization.

This notion of psychosocial development and "successful" or unsuccessful socialization also appears in Svetlana's dissertation. She writes that the goal of social programming for people with disabilities should be to achieve a "degree of social interaction so that a young person's personality can achieve a successful or 'normal' kind of socialization" (Driakhlitsina 2009b:16). She uses this framework of socialization to argue that the purpose of social programming should be to support young people with disabilities in having varied and multifaceted life experiences - in contrast to the frequent situation in which a person with mobility impairments, unable to leave his or her apartment without the help of one or two people - might spend most of their days home alone. In this way, both Anya and Svetlana, the two members of my interlocutors who engage with scholarly discourses on disability, reached for psychological frameworks in describing and arguing for more liberatory perspectives on disability. This is significant, in that both view the issue of stigma as psychosocial, rather than as political in the sense of civil rights.

Anya and Rudak, as the two people amongst my core group of interlocutors who both identified as disabled and saw themselves as actively work to improve the social conditions for people with disabilities, were more likely to talk about disability in the abstract. While Alina would sometimes relate a specific complaint about finding work or transportation, and relate it to disability, Anya and Rudak would happily talk at length about disability as a collective and even political identity. Anya, because she had written her masters thesis on disability, was quick to reference academic jargon, and could easily produce theories about the history of *invalidnost'* as a marginalized status. For instance, in one interview, she told me:

We are talking about the meaning of the word *invalidnost'*. In reference books, they'll spell it out, as a persistent [*stoikiye*] impairment, intellectual or physical. So that's that - *invalidnost'*. But strictly speaking and all...

A long time ago, years ago, we had a kind of ideological movement, when they tried to build a "healthy society" [*zdorovoye obshchestvo*]¹⁶. And all the people who were born with disabilities [*vsekh rodivshikhsya lydei s invalidnostu*] they hauled off and locked up somewhere... so that they were out of sight... So, that's probably where it comes from, more or less... or else... I don't want to say anything bad about the church... But I was just dealing with this problem, that for some reason or other the church is saying that *invalidi* - "the defective (weak, malformed, imperfect) strata of the population" [*usherbnyi sloi naseleniye*] ... [indignantly] Why *defective*?! ... Basically, if you tell a person over and over again that he's a pig, eventually he'll end up oinking. If the church - this great institution that's been so meaning for people - goes and says "Yes, you have to help *invalidi*, they're feeble [*usherbniye*]," then people *s invalidnostu* end up thinking, "Aha, we need help. So let them come and help us." It creates a wrong-headed understanding of your own existence. Well, I'm against it...

This raises an interesting issue about when my interlocutors used *invalid* - as in designating a particular person or group of people as disabled - and when they talked about *invalidnost'* - disability - as an abstract concept or collective identity. For example, I can make a list of categories of people who talk about disability in their daily lives, whom I encountered in the course of my fieldwork:

- *interlocutors with disabilities*
- *advocates working on legal/civil rights (e.g. right to attend school, to represent oneself)*
- *advocates working on legal/social rights (e.g. pensions)*
- *NGO employees working on disability issues*
- *people with disabilities*
- *social workers and psychologists serving people with disabilities*
- *reporters covering social issues*
- *teachers and administrators, especially in special education facilities*

¹⁶ It's unclear here if she's referring to the Soviet concept of the social body, or to Erich Fromm's "Sane Society" - given the context, she may be substituting Fromm's phrasing (from her training as a psychologist) for the historical Soviet mentality.

- *medical practitioners, especially in special education or rehabilitation facilities*

This list could also reflect, to a certain degree, the people who agreed to speak with me, or to whom I was directed as a potential source, when I was doing this fieldwork, that is, people who recognized some element of themselves or their work in my topic.

The list then is naturally divided into those who understand disability as an element of their own identity, and those who simply understand that they have some degree of disability themselves. Those who worked with people with disabilities tended to use the word *invalid* or talk about people with disabilities in the abstract fairly frequently: *lyudi s invalidnostu*, *lyudi s ogranichennimi vozmozhnostyami*. The category was a part of their professional expertise. People whose work only occasionally or tangentially related to disability, except for journalists, were likely to be uncertain about what terminology to use to describe this group of people. People who themselves had disabilities, on the other hand, tended to rarely use the word *invalidnost'*. If they did use it, it was frequently in the context of a change in disability status:

Vera: Actually, when I was born, I didn't have a disability [*u menia ne bylo invalidnosti*]. At ten years old I got a spinal cord injury. And so, from age ten onward, I've been in a wheelchair.

Meanwhile, Alina only used the word *invalid* to talk about herself if she was referring to her pension status. In other cases, she described her own physical characteristics as they were relevant to her point (e.g. "I need help standing up to go to the bathroom, so the volunteer used to help me and we got close"; or, "my arms are sort of - they're not very strong, I manage to get around the apartment, but to walk somewhere outside I need help"). Vakas, as far as I can tell from my fieldnotes, never used the word *invalid* to refer to himself or anyone else. This could be a factor of his literary manner, but I also wonder if he found it to be stigmatizing. When he related stories from his childhood to me, he used the phrase, "when I had my accident..." [*kogda u menia byla travma*].

In this case, *invalidnost'* refers to an attribute of an individual, or to a particular change in one's individual body and related social role and social benefits. An exception to this is Anya. As someone who belongs to both categories - someone who has a disability, and someone who works with disabilities, she was able to speak as both a professional and as a person with a disability using the vocabulary of collective identity, *invalidnost'*.

This offers an important distinction in the mode of understanding the meaning of *invalidnost'*: that is, there is disability, the status, and disability as a collective identity, or minority special interest group. That is, one did not need to be talking about rights to be talking about disability as a collective identity with shared problems, interests, and desire for justice.

Significantly, there was one other person who used *invalidnost'* in both manners, or, rather, one other person with a disability himself who used it in both ways: Rudak. In this sense, there is a direct relationship between the use of disability to refer to a collective identity or special interest group rather than as an individualized social status and a person's understanding of disability as a political issue or point of social advocacy.

This was not necessarily static, however. Over the course of the time we spent together, Sergei, in telling his story and narrating his perspective, reflected on the category more and more. Interestingly, his father, who is friends with Rudak, and is also a journalist, already seemed to think of disability as a collective identity. Sergei most frequently talked about disability as an abstract concept when referring to his parents, or to someone that he perceived to be an activist. Sergei was interested intellectually in thinking sociologically, but he hadn't had any training in thinking about social systems; he had studied advertising and media design in college. So, although he knew that disability advocacy exists - his parents were both very active with NGOs during his childhood - he rarely thought about himself in relation to his social status.

The chart below offers a rough representation of some of the variegation of words related to the idea of disability or *invalidnost'* in Russian. However, while I have provided the English term which I think most approximates the register and translation of the Russian, I cannot do so without a disclaimer that the social assumptions embedded in the English term cannot cleanly apply to a Russian term. For instance, for a term that is used primarily in medical contexts in Russia I have offered an English term that is also used primarily in medical contexts; but this masks or elides the important and significant difference in US and Russian medical systems of care. Likewise, as language changes, many of these terms change in meaning and tone; they are listed here according to the meaning they held to the best of my ability to discern during the time of my major dissertation fieldwork trip in 2012-2013.

Figure 2 – A Russian Lexicon for Talking about Disability

Russian	Russian transliteration	English translation	Notes
инвалид	<i>invalid</i>	disabled person; person who receives state disability pension	as with disability US English, this is both the legal term denoting a class of people, and the word most often used in newsmedia to refer to disability identity. In certain cases, the word could be used somewhat dismissively or disparagingly: He's an <i>invalid</i> .
инвалидность	<i>invalidnost'</i>	disability, or the abstract noun indicating a state of disablement	See above. The abstract noun is perhaps even more technical than the noun, likely only to be used in writing or in specific professional contexts.
калека	<i>kaleka</i>	cripple	similar to the English <i>cripple</i> , this term denotes a visible

			physical impairment and related stigma and poverty, especially associated with earlier historical eras and beggarly behavior; it would be rude, shocking, or ahistorical to refer to oneself as a <i>kaleka</i>
убогие	<i>ubogiye</i>	wretched (as in Biblical “wretched of the earth”)	Occasionally referenced in contemporary Russian discourse ; carries a sense of reverence toward the person indicated.
юродивый	<i>yurodivyi</i>	holy fool	Although religious in derivation, punks might embrace the "holy fool" role, as in one who speaks the truth to power by performing nonsense (e.g. see Pussy Riot's trial statements). Like <i>ubogiye</i> , implies a sense of blessedness, of being close to God.
нарушение	<i>narusheniye</i>	impairment	in Russian usually only appears in medical contexts; is used in Russophone sociology to discuss the impairment/disability distinction
нездоровой	<i>nezdorovoy</i>	unhealthy	
ненормальный	<i>nenormalnyi</i>	abnormal	A colloquial manner of indicating someone's difference from the norm. Could refer to any manner of social deviance, such as sexuality or bodily difference, or to mark general dislike for a

			person's particular social persona " <i>onenormalnyi</i> " e.g. a <i>weirdo</i> .
болезнь/ больной	<i>bolezn'/ bolnoi</i>	illness, ill or sick	similar to English, an illness as a noun is usually an affliction of any severity; but the adjective <i>bolnoi</i> or <i>sick</i> can be used in the abstract to mean depraved or deviant, as well as to reference a person suffering from an affliction
диагноз	<i>diagnoz</i>	diagnosis	particular diagnostic categories also circulate in pop culture (e.g. autism)
наши/такие люди	<i>nashi lyudi/takiye lyudi</i>	our people/those people (such people)	Russians frequently use pronoun formulations to indicate a group of people already implicitly being discussed. This can either be an in-group or out-group designation, and the group in question depends solely on the context. In some cases the out-group mode becomes euphemistic in a manner that Westerners might consider rude or otherizing (e.g. when speaking about a particular racialized - or in the case of disabled people- group without actually personifying them). Inversely, someone with a disability may refer to someone else as "nashi" - meaning a

			member of a given community of people with disabilities.
люди с особенными потребностями	<i>lyudi s osobennimi potrebnostryami</i>	people with special needs	
люди с ограниченными возможностями	<i>lyudi (deti) s ogranichennimi vozmozhnostyami</i>	people (children) with limited abilities	This phrase has recently replaced <i>invalidi</i> in state social services language and in corporate documents regarding diversity. However, disability pension law still refers to <i>invalidi</i> . The length and awkwardness of the phrase LSOV is logical in print, but creates some havoc in spoken language when polite or professional context require its unwieldy use; most people who are themselves disabled continue to use <i>invalid</i> to talk about themselves or their cohort.

Conclusion

This complex mode of considering disability or *invalidnost'* as a symbolic arena for meaning making plays out both on the ground in Russia and in international contexts. The meanings and values that conversations about disability or *invalidnost'* take on depend on how and why and by whom talk about disability or accessibility gets enacted. This raises a question about what meanings and debates disability stirs in the many different contexts in which these terms circulate. The following chapter will explore how debates about the definition of disability, and its population prevalence in Russia and other nation states, show what is at stake for

international specialists working disability as a way of addressing public health, human rights, or national economics. The bureaucratic categories of disability and the definitions of disability in demographic studies get enacted in surprising ways. Then, further chapters of the dissertation will again take the questions of how vernacular meanings and classifications of disability, 'invalidnost' and access are enacted through embodied practice and social performance in Petrozavodsk.

That is, in order to understand the concept of *invalidnost'* as embedded in enacted relations in contemporary Petrozavodsk, we need to understand how concepts of disability and *invalidnost'* have emerged and circulate locally, nationally and internationally, as well as historically. We need to excavate the classificatory systems of interlocking but heterogeneous parts that make up *invalidnost'* as a performed social identity, bureaucratic and medical category, reason for exclusion from the labor force and inclusion in the welfare state, and emerging or appearing/disappearing in given material and virtual worlds.

CHAPTER III
GLOBAL BODIES:
DEFINITION & DEMOGRAPHY OF DISABILITY IN INTERNATIONAL CONTEXT

This dissertation takes as its subject the ideological category of *disability* or *invalidnost'* in contemporary Russia. Yet, readers may be dissatisfied by this assertion. Which disability? Who counts as disabled? How many people are disabled in Russia today? All of these are reasonable questions in response to the presentation of this subject. It is precisely the difficulty of answering these questions that makes *disability* or *invalidnost'* an important and compelling subject of ethnographic study. Answering the question of *how many* people with disabilities live in Russia today depends first on how we define *disability*.

This chapter will explore some of these debates in order to demonstrate the ways in which the meaning of the word *disability*, as a universal concept or category, is unstable and contested. In relation to other chapters, the reader will see that what is at stake in the definition of disability for demographers, and for policymakers seeking disability prevalence statistics, is quite different than what is at stake for people with disabilities themselves. As these notions of disability get handed down through international NGO structures and national governments, enacted through policies and bureaucracies, they will come into tension with other frameworks for thinking about disability that do not map one-to-one, yet functionally perform as a unified category. That is, the expert cultures discussed in this chapter can be conceptualized as one link in the chain of heterogeneous notions of disability that come into friction through sequences of global exchange. That is, approach of this

chapter is anthropological, an ethnography of global expert cultures of disability demography, and aims to cast a backdrop that will help the reader to situate the events unfolding in Petrozavodsk in international context.

While demography and population studies seek to give us aggregate information from which to draw conclusions and make policy decisions, qualitative research is needed to attend to the ways in which categories may create some problems or disguise others. Ethnographies of bureaucracies and expert cultures help us to unpack the ways in which commonsense assumptions get enacted and domination and hegemony of non-agentive power can be disseminated not through exertion of force, but through habits enacted in material worlds¹⁷.

Given this example, we might make an analogy to help us understand the way that *disability* functions as a contested category. If *race* is the category, and racial identities are subcategories, we might think of *disability* as its own shifting, contingent cultural category, and particular disability diagnoses (e.g. Autism, Down Syndrome, Cerebral Palsy, Traumatic Brain Injury, Deafness) as sub-categories that are local, emplaced, and rooted in historical trajectories. That is - specific disabilities are not necessarily consistent across cultures or time, and even within a given cultural time and location, boundaries are contested and

¹⁷ Anthropologists have long been interested in the ways that humans make sense of the world: the variegation of words, ideas, and categories that circulate in cultural groups are foundational to our cosmologies, or working concept of the world around us. For example, recent exhibition by the AAA, which travelled to museums throughout the United States and continues as a digital exhibition online, was devoted to revealing the slipperiness of American colloquial categories of race (<http://www.understandingrace.org/>). Scholarship on related topics has tracked the ways that racial categories, which are often taken in public discourse to be absolute, obvious, and static, are actually shifting and continually troubled by people who do not fit easily into any one category, or whose identity is overlooked by the categories all together. For instance, when medical anthropologists sought to track maternal and child health outcomes amongst Haitian immigrants in Florida, they found that changing categories for racial self-identification on birth certificates confounded this effort (Fordyce 2013).

membership is overlapping.¹⁸ The same way that an anthropologist might take as a subject the ways in which racial categories are made, contested, and enacted in a given cultural context, this dissertation considers how *disability* or *invalidnost*' is made, contested, and enacted in contemporary Russia.

In taking this approach to considering disability, this chapter contributes to an existing body of contemporary critical ethnography which takes demography as its object, as well as to medical anthropology and anthropology of human rights that interrogate the ways in which purportedly neutral or universal international humanitarian, public health, and human rights initiatives and studies are tied up in economic and national agendas. That is, I am arguing that there is no unbiased way to measure rates of disability in a given population¹⁹. This is related to a line of critical scholarship that Michele Rivkin-Fish has called a *feminist anthropology of demography*, which argues that "much is at stake theoretically in considering demographic policies as a site of governance," including in the postsoviet context, as well as elsewhere (Rivkin-Fish 2010:702-703; Gal and Kligman 2000; Read and Thelen 2007:3-18)²⁰. This both builds on the insight of feminist anthropology of demography, by highlighting the way that disability rates in a given population, and the resulting social welfare policies "are a key site for the deployment and transformation of state

¹⁸ I offer this analogy of racial identities and disability diagnoses as a way for readers unfamiliar with disability theory to consider *disability* as a contested and unstable category. I do not mean to say that disability is "the same" as race.

¹⁹ This does not mean that bias is always negative, only that it is always present.

²⁰ This notion of demographic anthropology offers a critical assessment of processes of demographic analysis, both the processes by which demographers come to know, and what states and institutions do with demographic knowledge once they have it (e.g. Howell 1986; Scott); this is quite a different project than the work that biocultural anthropologists do which makes use of population data.

power" (ibid 702). This chapter adds a critical disability studies lens to the anthropology of demography, or anthropology of population studies²¹.

The modern nation state has, since the early 20th century, supported the dissemination of the category of *disability* as a complex association of legal, social, physical, and medical measurements of individual capacity to achieve subsistence-level behavior. Anthropologists have rarely unpacked this category. Yet, as Matthew Kohrman observes,

Disability scholars like Lennard Davis, Deborah Stone, and Henri-Jaques Stiker have shown that such processes of aggregation, standardization, and medicalization have played out at different speeds and in different ways from location to location. They have further documented that the processes have been closely linked to modernity, particularly the growth (initially in Europe and North America) of the nation-state as the preeminent unit of mass political organization and, in turn, the nation-state's dependence on the growth of biomedical, legal, and educational institutions (Davis 1995; Stiker 1997; Stone 1984).

(Kohrman 2003:6)

In this way, researching the category of disability becomes a way to know about citizenship, the welfare state, modes of governance and expectations of productivity, about who is included or excluded from education or medical care of the workforce, and about the moral calculus of what is considered normal or valuable about human bodies.

As long as states have considered "disability" to be a category, there has been interest in the measurement of disability prevalence; disability rates in a given population has significance for economists, sociologists, health researchers, and policy-makers alike (Mont

²¹ This claim is based in a definition of demography as the study of population dynamics including birth, lifespan, and illness. While some expert cultures include illness and epidemiology under the umbrella of demography, others reserve the word demography to deal with reproduction and population levels e.g. The Max Planck Institute does not include illness specifically: "Demography is the science of populations. Demographers seek to understand population dynamics by investigating three main demographic processes: birth, migration, and aging (including death)."

Indeed, "disability" most frequently appears in conversations about demography in relation to old-age. In critical assessments of demography, disability is rarely taken as a factor or subject unto itself (though it may appear in discussions of aging and comorbidity). Population studies, a bit more broadly, also encompasses epidemiology, and population economics. In this sense, this chapter is more accurately about population studies than demography per se; this is an important distinction, but I think, in regards to whether or not disability is a topic of demographic research, ultimately semantic rather than substantive.

2007:5). Yet, in spite its relevance to numerous stakeholders, measurement of disability prevalence remains inconclusive. The United Nations has estimated based on demographics from industrialized countries that worldwide prevalence is roughly 10% of the global population, with other measures indicating a slightly higher percentage (Mont 2007:5), but an examination of how that figure was derived, and the results of other studies show that this demographic "fact" is not as stable as it seems. In fact, Kohrman has documented the ways in which the "ten percent figure" was not only initially fabricated, but has, at least in the case of China, served to invert the expected relationship between definitions and population prevalence: he argues that the goal of achieve a figure of "ten percent" disability prevalence in Chinese population actually shaped the process of defining disability for the Chinese state, and not vice versa. That is, the definition of disability was derived from the intended statistical prevalence of ten percent. Kohrman's research implies that efforts to answer questions about "how many" people live with disabilities in a given location - the world, or in the US, Russia, or China, for example - offer competing claims that are tenuous at best, and "measures" are tied up in state agendas and the tensions of international development.

This assertion will come as no surprise to many critical anthropologists, who have long paid attention to the ways in which population data is a key element of *biopolitics*, or the surveillance, control, and manipulation of subjects by a ruler or state for governance projected through welfare systems. Nor will it surprise disability studies scholars, who, like critical anthropologists, are well-aware of the foundational work of Canguilhem and Foucault, which argues that the invention of statistical data allowed states and governing entities to think about a new subjects in new ways (Davis 2006). Both of these scholarly communities agree that "seeing like a state" means reducing complex lived realities to hard

figures, statistical norms, and economic facts (Scott). However, outside of disability studies, not enough credence has been paid to the scholarly work documenting how *measures of disability prevalence* reveal *disability* to be a contested, unstable, and continually negotiated concept. This lack of critical attention to *disability as a category* has the effect of leaving the concept of disability uncontested, which, in turn reinforces and shores up ableist attitudes, which, like racist or sexist attitudes, assume that the boundaries of disability as a category (like race or sex/gender) to may be considered natural and absolute.

This chapter seeks to demonstrate that the meaning of *disability* is contested not only between the powerful and the disenfranchised, or between political elites and those dependent on disability benefits. Rather, the meaning of *disability* is contested within expert cultures. That is, those who seek to study, research, and create policy about disability - on behalf of governments, international rights, public health, or humanitarian entities - do not agree on any single definition of *disability*. This lack of expert consensus does not mean that the word "disability" or the cluster of concepts related to it need be dismissed as unimportant, or in some way untrue or invalid. Rather, it marks *disability* as a concept that deserves to be addressed critically by anthropologists. In this chapter I suggest that any further discussion of an anthropology of disability must take this contestation - this revelation that disability is a category born of science and state demography - as a point of departure.

In order to do so, I will first review the principle reasons for and means with which global and national expert cultures might create estimates of disability prevalence. Then I will summarize existing measures of disability prevalence in the Russian Federation. Next, I will discuss contestations within expert cultures about rates of disability prevalence in the US

(which often projects itself as a leader in global human rights). Finally, I will discuss ethnographic evidence that wildly cited rates of disability occurrence in China and Ukraine - as postsocialist states that might be grouped with Russia in geopolitical or political economic analyses - are deeply contested and strikingly linked to elements of global and national political dynamics. That is to say, a critical review of relevant data and its provenance, in global contexts and not only in Russia, reveals that the boundaries of the category that we call *disability* is not based on *inherent characteristics of particular human bodies*, but is always linked to context, not only environmental and social, but economic and geopolitical. An environmental model of disability is one that has long been proffered by disability advocates; yet too little attention has been paid to how geopolitical influence of how the measurement of disability gets enacted impacts the way that the category travels.

Demography of Disability: techniques of measurement

There are two major ways that demographers, epidemiologists, or population researchers might seek information about disability rates in a given population. The first is to use and aggregate data from government social service programs. The second is to conduct population-level surveys, in which randomized respondents answer questions about whether they themselves or someone in their household identifies as "disabled." Both methods have strengths and weaknesses. Using social service data is often both unreliable, and inaccessible to nongovernmental researchers. Federal governments, which are often in the business of providing social services, like disability pensions (monthly monetary stipends) to people deemed to have a disability in the eyes of law, do not always aggregate and publish their data about how many people receive such benefits, in which regions, of what ages, and due to what kinds of impairments and conditions. And, social service recipients do not necessarily

represent all those who consider themselves to have a disability, as not everyone who applies qualifies for benefits.

As such, a great many researchers who are interested in such demographic information rely on other means of estimating the existence, prevalence, nature, and geographic distribution of disability in a given population. Economists are frequently interested in legal disability status as a category that is related to the potential productive capacity of a nation state. If disability means that an adult can't work, this has implications for potential labor contribution to a country's economic productivity; likewise, if someone receives a disability pension (usually because they are either partly or wholly unable to work), this means that they are not contributing to the national economy, and moreover, represent a drain on national expenditures; there may be other economic entities, like insurance estimates seeking disability prevalence data (e.g. Becker and Merkurjeva 2003:1). Public health practitioners are interested in rates and geographic prevalence of disability as a way to understand population health and the comorbidity of disability with other factors, like age, gender, and epidemiologically significant illnesses. Health policies may consider disability as a factor. Disability advocates working in international human rights need quantitative measures of disability prevalence to make their case for international governing bodies like the UN to put pressure national governments to pay attention to disability rights violations within their countries. International NGOS working to protect human rights and uncover instances of human rights abuses, like UNICEF, Human Rights Watch, and the Soros Foundation (or smaller organizations focused specifically on disability lobbying or executing programs to support disability rights, like Disabled Rights International, the MDAC, the Abilis Foundation, and others) need these figures to help identify places where

disability rights violations may be ongoing and to make the case for intervention.

International Education experts also require very specific strategies and assessments of disability in order structure public education efforts and inclusive education policies that are locally relevant.

Because state social services figures in regards to disability prevalence frequently fail to address the nuances these organizations and actors seek, they often use independent demographic research data. Frequently this data comes from census surveys or other household surveys; in these cases, disability is one factor in a long survey questionnaire, and usually refers to adults who receive disability pensions. Or, an independent research survey is designed specifically to derive figures representing a particular measure of, definition of, or aspect of disability. For all population data, the statistical prevalence of disability is an aggregate number derived from surveying a random sample; that is, it is not the actual rate of disability, but an estimate based on the portion of the population that was surveyed.

New and evolving models for survey design measuring disability prevalence are continually being proffered by researchers representing various interests, and demographers are continually working to refine mathematical models.

The World Health Organization's *International Classification of Functioning, Disability and Health* is broadly recognized as the first major policy standard to incorporate a social model of disability that considers individual-environment interactions on a non-totalizing scale. Adopted by the WHO in 2001, the ICF attempts to create a multi-dimensional portrait of capacity, and to provide a standard for international disability prevalence measurement as it pertains to health as well as economic function. The document was created in response to criticisms of an earlier model and activism in accordance with

global discourses of human rights and development (Baylies 2002: 729). It incorporates components of the functional and participation indexes described above, and attempts to consider both biological and environmental aspects of disability and impairment (Mont 2007: 7). Since 2001, researchers have adapted and critiqued the ICF model.

Critiques of the ICF come both from disability advocates and from scientists concerned about its capacity to capture cultural difference and fuse definitions of disability. First, the model remains rooted in a medical model of classification and functioning, which has been critiqued by disability activists and medical anthropologists as failing to capture culturally-specific experiences of the body, and reinforcing a rubric of normality (Baylies 2002: 729-730). At its very core, the ICF continues the practice of creating categories of difference, which disability advocates maintain obscures lived experience and produces a hegemonic norm (Hammell 2004:408-409). Second, “the instrument lacks a comprehensive tool for assessing the performance of governments, environments, social situations, etc.,” thereby failing to capture the institutional biases that influence access and shape individual capacity given the local environment (729). Third, the ICF may fail to account for autonomous decision-making: that is, “participation” in social life as defined by the framework may be the result of barriers to access or *it may be the result of personal choice*. That is, the instrument contains an inherent assumption about what a normal, valued life might be that may not align with the actual self-assessment of the individual (Cardol et al 2002: 970-971). Finally, the ICF attempts “to synthesize across perspectives and models, eclectically offering what is termed a ‘biopsychosocial’ approach,” fusing several varied understandings of impairment and disability (biological-psychological/behavioral-social), particularly, health-related and economic-related into a single analysis. This attempt to

produce “a universal language of disability” remains tenuous at best (Baylies 2002: 729-730).

Defining Disability

For both of the aforementioned tactics, a working definition of what counts as "disability" for the purposes of a survey or a legal framework must be established or referenced. A great deal of policy, political, and scholarly work has been done in relation to this issue. This is because once the category of disability must be clearly defined at a level of specificity sufficient to proceed with science, the slipperiness of the category quickly becomes apparent.

A 2007 working paper of the World Bank titled *Measuring Disability Prevalence* succinctly stated the challenges that the multiple definitions of disability pose to demographers:

Reported disability prevalence rates from around the world vary dramatically, for example from under 1% in Kenya and Bangladesh to 20% in New Zealand. This variation is caused by several factors: differing definitions of disability, different methodologies of data collection, and variation in the quality of study design. The result is that generating disability prevalence rates that are understandable and internationally comparable is a difficult enterprise. This situation is complicated further by the idea that there is no single correct definition of disability, that the nature and severity of disabilities vary greatly, and that how one measures disability differs depending on the purpose for measuring it. (Mont 2007)

The paper goes on to pose one methodology for international data collection that attempts to minimize the effect of differential definitions.

The problem of effectively gathering statistics on disability is so significant that "Disability and Statistics" comprises a major agenda of UN Enable, the United Nations working group on disability. The UN has prepared numerous publications advocating for the collection of more nuanced and useful statistical data on disability prevalence, and providing detailed and summarized instructions as to how those organs involved in the creation of

statistics might better serve the goal of inclusion and the furthering of rights of people with disabilities by collecting more nuanced data (UN Enable).

This demonstrates the existence of a global expert culture focused on producing standardized definitions and measures of disability (which do not yet exist, and may never exist), and pressuring those nation states not in compliance with present practice, as exemplified by UN Enable model protocols to "catch up" with their "more compliant" peers. For instance, a statement on the webpage of UN Enable at the time that this chapter was written read:

The General Assembly has stressed, including in its most recent resolutions [63/150](#), [64/131](#) and [65/186](#), the importance of improving disability data and statistics, in compliance with national legislation. This is recommended in order to better compare data at the national and global level for purposes of policy design, planning and evaluation from the disability perspective. The General Assembly has also urged Governments to cooperate and to avail themselves of the technical assistance of the [Statistics Division](#) of the Department of Economic and Social Affairs of the Secretariat. (UN Enable 2014)

Meanwhile, graphics provided in relevant reports posted to the website indicated a continued lack of consensus about the definition of disability (see figure below).

UN Enable is both at the forefront of the generation of the global expert culture, and genuinely concerned that the lack of useable, reliable, consistent population data in regards to people with disabilities makes it extremely difficult to advocate internationally for the rights of some of society's most consistently abused, incarcerated, and marginalized people.

Understanding the impetus behind the creation of a task force to define disability requires a review of disability theory in order to better understand what it is that demographers and international human rights activists are attempting to capture by creating more nuanced disability definitions, like the ICF.

Global Disability Prevalence Rates*

High-income countries			Low-income countries		
	Year	%		Year	%
Canada	1991	14.7	Kenya	1989	0.7
Germany	1992	8.4	Namibia	1991	3.1
Italy	1994	5.0	Nigeria	1991	0.5
Netherlands	1986	11.6	Senegal	1988	1.1
Norway	1995	17.8	South Africa	1980	0.5
Sweden	1988	12.1	Zambia	1990	0.9
Spain	1986	15.0	Kenya	1989	0.7
UK	1991	12.2	Zimbabwe	1997	1.9
USA	1994	15.0	Malawi	1983	2.9

* Sources and methodologies are country specific.

14

Figure 3 – Global Disability Prevalence Rates

This slide was included in a presentation about disability statistics, and the potential variation of prevalence rates, and the meaning, of said prevalence rates, depending on the intention of the survey and the definition of disability inherent in the design of the survey questionnaire. From Hadans 2014.

The notion of disability as a blanket term referring broadly to impairment in work capacity, is rooted in industrialization itself (Baynton 1996). Prior to the late 19th century, the category of disability, as we understand it today, did not exist (Stone 1984). Terminology that now sounds outdated, such as *crippled*, *destitute*, *needy*, and so on, described what we now think of as "disability" during an era when caring for people with disabilities was not the responsibility of the welfare state, but of communities, families, and church or charity organizations (Stone 1984; Lindemeyer). With industrialization, came the rise of population-based thinking. As factory work became an increasingly critical aspect of social organization,

the category of being unable to work took on increasing significance as an organizational factor. For workers, being unable to work meant the inability to earn a wage and subsist. For factory owners, disability was inherently related to the capacity of individual laborers: Henry Ford once wrote in praise of his factory its ability to deploy productive labor power from individuals with a range of impairments from missing limbs to blindness (Jain 1998: 34). For the nation state, the welfare of workers became an increasingly important strategic component of successful economy. These attributes of disability continue to hold sway today. Thus, while *causes* of disablement are so diverse that disabled people, aside from this one aspect, are frequently more different from one another than alike, the notion of disability persists.

The diversity of disabling conditions in severity, origin, and associated stigma creates a great deal of contention around the cohesion of the category. Indeed, conflicting notions of what constitutes “disability” exist in legal discourse, popular lexicon, medical arenas, disability activism circles, and personal experience. Scholars of disability studies have proposed a “social model” of disability that separates impairment (an objective condition or capacity) from disability (associated stigma and barriers to access) (Linton 1998:11; Stone 2001:52). In this sense, a person may have an impairment (getting around in a wheelchair) that does not prevent them from working, but carries stigmatized meaning that results in a colloquial perception of “disability”. Imagine that such an individual that lives in Durham, North Carolina and works as lawyer. In this case, she would be disabled in the eyes of peers, disabled by measures of physical capacity, but not disabled in ability to achieve subsistence. Meanwhile, imagine an individual with identical physical impairments, living in the outskirts of Moscow, with different educational background (say, up to fifth grade), no access to a

wheelchair, and infrequent access to medical care. This individual would be more seriously disabled in her ability to achieve subsistence than her imaginary counterpart in Durham, and, she would face a different set of institutional and state barriers as well as culturally-based stigmas. That is, class, geography, race, and other intersectional identities all contribute to disability experience and severity, so that similar impairments may result in difference experiences of disability.

Ultimately, this means that a universal definition of disability faces the problem of imagining a single category representing extraordinarily divergent experiences. For example, a universal human rights or colloquially relevant definition of disability must capture both a sixty-year-old man in Queens New York with diabetes who cannot survive without daily dialysis, and a child with downs syndrome in rural Kyrgyzstan. This is a tall order, and one which most existing disability prevalence figures do not capture.

The problem of estimates of disability rates varying greatly depending on the definition of disability used can more easily be recognized by comparing data from within North America. For the United States, the *Annual Statistical Report (AST)* on the Social Security Disability Insurance Program states that over 8.5 million Americans received monetary benefits in 2008, which would suggest a disability rate of $(8,500,000 / 304,059,724 \text{ total population}^{22} =)$ *less than 3 percent* of the population. Meanwhile, a 2010 report based on census data that used a broad definition of disability found that *17%* of Americans self-reported living with a disability (Census Newsroom July 25, 2012). The discrepancy in the

²² Table 1: Annual Estimates of the Resident Population for the United States, Regions, States, and Puerto Rico: April 1, 2000 to July 1, 2008 (NST-EST2008-01). Source: Population Division, U.S. Census Bureau. Release Date: December 22, 2008. Accessed August 3, 2014 Via http://www.census.gov/popest/data/historical/2000s/vintage_2008/

prevalence can be partially explained by a difference in definition of disability: people who receive benefits, versus people who, when asked, say that they have a disability. And, "the report shows that 41 percent of those age 21 to 64 with any disability were employed" (ibid) - which means that those persons would not be captured by the Social Security Administration's record keeping of people receiving disability pensions (who by definition, for certain categories of disability, must prove that they have impairments that prevent them from working)²³.

In this sense, we may surmise that there are certain benefits to estimating disability prevalence based on self-reported rates of disability. But self-reported rates are *also* highly variable, even within a single country, depending on the rubric of disability used. For instance survey estimates of disability prevalence in Canada ranged from 13.7% to over 31% for 2008 (see Table 1). Scholars have noted a predictable range of positive responses for each type of instrument. *Self-identification*, frequently included in household censuses, asks a respondent outright if a household member disabled (yes or no). This approach yields the lowest percentage of responses [see table] most likely due to stigma that the word disability implies, or because respondents think it refers to whether or not someone receives a disability pension (Mont 2007: 7).

²³ In the United States, for the purposes of social security, an individual whose condition is not shown to be terminal (likely to result in death in six months or less, must show not only that their medically documented impairment prevents them from performing their work, but that it prevents them from doing ANY work. This means that if our imaginary lawyer were to suffer a stroke and be unable to speak, but would still be theoretically capable of holding a job as a bagger at the grocery store and thus able to earn a minimum wage (whether or not she actually was able to find such work), she would not be considered disabled in the eyes of the Social Security Administration. The entire body of Social Security Code is available online at <http://www.ssa.gov/regulations/index.htm>. On average, 51% of individuals who sought disability benefits between 1998 and 2007 (and therefore purportedly consider themselves to have impaired subsistence capacities) were denied coverage (AST 2008: Chart 11). Additionally, the figures do not represent individuals who failed to complete applications for coverage. Furthermore, by definition, social security statistics provide information on economic disablement pertaining to the ability to work, but do not capture information about socially stigmatized impairments that do not prevent work.

Figure 4: Variation in estimates of Disability in Canada: Adult Disability Rates for Major Canadian Surveys, 2008

Instrument	Percent
Participation and Activity Limitations Survey – Filters	13.7
Participation and Activity Limitations Survey – All	14.8
Census	18.5
Survey of Labor and Income Dynamics	20.5
Canadian Community Health Survey	31.3
Source: Rietschlin and MacKenzie, 2004; Mont 2007	

A manner of questioning that scholars have found to yield higher rates of disability self-identification responses are *activity-based measures* including *Activities of Daily Living* and *Instrumental Activities of Daily Living* (ADL and IADL). These instruments are not a single question, but involve a series of yes or no questions related to whether or not the person in question considers himself to "experience difficulty" conducting daily tasks (ADL) or earning a living (IADL) [see above chart]. A related mode of questioning asks about economic and social *participation*, also without using the word disability (Mont 2007).

Although the ADL and IADL seem thorough in breaking disablement down to functional results of impairment, the lists of questions can pose problems for cross-cultural comparisons and international application. For example the question “Do you have difficulty dressing yourself?” will imply a very different set of parameters considering local clothing practices (loose shirt and pants, versus intricately wrapped sari, versus tying shoes) (Mont 2007: 12). Meanwhile, while vision impairment does not result in a disabling condition

captured by participation measurement instruments in the United States, “40 percent of disabled children not attending school in Brazil were found to be not attending because of vision problems correctable by glasses” (Mont 2007:19). Thus, scholars concerned with international and cross-cultural comparisons of disability have observed that a single, carefully designed survey instrument will capture different elements of impairment and disability in different cultural contexts.

Figure 5: Survey Instruments to Measure Self-Reported Disability and Impairment

Instrument	Description	Range of Population Percent Generated in Global Statistics
Self-identification	Are you or a member of your household disabled? (Y/N)	0.5 (Nigeria) to 6.3 (Jamaica)
Diagnosable Conditions	List of Y/N Questions: Do you or a member of your household have polio? epilepsy?... cerebral palsy?... etc.	1.8 (Colombia) to 5.7 (Hungary)
Activities of Daily Living (ADL)	List of Y/N Questions: Do you experience difficulty feeding yourself?... bathing?... performing other tasks of self-care?	10 (Poland) to 19.4 (United States) “
Instrumental Activities of Daily Living (IADL)	List of Y/N Questions: Do you or someone in your household experience difficulty managing money, procuring groceries, operating your household?	
Participation	Do you or someone in your household have a disability or health problem that prevents (you/them) from working or attending school, or limits the amount or kind of work/school (you/they) can do? (Y/N)	
(Data adapted from Mont 2007: 7-10)		

Additionally, research has found several further biases in self-reported assessments of health and disability. For one, social support has been shown to affect perceived health status, so that a strong network of social support will lead an individual to downplay the

degree to which her impairment hampers her functioning (Kutner 1987). This study was designed to examine the cognitive and psychological support of feeling loved and valued, rather than any practical functional benefit received through relationships with friends and family. More generally, research has found a correlation between perceived stress level and perceived health status, so that “greater psychophysiological disability, recent illness and life changes and perceived life stress are associated with poorer self-assessed health status” (Garrity 1978). However, more recent assessments have problematized the relationship between disability status and health status: functional limitations do not necessarily imply poor perceived health-status, and new models that encompass a normalized manner of living a healthy life with impairments are in development (Krahn 2009).

Given the variability demonstrated in these tables, we can see that even within North America, a region considered to be comparatively easy to survey and with a wide availability of existing population data for assessment, disability rate data are not only inconclusive, but contradictory. Major concerns exist not only about the lack of consensus about how disability ought to be defined, but also about how effective a given survey method might be.

In an effort to respond to the universal human rights agenda, UN and WHO recommendations for population-level disability statistical data suggest a model definition of disability that includes bodily, social, and environmental factors, including the built environment, cultural expectations of work given gender and social class, and severity of a condition in terms of the resulting difficulty in conducting the activities of daily life (ADL). This rubric of complex factors would allow an assessment of how many people face a stigmatizing, exclusionary impact in their daily lives that might fit an international standard of disability, regardless of whether that person does or does not qualify as disabled by either

colloquial local definitions or national law. This delicate work of approaching a universal definition of disability has resulted in a far more complex set of questions [see figure below] for demographic surveyors than previous models (which frequently simply relied on whether or not someone was disabled according to the legal definition of the nation state in question, if the national census included a question about disability at all) (Strategic Action 2010).

Text Box 1. SHORT SET OF QUESTIONS

“The next questions ask about difficulties you may have doing certain activities because of a health problem:

1. Do you have difficulty seeing, even if wearing glasses?¹
2. Do you have difficulty hearing, even if using a hearing aid?⁴
3. Do you have difficulty walking or climbing steps?
4. Do you have difficulty remembering or concentrating?
5. Do you have difficulty (with self-care such as) washing all over or dressing?
6. Using your usual (customary) language, do you have difficulty communicating, (for example understanding or being understood by others)?”

Each question has four response categories that result in a severity scale:

- (1) No, no difficulty,
- (2) Yes, some difficulty,
- (3) Yes, a lot of difficulty and
- (4) Cannot do it at all.

Source: Washington Group, 2009, http://www.cdc.gov/nchs/citygroup/citygroup_questions.htm

Figure 6: Sample questions to elicit prevalence of disability according to a functional model definition, as recommended by the Washington Group and provided as an example in UN recommendation to member states. (Strategic Action 2010:22).

Because activist, medical, and work-related definitions of disability differ, a significant difference in goals arises between population estimates that seek each type of information (Davis 2006: iv, 175). Thus even as the UN and WHO respond to disability advocates' lobbying to use a more nuanced definition of disability in order to better address human rights violations, economists continue to be interested simply in whether or not a given population is able to work, and therefore are satisfied with adult disability pension data as a defining disability. Of course, as UNICEF and others have pointed out, such a rubric

frequently (intentionally) misses children, yet the statistics come to stand in for "disability prevalence rates" for a given country. As the figure above demonstrated, the variability in reported rates of disability is vast, and the method of analysis (definition, data collection, and statistical modeling methodology) are almost always left out or obfuscated. As such, the current effort to shift disability statistics toward an internationally comparable standard remains an unrealized, if stringent, battle for a small cohort of devoted international experts.

Measuring Disability Rates in Russia

So what *is* the rate of disability prevalence in Russia? What estimates have been calculated, and by which international actors?

As discussed in the previous section, establishing a concrete figure to conclusively discuss the percentage of a given population which has a disability is extremely difficult.

Basic internet searches will turn up almost no immediate figures. Human Rights Watch writes that "according to official statistics, at least 13 million people with disabilities live in Russia, or approximately 9 percent of the population" (HRW Sept 2013). This figure is repeated throughout various publications, such as the independent English-language newspaper *The Moscow Times* (Krainova 2014). A UNICEF press brief cites the same figure and attributes it to the Russian Ministry of Health and Social Development. As we have seen in the previous segment, in order to understand this figure, we must unpack how it was derived.

Finding Demographic Data about Russia

During the Soviet era, estimates of disability prevalence in Russia (then the RSSR) were hard to come by in entirely different ways. As Sarah D. Phillips has documented, there was little if any discussion of disability in Soviet public discourse. And, shockingly, a Soviet

official even once claimed that, "There are no invalids in the Soviet Union" (2009)! Official statistics from the Soviet era are difficult to find.

With the collapse of the Soviet Union, the Russian national economy, transitioning from a centrally planned economy to capitalism, became the object of international study. In many ways, between the early 1990s and roughly 2010, the Russia Federation was a sort of living laboratory for economic theorists to test their ideas. Economic policies, social welfare policies, and the legitimacy of political rights were constantly in flux. While global expert cultures debated and argued over how Russia might most effectively transition from a socialist model of governance and centrally-planned economy to free-market democracy, Russian citizens experienced an era of deep uncertainty. World Bank policy research and international scholars analyzed minute aspects of the Russian population, from market economics in Moscow to heart disease in rural Siberia to domestic violence rates. Much of this work was undertaken with an agenda of humanitarian intervention, as well as a deep curiosity on the part of Western researchers to meet and learn from their colleagues from the other side of the wall. As a result, there is a large amount of data regarding Russian population statistics for the 1990s and the first decade of the 21st century.

For contemporary demographic data about Russia, researchers may choose from existing population surveys, or conduct a new survey. Randomized population data relies on household surveys, similar to the US census to amass the information. The work of gathering this kind of household survey data is not insignificant, and in Russia faces certain cultural obstacles. Still, demographic data is valuable, and at least three major household surveys are recognized as relevant by economists and demographers: the Household Budget Survey (HBS), conducted by the Federal State Statistics Service of Russia (Goskomstat) and not

available as a data set for public use though Russian researchers have access to aggregated statistics; the National Survey of Household Welfare and Program Participation (NOBUS - a transliteration of the Russian acronym), the largest household survey by sample size (50,000 households) which was conducted in 2003 by Goskomstat with support of the World Bank and for which the data is publically available; and the Russia Longitudinal Monitoring Survey, conducted by the Carolina Population Center in partnership with the World Bank and the Higher School of Economics in Moscow, which has a sample size of roughly 4,000 households (Lokshin 2008:11-12)²⁴.

However, even these existing surveys do not offer a particularly robust concept of disability for population researchers to work with. In one study, economists summed up the problem given available population data:

There is a serious methodological problem with disability estimation in Russia. Two different approaches are used. The first counts all individuals receiving a disability pension. The second includes recipients of all types of social benefits. Both methods trace the recipients of pensions, but not individuals actually suffering health deficiencies. These estimation methods imply some limitations on disability problem analysis.

(Becker and Merkurjeva 2003:3)

This indicates that for economists, the actual implications of population data which claims to document disability rates in Russia have serious weakness related to the definition of disability available given the wording of the household survey.

A closer look at how household survey data is collected and aggregated suggests that even these estimates are extremely tenuous. Establishing a sufficient sample size in order to arrive at a data pool large enough to estimate population demographics is a complex, lengthy,

²⁴ To be clarified: some studies seem to refer to NOBUS and RLMS as the same data set. It is unclear to me if the projects overlap at some points but not others, or if they were conducted at once and the data is available at different levels. I will follow up by contacting Dr. Becker and the CPC for interviews or clarifying emails exchanges.

and expensive process. These difficulties are explicitly addressed in the project information on the website of the Russian Longitudinal Monitoring Survey (RLMS). The researchers, in their description of the survey process, discuss both the history of the project since the 1990s, and the specificities of conducting a household survey in postsoviet Russia.

The RLMS is a household-based survey designed to measure the effects of Russian reforms on the economic well-being of households and individuals. In particular, determining the impact of reforms on household consumption and individual health is essential, as most of the subsidies provided to protect food production and health care have been or will be reduced, eliminated, or at least dramatically changed. These effects are measured by a variety of means: detailed monitoring of individuals' health status and dietary intake, precise measurement of household-level expenditures and service utilization, and collection of relevant community-level data, including region-specific prices and community infrastructure data. Data have been collected 21 times since 1992.
[RLMS "About the Study"]

A key goal of the RLMS is to create demographic and population health data about the Russian Federation of a quality that can be used for international comparisons and scholarly assessments. On the webpage, the RLMS coordinators write:

In the initial two years of this effort, a main goal of the RLMS was to work with the Russian State Statistical Bureau (Goskomstat) and the All-Russia Center of Preventive Medicine to upgrade the systems in place for monitoring these issues. A breakdown in the collection of statistical data was occurring throughout the former Soviet Union. In addition, it had become clear that Russian Federation data collection systems did not provide a representative profile of the economic and social dimensions of the population. In particular, adequate monitoring of the poor did not take place.
[RLMS "About the Study"]

Subsequently, after 1994, the RLMS ceased to partner with governmental organizations.

With this move, "the emphasis of the work changed from institution-building to providing timely, high-quality information. The new RLMS sample is smaller, but the number of primary sampling units was doubled to enhance the representation of the survey." Although disability is not the only thing that the RLMS measures, it is one of the questionnaire modules.

While the outcomes of the study can be easily summed up in charts and figures, the work of gathering household survey data was a messy one presenting complex logistical challenges. The description of the sampling design on the project's website notes that

Even in the best circumstances, drawing a good sample of an entire country is a daunting exercise. Russia presents some of the most challenging circumstances: the territory is vast (spanning 11 time zones and covering more than one-tenth of the land mass of the world), the population is ethnically heterogeneous, and the residential patterns are complex. For example, a large fraction of the population--up to 10 or 12 percent--lives in dormitories or communal apartments. Many of the census statistics that Western samplers take for granted are inaccessible or nonexistent.

[RMLS]

The work of survey sampling required workers to literally slog through the mud to reach each of the randomly selected representative clusters.

a list of all household addresses in each SSU was compiled, where "household" was defined as a group of people living together and sharing income and expenditures. Adjustments were made to take into account single addresses at which several households lived (e.g., adult dormitories and communal apartments).

[RMLS]

Study coordinators worked to ensure that data was collected from a representative cross-section of the Russian population, taking into consideration identity elements including urban/rural, geographic region, gender, ethnicity and religion. Once gathered, data had to be processed (see photo). This meant processing piles of survey forms into digital databases, which are now available to select researchers for statistical analysis. Subsequently, a great many scholarly and policy papers have been written utilizing the diverse data points collected in the RLMS (<http://www.cpc.unc.edu/projects/rlms-hse/papers>); disability was not central to the overall goals of the study, but was simply one element of population characteristics that can be tracked using the survey data.

Figure 7: Photo of Household Survey Data Processing



A charming low quality photo shows a RLMS staffer in an office space surrounded by piles of survey forms to be logged. The photo appeared on one version of the RLMS website at the CPC of the University of North Carolina at Chapel Hill, with the caption, "RLMS staff member Irina Kiseleva is checking filled questionnaires from regions."

Working with Household Survey Data to arrive at Disability Prevalence Estimates for the Russian Federation

One paper on disability prevalence (which used the NOBUS data set) was presented by a team of economists at the Duke University Russian Futures Conference (Andreev and Becker 2010). The paper notes that previous estimates had failed to account for old age as a comorbid factor that would make adult respondents more likely to have a disability²⁵. Given

²⁵ Andreev and Becker cite the following studies as having addressed disability prevalence in Russia: "Very little is known about the likelihood of recovery from disability or the characteristics of the Russian disabled population or, for that matter, the disabled populations of middle- income countries in general. Notable exceptions include Mont (2007), Braithwaite and Mont (2008), Mete, Braithwaite, and Schneider (2008), Scott

that the relative age of an aggregate population in a given region would impact the rate of disability in that region - e.g. a region with an older population profile, by this logic would have a higher incidence of disability (as defined by the NOBUS questionnaire). Andreev and Becker offered a new calculation of age-adjusted disability rates in the Russian Federation based on the disability data collected in the NOBUS. This paper offered this population analysis as a data set for future researchers to utilize.

The bias in any disability estimates which utilize data from the NOBUS or RLMS household surveys is to define *disability* as *the social status of being recipient a federal government disability pension*. Few papers explicitly discuss this, nor the implication for disability rates if another standard of disability, such as Activities of Daily Living (ADL) were to be used in such a survey. The relevant data point in the RLMS asks an adult respondent if he or she receives any government stipends, then lists several potential stipends, amongst which the disability stipend is named (see figure below). Thus respondents are channeled into an answer that indicates a particular definition of disability, that of the state legal code relating to disability benefits.

In Russia, disability status is determined by a commission of experts. Having reviewed the case of a person seeking disability status, the committee votes on whether or not the citizen in question meets the criteria of the legal code which lays out the definition of disability for legal purposes. There are three possible "groups" of disability, designating severity of the impairment in preventing the person in question from participating in labor for

and Mete (2008), and Hoopengardner (2001). There is also detailed presentation of disability patterns in Russia in Baskakov et al. (2001), Merkuryeva (2007), Becker and Merkuryeva (2009), Schultz (2008), Mosgorzdrav (2005), FBEA (1999), and FBEA (1998)." (2010:2)

earned income, each with corresponding benefits. In many ways, the system is similar to US social security disability determinations²⁶.

15PENSIO	<p>73. Do you now receive a pension?</p> <p>Yes 1</p> <p>No 2⇒ [SKIP TO 77.]</p> <p>DOESN'T KNOW 7⇒ [SKIP TO 77.]</p> <p>REFUSES TO ANSWER 8⇒ [SKIP TO 77.]</p>
15PENSTY	<p>74. What kind of pension do you now receive?</p> <p>A retirement pension 1</p> <p>A disability pension 2</p> <p>A pension for loss of provider 3</p> <p>A pension for years of service 4</p> <p>DOESN'T KNOW 7</p> <p>REFUSES TO ANSWER 8</p>
15PENSLM	<p>75. Did you receive a pension in the last 30 days?</p> <p>Yes 1</p> <p>No 2⇒ [SKIP TO 77.]</p> <p>DOESN'T KNOW 7⇒ [SKIP TO 77.]</p> <p>REFUSES TO ANSWER 8⇒ [SKIP TO 77.]</p>
15AMPENS	<p>76. How much money did you receive as a pension in the last 30 days?</p> <p>_____ rubles</p> <p>DOESN'T KNOW 7</p> <p>REFUSES TO ANSWER 8</p>

Figure 8: Excerpt from the RMLS Adult Questionnaire (Phase II, Round V, English, Section J, p14). Following many questions about work and income, a question about disability pension is included in Section J "Work." A separate set of questions, in Section L "Medical Services" asks about illness and access to medical care, but not about disability. Thus, the RMLS offers a state pension assessment of disability rates, but not an activities of daily living assessment.

²⁶ Disability pension policy in Russia is governed by "the 24 November 1995 Federal law "On the Social Protection of Disabled Individuals in the Russian Federation." The law defines as disabled an individual "who has a health impairment with a continued disruption of bodily functions caused by illness, the results of trauma, or [anatomical] defects, leading to limited capacity for life and requiring social protection" (Russian Federation, 1995)" and rules regarding the distribution of various impairments into the three groups of severity by the 17 December 2001 federal law "Concerning Labor Pensions." (Andreev and Becker 2010:2)

Thus the individuals in the RMLS population sample will tend to answer in a manner that would produce data roughly akin to a survey in the United States that asked if respondents received Social Security Disability benefits (the legal code for definitions of disability for social benefits in Russia and the US are not identical; I mean to imply that only someone who did receive a monthly benefit check would answer yes to this question). Andreev and Becker's age-adjusted prevalence data²⁷ therefore is not considering actual health status or work capacity, but rather successful application for and receipt of government disability benefits, although the paper does not explicitly consider this. These measures say little about social impact or causation of the reported disablement: variation in local prevalence may represent anything from a particularly proactive regional social work office, to a concentration of injured war veterans or mine workers, to environmentally affected increase in birth defects. The Andreev and Becker analysis of the NOBUS provides ages and distribution by region; however, sample sizes are too small to allow close investigation of distribution within regions (personal conversation with Andreev).

Another way in which household survey data can confound researchers seeking to establish rates of disability is that people with disabilities are frequently institutionalized, abandoned, or homeless. Survey data includes sample populations of "community dwelling adults" (Altman 2009: 545), and in most cases, "household" means literally a family group sharing a place of residence. As such, if a family member has been institutionalized or abandoned due to disability, these individuals will be invisible to population surveys, as institutionalized or homeless individuals will not be randomly selected to participate in a

²⁷ Andreev and Becker refer to this survey by its Russian acronym as NOBUS. The NOBUS was conducted in 2003 by the Russian Federal Statistical Survey (Goskomstat).

telephone or door-to-door survey, and relatives will not consider them “household members”. This critique applies, for example, to Andreev and Becker's study, wherein, they have eliminated from consideration children and anyone who has received no schooling (2010:14). For the purposes of an economic study concerned with maximum possible productivity of a labor force, the dismissal of such categories make sense; however, for a study seeking to understand the actual rates of people considered disabled in their daily lives and facing the stigma of living with a disability, such an omission erases the existence of probably tens of thousands of Russian citizens who were born with disabilities or acquired disabilities in childhood, many of whom may not have had the opportunity to attend school may have been institutionalized for their whole lives.

Furthermore, a "disability pension recipient" measurement of disability rates results in a rubric does not capture either severity of impairment or acclimation the challenges an impairment presents (e.g. an individual born blind compared to an individual who lost sight in an accident will have very different functional capacities but an identical diagnostic profile (Mont 2007:12)).

Writing Disability Rights

These elements of difficulty create a conundrum for disability rights researchers charged with gathering relevant statistics for disability rates in Russia. Because qualitative reports are expected to include a brief reference to quantitative data, researchers are pressured to find the most reliable statistics available, and then to sum them up succinctly. In this way, because the task of much reporting on disability rights issues must very quickly refer to demographics, as a standard practice in establishing an authorial voice, reports like that from Human Rights Watch cited above do not offer space to explicate or problematize

statistics. This is both a question of intended emphasis, and a problem of authoritative writing: if a report undermines its statistical basis, it loses credibility. Therefore, it would have been inappropriate for a report on barriers in the built environment to devote five pages to the problem of finding reliable estimates of disability rates in the Russian population.

Figure 9: Table: Estimates of rates of disability in Russia

<i>Study Title</i>	<i>Study Sponsored/Conducted by</i>	<i>Sample Size</i>	<i>Rate of Disability</i>	<i>Data Source</i>	<i>Disability measurement</i>
NOBUS (2003)	World Bank, Goskomstat	120,000	6.3%	Household Survey	Receipt of disability pension
RLMS (1992-present)	Carolina Population Center, Moscow Higher School of Economics	4,000	10-13% (according to Becker & Merkurjeva, citing the 2000 Goskomstat Russian Statistical Yearbook)	Household Survey	Receipt of disability pension
Age Adjusted Disability Rates and Regional Effects (2010)	Andreev & Becker	120,000	6.47% for women and 6.08% for men	NOBUS (adjusted for average age by region)	Receipt of disability pension
unknown	The Russian Ministry of Health and Social Development (according to UNICEF)	unknown	9%	unknown	unknown
Disability Risk	Becker and Merkurjeva 2003			RLMS data modeled to estimate risk of disability by region, by decade, and in terms of	

				comorbid factors (gender, smoking, age, etc.)	
<i>Russian Statistical Yearbook</i>	Goskomstat, The Russian State Statistics Board (2000; via Becker and Merkurjeva 2003:22)		varies from 10-13% between 1990 and 1999; The total number of people receiving disability pensions each year 1990-1999 varied from 3,363,000 people to 4,816,000 people.		Receipt of disability pension (also notes that disability pensions represent 87%-97% of all monetary gov't pensions paid)

At the same time, researchers are well aware of the problem. One of the researchers of the Human Rights Watch report on disability rights violations, *Barriers Everywhere* shared the following concerns:

[I looked back at the research, and as far as I remember] we cited a document from Rosstat on the accessible environment program. We also consulted with Perspektiva, which draws many of their stats from government sources as well. They usually say almost 10 percent. In *Barriers Everywhere* and [in] our upcoming report on orphanages, we state that the government lacks clear and publicly accessible statistics on the number of people with disabilities in Russia, including stats disaggregated by age, gender, and disability. I will list below what I see as the problems with counting people w/dis in Russia. I don't think any of this will be news to you, but maybe an additional opinion would support your case:

--In its various publications, the government does not always specify whether it defines having a disability as being registered as having *invalidnost'*, or as having been diagnosed with a specific *bolez'n'*, like a cardiovascular disease, for example. The former would come from the MinTrud & Sotzzashchit [Ministry of Labor and Social Protections], and the latter from Minzdrav [Ministry of Health], and they don't always talk to one another.

--We know that self-identification is really the only [survey method] that international disability rights law recognizes as legitimate for defining a "person with a disability," and that in Russia, many who would like *invalidnost'* cannot get it for various bureaucratic and accessibility reasons. So the government's count could be an undercount. At the same time, it is also possible that many people who would not like to be seen socially as "having a disability" have and gladly use their *invalidnost'* benefits and pensions to do basic things like buy groceries in the absence of reasonable accommodations to work, for example. This is also legitimate, but it means that they shouldn't necessarily be counted as part of a population; their experiences might be seen as evidence that communities aren't accessible to everyone.

--To the extent that the government does not keep clear and publicly accessible statistics on children with disabilities, it is quite possible that millions of Russians are being left out of the government's

count. We know based on our conversations with NGOs that children with disabilities are greatly overrepresented in orphanages but there is very little info on exactly how many there are living in these places. We also know that children under 3 generally don't appear before the Bureaus of Medical Social Expertise, even though their parents might see them as having a disability.

[Mazzarino, personal communication]

In this sense, the concerns that I have raised here are shared by international human rights researchers working on disability advocacy. Researchers are under pressure to both document the ways in which disability rights are being violated, and also to aim their critique at the government of the nation state in question (Mazzarino, personal communication). This habit of directing critique at the Russian government comes through in the above correspondence: as we have seen from earlier sections of this chapter, the Russian government is not alone in the absence of reliable statistics on disability prevalence. I would suggest that it is highly probably that many human rights workers working in a variety of countries have similar concerns, but assume that their region is the exception, and that reliable disability prevalence rates exist elsewhere. The bottom line concern of documenting the difficulties facing people with disabilities, and, indeed, the emotional task of travelling to witness and record human rights violations can easily turn questions about the viability of statistical representations into a footnote or less. Where advocacy is concerned, witnessing and documenting stories of injustice becomes far more important than calling for more rigorous surveys.

Yet, survey data are still required in nearly every discussion of disability rights as human rights. This practice points to an implicit proposition: that disability rights violations matters because of the number of people affected. This raises important moral questions: how many people should qualify as "disabled" before the nondisabled care? When does a system of oppression that privileges the able-bodied become a "problem"? What rate of disability in a population demands majority attention? Or, is disability *always* produced as a category that

will always be a minority? If so, what are the implications for theory and ethnography? Is the problem survey techniques, measurement tools, or the category itself?

Defining Disability in Global Friction

As we have seen, the international standard for assessing disability is a self-reported assessment of functioning, although very few populations have statistically significant data reflecting this measure, as this mode of questioning is almost never included (at the time of this writing) in routine census-taking. UN experts have begun to suggest that more detailed disability measures be included in census surveys, and global bodies may push for this in the future (Hadans 2014). At the same time, nation states are free to define what counts as a disability for the purposes of state welfare programs for themselves.

The way that a given state defines the category of disability has real impact on the lives of people whose bodies do or do not fit this category. It also has direct ramifications for rates of disability: shift the definition a bit in one direction or another, and hundreds or thousands of people will suddenly become entitled to or lose their entitlement to social services.

My interlocutor Anya told me a joke (or, rather, a true story with a punchline) about the idiosyncracies of what counts as disability according to official definitions:

When is it enough of an illness (*zabolevaniye*), that a person can be accepted as an *invalid*? So, in the previous group of [rehabilitation patients at the center where I work], a man came, who had amputated limbs. [wryly] Well, an amputation, but they didn't cut of much, you know?

And he says to me, "Listen, they want to take away my disability status." And he has a group three *invalidnost* and they want to take him out of this group [to a lower level of disability, with lower monthly benefits].

So I jokingly ask: "What, your leg is growing back?" And he answered back, in jest, "Obviously it is!"

So, I spent some time with the documents, and I found out that our legal code about finding a person to be an *invalid* is pretty hilariously written. A person can actually have no legs and no arms, but [...] if

you can care for yourself, if you have a professional occupation, and a bunch of other things, then they can take away (*mogut snyat'*) [the status and benefits of] *invalidnost'*.²⁸

In this commentary, Anya underlines the ways in which the legal definition of disability for functional purposes - that is, productivity - contrasts with colloquial understandings of what counts as an extraordinary body. She makes a joke about the ways in which disability and bodily states are not static, but changing (although, of course, limbs don't grow back, there are many other reasons why a person's capacity to care for themselves might change over time). Then, her description of a humorous exchange turns serious. She underlines the fact that a series of very dry and tedious to read provisions might mean a great deal of difference in livelihood for someone whose status is contested.

Anya's commentary places disability determination as a wholly illogical process. Centering the perspective of a person with a disability, she paints the reasoning behind the legal provisions governing disability status in the Russian welfare state as absurd and practically unbelievable. Yet, the provisions that she describes set by the Russian government are not very different from clauses in the US social security code, which also states that a person's disability benefits should cease if she is found to be able to work again.

²⁸ С. У меня на работе сейчас тоже поднимают этот вопрос, когда есть не достаточная степень заболевания, чтобы человека признали инвалидом... Так вот, в прошлом заезде приехал молодой человек – у него ампутация стопы... (говорит с иронией и смеётся) Ну ампутация – мало отрезали, понимаешь...

К. Да (смеётся)

С. И он мне говорит: «Послушай, мне хотят группу снять.» А у него третья группа инвалидности и эту группу у него хотят снять. Я шутя спрашиваю: «Что, нога что-ли отросла?» Он мне шутя отвечает: «Видимо отросла.»

К. (смеётся)

С. Я изучила все документы и поняла, что у нас законодательство о признании человека инвалидом написано очень комично... Человек может быть даже без двух ног и без двух рук, но если ты отвечаешь требованиям, которые прописаны в классификаторе: сам себя обслуживаешь, ведёшь трудовую деятельность и многое другое, тогда тебе могут снять инвалидность.

This points to a fundamental friction between what counts as disability for citizens on the ground, and what counts as disability for those technocrats charged with assessing who should be entitled to government pensions and receive a (semblance of) livelihood without working.

The economic measures and concerns highlighted by Becker and Andreev in the previous section help to situate the interest of the welfare state. From the perspective of state economic planning, with the goal of growing the national economy in mind, the economist's intention is to maximize the labor force without costing the economy and public moral by not provisioning the needy. In this sense, the threshold for a disability benefit should be set just at the level that the difficulty of obtaining the benefit does acts as a disincentive to those who might otherwise participate as laborers in the national economy. It also means that for someone who has a stigmatizing or very visible disability - like amputated limbs - and perceives him or herself as significantly disabled, but able to work, the determination that his disability is only partial might come as a shock. This mismatch - between the worker who wants disability benefits, and the state welfare agent who considers the claimant able to work is by now a familiar one.

In contrast, what is rarely addressed is the way that global power dynamics and the fallibility of disability prevalence measures may also affect the definition of disability in a given nation, and, in turn, people on the ground.

Kohrman offers an important illustration in this regard. He found in his research in China in the 1980s and 1990s that the way this work of defining and counting disability prevalence played out in unexpected ways. He begins from a scene that could have taken place in any contemporary nation state: a woman with a particular physical problem visits a

state office to apply for official disability status, and is denied, a bureaucrat telling her that her affliction does not meet federal standards of disability, or, *canji* in Chinese. Kohrman's interlocutor, Ma Zhun, who lost a section of one of her feet in a mechanical accident and as a result has trouble walking, remarked to the bureaucrat before leaving the office:

Where did your *canji* standard come from? It doesn't make any sense. If that damn industrial machine that fell on my toes ten years ago had cut off more of my foot and I had trouble walking just as I do now, I'd be able to get an ID. But because my foot isn't more mangled, I have to lose my job. That's stupid. If someone can barely walk, why doesn't that count as *canji*?
(Kohrman 2003:6)

Kohrman documents the derivation of the disability or *canji* standard in China. He writes:

The denial of a disability ID to Ma Zhun that day in the mid-1990s occurred largely because her body did not fit criteria created some ten years earlier for an epidemiological exercise. In the mid-1980s, in coordination with several international organizations, branches of China's party-state crafted those disability criteria for what is called the 1987 National Sample Survey of Persons with Disabilities. This survey reputedly was China's first "nationwide" count of *canji* adults and children. It was a mammoth undertaking, one that collected data on more than one-and-a-half million people residing in 424 rural and urban communities distributed throughout China's provinces and autonomous regions. And by the time it was conducted, after several years of preparation, the 1987 survey had become a decidedly biostatistical study, one informed by several internationally anointed standards for what is and what is not disability.
(2003:7-8)

Conducting interviews with stakeholders and government officials, Kohrman patched together the story of how the Chinese government came to be interested in a household survey to measure disability rates - which up to that point had not occurred in living memory in the Chinese population.

In the early 1980s, with the growing strength of the Open Door policy, many high-ranking Chinese officials increasingly interacted with visiting foreign dignitaries. Prompted by the U.N.'s Year and Decade programs (and the encompassing global fervor around disability), the foreign dignitaries asked many epidemiological questions about China's disability situation. Because the Chinese government had never made disability an object of wide-ranging study, its officials had no way to answer. This caused a number of the Chinese officials to feel not just personal frustration but also a sense of national embarrassment. On more than one occasion, my informants described the situation in terms of the highly embodied idiom of "face." As one of the officials responsible for the survey of disabled children told me, "To stem this problem, to stop China from losing face, we felt our only choice was doing a big study based on the most scientific of international techniques."
(Kohrman 2005:73)

A 1983 survey of children made way for a 1987 survey of the health of the entire population.

However, officials were embarrassed and worried when their survey, with their carefully

designed questions based on the best international survey technology turned up a rate of 14% disability. According to UN statements, the officials were sure that a proper survey instrument should return a disability rate of 10%. The figure of 10% disability prevalence had been included in a major UN speech on disability policy. Kohrman shows that the figure was always an estimate, tossed out by a disability advocate from New York in the course of his advocacy activities, that got picked up and amplified. It was never based on statistical research, but the Chinese survey designers did not know that. In Kohrman's telling, the promotion of a figure intended as an estimate - that 10% of the world's population is disabled - became a metric by which Chinese officials assessed the accuracy of their own measures of disability. If other countries had a disability rate of roughly 10%, they reasoned, then so should China.

On the one hand, the 10 percent rhetoric created pressure for a certain kind of number. If the survey's rate did not fall at or above 10 percent, some within China and in international circles might view the leadership group (and by extension the CCP and China) as unequipped to handle basic scientific methodologies and thus as backward and incompetent. On the other hand, there were powerful forces within China militating against a 10 percent or higher figure. For example, some government agencies that the leadership group consulted thought a figure of 10 percent or higher might be damaging to the CCP's authority. Because of how many people across the PRC historically viewed *canji* (and its more idiomatic cognates *canfei* and *feiji*)²⁵ as shameful and to be hidden, and because of the colonial legacy inherent in the "sick man of Asia" concept,²⁶ the worry was that a 10 percent or higher prevalence rate could potentially call into question the very ground upon which the CCP rested its legitimacy in the early 1980s: the purported successes of Mao's revolution. (2005:76)

Officials also worried that a figure higher than 10% could create a financial drain on the nation if disability benefits were to be paid out consistently. A UN official recalled that an initial questionnaire draft that had used a colloquial line of questioning was jettisoned when it produced rates of disability higher than 13% in a pilot study. As a result, Chinese officials sought to translate more biomedical and epidemiological rubrics, which had up to that point been largely foreign to Chinese discourse, in a new draft of the questionnaire (2005:78). Ultimately, the Chinese technocrats succeeded in designing a survey that produced the

sought-after disability prevalence rates: not much higher or lower than the arbitrarily determined, but internationally disseminated, 10% mark.

Kohrman's scholarship helps us to understand the ways in which information infrastructures are shaped by complex global systems. Definitions of disability or *canji* are far from obvious, or self-evident. Layperson perceptions of impairment or bodily difference, like Ma Zhung's assertion that her missing toes and difficulty walking should qualify as *canji*, are produced as secondary to medico-legal definitions of disability derived from global expert cultures that are in turn wrapped up in a politics of global ordering. These dynamics are neither fully positive, in terms of a standard of progress toward a healthier and better supportive population, nor wholly negative, in terms of a Chinese population at the whim of officials trying to save face in a global system. Rather, as Anna Tsing suggests, "universalizing rhetorics of rights and justice" - in this case the globalization of the category of disability as an element of citizenship and attribute populations - exist in productive friction, "heterogeneous and unequal encounters (which] can lead to new arrangements of culture and power" (Tsing 2005:5). Kohrman's telling does not insinuate a global hegemony of Western definitions of disability; rather, he goes on to demonstrate the complex and unexpected ways in which the "foreign standards" of disability get taken up and mobilized by Chinese *canji*.

Conclusion

This chapter has reviewed some of the ways in which the questions "How many disabled people are there in Russia?" or "Are there more disabled people in Russia than in other countries?" are difficult to answer and contingent on numerous variables. Moreover, throughout this chapter, we have seen some of the debates unfolding in international expert

cultures about how these questions *ought* to be answered, thereby revealing what is at stake in answering this question to a variety of different stakeholders. Complex international power relations, as well as contrasting motivations within national policy work, are enacted in ways that influence disability prevalence estimates, and legal definitions of disabilities. These disability definitions, enacted in friction with demographic politics, in turn come to bear on disability determinations and real life experiences of people living with disabilities. From the perspective of citizens on the ground, like Ma Zhung in Kohrman's account, or Anya's client with the (not) growing limbs, the boundaries of what counts as disabled or nondisabled seem arbitrary as the process of how a definition has been arrived at is mystified by bureaucracy and the idiosyncrasies of policy decision-making.

Therefore, for anthropological purposes, demographic measures of disability must be thoroughly interrogated as to intent and purpose, and cannot be accepted at face value. In a sense, this serves as a call to medical and biocultural anthropologists to contribute new studies to the demography of disability. An integrated approach that considers local cultural factors that may influence self-reporting will considerably improve accurate understanding of disability prevalence, and actual experiences of health, impairment and subsistence activity.

For the purposes of this dissertation, the variability and contingency of measures of disability prevalence presents several important conclusions.

First, we cannot easily assess the rates of disability in Russia, either for the population as a whole, or for specific co-morbidities. Important work can be done by Russian demographers, advocates, and sociologists to unpack the biases of the best estimates, and to improve survey design going forward.

Second, future projects in anthropology of disability might interrogate this question of disability demography as a manner of getting to an anthropological understanding of the ways in which disability as a category is not only contested, but made up in complex transnational discourses. When we assert how many people with disabilities exist in a given population, we are also referencing myriad assumptions about what counts as a disability, when and why disability counts and for whom, and about which global bodies are qualified to speak about transnational injustice. What is at stake in defining disability as a category is mismatched not only between individuals and states, but between states and global standards of governance, for transnational expert cultures, and for disability advocates.

Finally, disability studies and transnational disability advocacy are implicated in the way that definitions of disability spread. Statistical figures, even when spouted off-hand, may hold cultural cache and unexpected power when political economic interests and global hegemonies of what counts as justice, modernity, and adequate governance have the power to shift disability prevalence assessments, and, therefore, definitions of disability. Global disability rights advocacy must be careful to consider potential complicity in global development discourse, and question how transnational aspirations about disability rights might operate in ways that reproduce neocolonial dynamics.

PART II
Materializing *Invalidnost*'

CODA I
THE VALAAM MYTHOS

Mythos, n. a myth or mythology.

- (in literature) a traditional or recurrent narrative theme or plot structure.
- a set of beliefs or assumptions about something.

(Google Dictionary, accessed December 14, 2014)

It would be entirely possible to tell the story of disability in Karelia without ever mentioning Valaam. After all, what happened there remains a mystery. Each assertion of fact or revelation of historical detail is covered by another. But, the truth is beside the point: it pales in comparison to the mythos of the invalidi of Valaam.

Petrozavodsk sits on the Western shore of Lake Onego, one of two large lakes in Karelia. To the south, bordering the Saint Petersburg administrative district is Lake Ladoga. Ladoga is famous for its strategic history as a supply route into and out of Saint Petersburg, including during the Seige of Leningrad. In a northern corner of the lake, set a clear distance through mists beyond the pine and birch lined banks, is the island of Valaam. Valaam is the largest of a small archipelago of islands, forested, edged with grey granite boulders and circling gulls.

The story goes like this.

After the Great Patriotic War (World War II to the West), there were many soldiers left unwhole. They had one arm, one leg, they were missing hands or feet. They were broken in some way. And so all across the Soviet Union appeared a problem: what to do with these

veterani-invalidi. *Now they could not work as they had worked before; they could not contribute. Yet they had already sacrificed everything.*

The next part is told differently by different writers.

Some say they were rounded up in the night. Others say it happened some other less violent or secretive way. But most agree that disabled veterans from around the Karelian republic were brought to the island of Valaam, where the men (were there any women? are there ever any women in the tellings?) were set up to live in the crumbling monastery on the island.

In the 1960s, a tourism initiative began offering boating excursions on Lake Ladoga, and tourists were brought to the island. Whatever it was that tourists glimpsed of the residents of internat in the monastery left an impression; their stories of the "hell on Valaam,"²⁹ where abandoned veterans wandered limbless, hungry and alone were passed as whispers or ghost stories. A strange publication appeared, "The Valaam Notebook," which told the tale.

These stories took on varied meanings. One telling is a fable of cruelty and injustice at the hands of the Soviet government, that imprisoned its bravest soldiers if their bodies did not fit into the imagined nation.

The myth of the prison-like institution for veteranov-invalidov did not appear suddenly. It seems to have begun with secrecy that surrounded the home for invalidi on Valaam. The author of the famous [book] The Valaam Notebooks, the tourguide Evgenii Kuznetsov, put it this way:

"In 1950 according to an order from the High Committee of the Karelo-Finnish SSR established on Valaam a Home for Invalidov of war and labor in the buildings of the monastery. And what an institution! It's not an idle question to ask: why there, on an island, and not somewhere on the mainland? Certainly it would have been easier to set up and cheaper to maintain. The formal explanation - there were many residences, that could be set up on the grounds, the land was tended

²⁹ The Russian Wikipedia entry for "Valaam Home for Invalidov" recently included the sentence: "The story of the Valaam 'hell' took many forms and continued to spread."

(there was just one farm there), there were beds from a vegetable garden, and fruit trees, and berry patches. But the informal, actual reason was that the Soviet people had already had an eyeful of tens of thousands of invalids: without hands, without legs, wandering, barely alive and begging in the train stations, on the trains, on the streets, and well, everywhere else. So, see for yourself: they have medals on their chests, but he has to beg for bread. He's of use to no one! To get rid of them, there would have to be some way to get rid of them. But where to put them? Well, in a former monastery, on an island! Out of site, from the heard of the war. In just a few months the victorious nation had purged its streets of this "mark of shame"! So that's how the asylums ended up at Kirillo-Belozerskii monastery, Goritskii monastery, Aleksandro-Sbirskii monastery, Valaamski monastery, and so on..."

That is, the remoteness of the island of Valaam is explained by Kuznetsov in the sense that people wanted to get rid of the veterans... although there were plenty of institutions in plain site.³⁰

Another telling offers the tale as an iteration of meaningless suffering: Imagine, those men survived the front, only to be gathered up and kept like criminals.

In yet another, the tale becomes a ghost story, something teenagers tell one another for shock value, a chill up the spine, so that the bodies of veterans are turned into monstrous warnings, half-human: on Valaam, there is a man with no arms and legs, just a head and a torso. He lost them all in the war. The other invalids carry him around in a basket. He can do nothing for himself... they live in a decaying monastery, with no heat or work, and they are not allowed off the island.

Recent retellings online have led to a new proliferation of accounts. Trolls and conspiracy theorists publish unsubstantiated blog accounts; journalists seek out archives; the state-funded center for social and political research attempts to set the record straight: the men were allowed off the island, they came shopping occasionally in Petrozavodsk. The air of scandal, secrecy, wronged souls, a society without justice follows the story.

³⁰ This excerpt is taken from one of the many websites contributing a perspective to the controversy about what "really" happened on Valaam. The author quotes extensively from Kuznetsov's *Valaam Notebooks*, both in this excerpt and throughout, but disputes Kuznetsov's interpretation, asserting that what's at stake in the retelling is the honor and moral character of the Soviet or Russian people. Truth or Falsehood: What Happened to the Veterans of WWII on Valaam (Pravda Ili Vymysel: Chto Bylo S Veteranami VOV Na Valaame) 2012. Newsland. <http://newsland.com/news/detail/id/1097458/>, accessed December 15, 2014.

The monastery-institution was closed, or moved, in the 1980s. Some accounts say that its survivors now live in another internat, no longer on an island, but in a rural town not far from the lake.

But the tellings haven't stopped. Just as someone suggests a summer excursion to the now renovated monastery, once again a religious destination, the onion domes repaired and painted a bright blue, so the story of the veterani-invalidi comes up. Do their ghosts haunt the island? What was their fate when it was decided that the monastery would be renovated? The real people who lived there are supplanted with ghostly symbols of the shadowland of Soviet morality, when there was no religion, only suffering.

Yet none of these tellings are ever presented in the voices of the survivors themselves.

The fate of these now fabled residents of the monastery haunts Karelia. The mythology that continues to swirl around them reflects a discursive pattern that stretches beyond the island, beyond their individual bodies. Valaam offers a location and form for a mythos of disability that resonates throughout Karelia, and the mythos that grounds this ethnography.

I sat at dinner one night in 2014 with my friend and colleague, historian John Little. We were eating Thai food in Washington DC, but our conversation was on disability in the Soviet era. I recalled an article by Robert Dale about the mythology surrounding the veterans on Valaam (2013). I asked if John had ever had a chance to visit the monastery, or heard the stories of Valaam. He hadn't. I asked if he had encountered anything in the archives in Saint Petersburg or Moscow. He hadn't, he said. I told him what I knew of the site, and that I didn't know where it fit into my ethnography. Perhaps it wasn't anything.

It fits, John said. Because it's part of the stories that we tell ourselves and that we hear about disability in Russia.

If we want to know about people with disabilities in Russia, they are always tucked away on a special island. They are always inside of some system of care - a church, a state, a family. They don't exist to speak for themselves or clear the record, rather they are tragic voices of the wronged, they are mythological, they are symbols.

Disability theorists David Mitchell and Sharon Snyder coined a now famous phrase, narrative prosthesis, by which the mean, the practice of inserting characters with disability into fiction as a way to symbolize greater themes. Or perhaps of bestowing fictional characters with particular disabilities as a manner of patterned lyrical suggestion: the blind man who can see the truth, the child with a sickly body but deep moral compass, the villain with a misshapen face. In these fictive iterations, non-normative embodiments are never simply themselves, they are symbolic vessels by which author or teller communicates with the reader or listener, a prosthetic aide to the course of the narrative. In this way, actual people with disabilities are doubly silenced - they are excluded as narrators from a dominant discourse, and, simultaneously, their physical characteristics are taken to speak more about their individual characters than their own ignored accounts.

The Valaam mythos offers a glimpse of a sort of Soviet and postsoviet incarnation of narrative prosthesis, yet in this instance, it is not a particular bodily attribute, but rather disabled bodies themselves, that come to stand for something else. Who were the heroes of the Soviet era, and who were the villains? Was the church a victim? Was the state to blame? How did so many people suffer, and what does that suffering mean? These debates get played out in the online tellings and retellings of the Valaam mythos. The stories are about disabled

bodies, but they are bodies that are always apart from the rest, separated, secluded; bodies that do not speak for themselves, that are victimized, or protected; bodies that were cursed, or blessed; bodies that occupy some other space of story, mythology, and history.

In this way, any story that I tell about disabled bodies in Karelia is a story that must wind its way past the mist of Valaam, twist through the eddies of Lake Ladoga's inlets, through the snail-like cochleae of everyone who has heard this tale. To come out on the other side, each disabled body must negotiate these narrative sinkholes, paddle past the mythos, burn off the mists of metaphor. The narratives that I share here are burning for this chance. To be seen as people first, people whose bodies might simply be, bodies beyond the mythos.

CHAPTER IV PLACE, SPACE AND DISABILITY IN PETROZAVODSK

[Space is] first of all heard (listened to) and enacted (through physical gestures and movements)

– Lefebvre (1991:200)

Whose knowledge counts? And what does this have to do with place, culture, power?

– Escobar (2008:4)

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 [*kruglaiia 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 across his body as if in the midst of a rhetorical gesture, or, in the winking observation of local tricksters, having just tossed a Frisbee. 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. 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.

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, Moscow to the East, and by extension to the wider world. 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.

In this chapter, I will briefly review the major themes in the history of the Karelian Republic. Because very few foreigners have knowledge of this small corner of the Russian Federation, I have included basic historical and geographical information, as well as a quick review of the ethnohistory of the region, which is a fascinating subject in its own right, with suggestions for further reading in citations and footnotes. The emphasis of this chapter is the Karelian Republic's status as a border territory of the Russia that maintains a special relationship with Finland. The proximity to Finland and partial access to observe and experience the Finnish way of life, I argue, marks the worldview to citizens of the Russian Karelian Republic: the horizons of possibility, concepts of European modernity, and perception of the government of the Russian Federation are all colored by the tangible proximity of another configuration of governance.

This configuration, I argue, emphasizes the arbitrary nature of the location of the international border, and for people with disabilities, highlights the injustices and experiences of discrimination and inaccess produced by the Russian built environment and political situation. I present this perspective as an orienting point of departure for further chapters in this section, which deal with the built environment and elements of public infrastructure in Russian Karelia as a way to think about the material reproduction of disability and in/access in the postsoviet conjecture.

Petrozavodsk: Territory and Place

When John F. Kennedy visited Moscow as a young man, he was not impressed. He later wrote that Russia is a "dreary, dusty and depressing country"³¹. The image of the Soviet and postsoviet Russian city as drab, repetitive, dull and near-military in lack of variation persists in the American imagination. Many Americans are surprised to realize that the Russian Federation spans 11 time zones, and the internal variation includes the nearly Mediterranean cultures lining the black sea, varied tribes of nomadic reindeer herders across the polar north, Japanese-style fishing villages in the Eastern Maritime region, the unpopulated volcanoes of the Kamchatka peninsula, the Silk road-influenced city of Kazan, as well as the famous fur-hat and onion dome dotted capital cities of Moscow and Saint Petersburg.

More than just snow and grey apartment complexes, Russia's internal variation is as dramatic as that of the large nations of the Americas. It's population and subcultures are equally diverse.

The Northern European peninsula that separates the Baltic Sea from the polar north is home to present day Norway, Sweden, and Finland. The territory that is currently the Russian Republic of Karelia has long been a border zone between Russian polities and other Northern European powers. History buffs often remember that the Russian Tsarina Catherine the Great was of Swedish descent. For much of history through the 18 century, the Russian and Swedish kingdoms were of great mutual importance, and frequently at war. Present day Finland, the border territory between the two monarchies, was part of the Swedish Kingdom until it was handed over to the Russian Empire with the conclusion of the Russo-Swedish

³¹ From a film shown at the JFK memorial library (find original document/quote?)

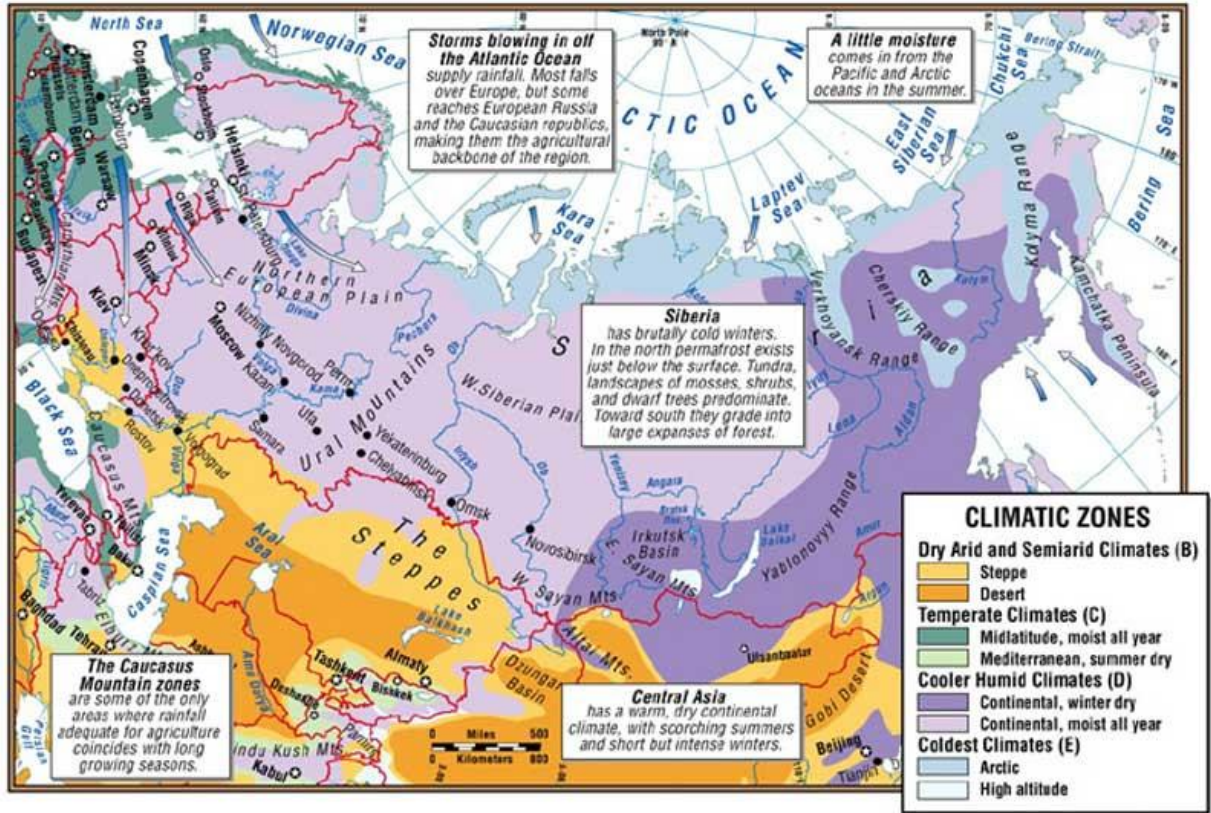


Figure 10: Map of Russia's Climatic Zones, via <http://www.roebuckclasses.com/maps/placemap/russia/russiaclimate.JPG>



Figure 11: Map of the Natural Resources of Russia. The major natural resources in the Karelian Republic are timber and iron. Map via http://wps.prenhall.com/wps/media/objects/2085/2135082/figure09_31.jpg

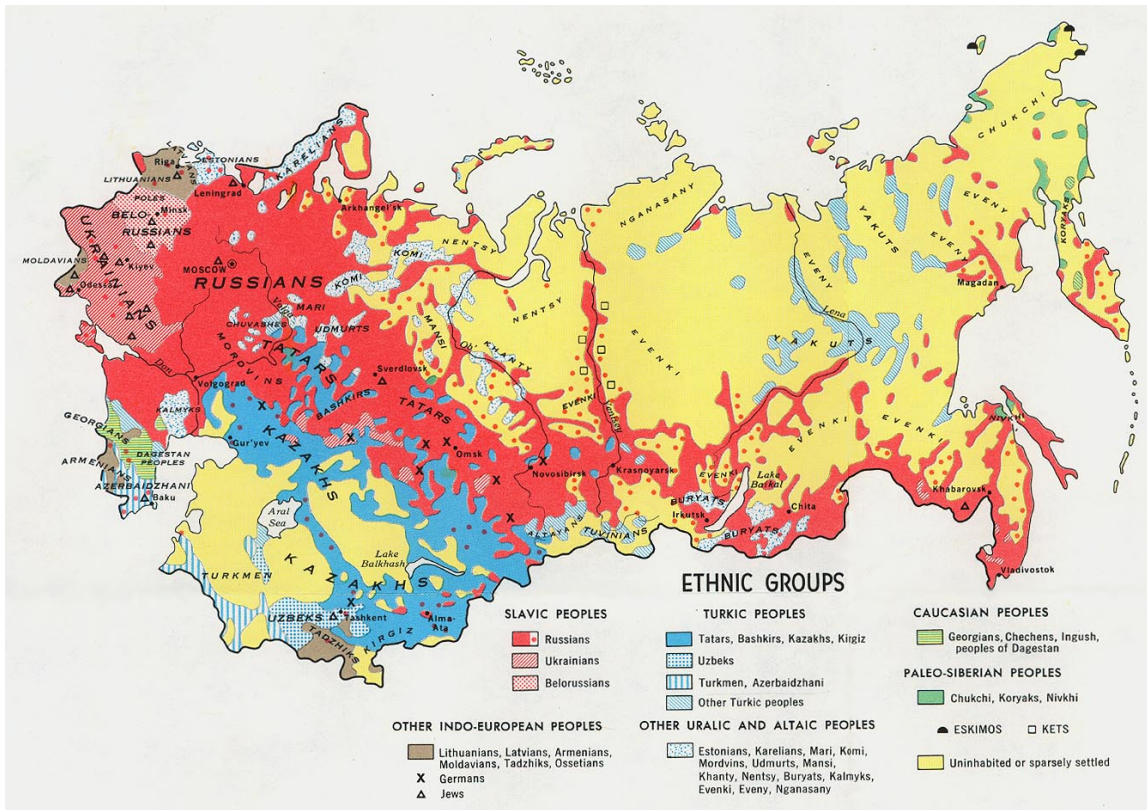


Figure 12: Map of Ethnic Groups of the USSR, 1974. The light blue region of Karelia designates the rural regions of the Republic as being primarily Karelian, though Karelians are grouped with numerous other ethnic groups. I was unable to find the derivation of this map or details about how this representation was created; I suspect that it is an American production based on Soviet ethnographic publications. Map via http://images.nationmaster.com/images/motw/commonwealth/ussr_ethnic_1974.jpg

wars in 1809. For more than 100 years, the Finnish territory, like neighboring Karelia, was politically under Russian rule. When Finland declared independence in 1917, following the Russian Revolution, Karelia became a worker's collective, and then a Soviet Socialist Republic.

Finnish archaeological records trace Finnish ethnic heritage stretching back to prehistory, but Finland was not an independent state until the 20th century. Today, Finland's history as a border territory is evident in contemporary language usage in the country: Swedish is recognized as an official language of Finland, and many Russian-speakers with Finnish heritage also live in the country. In the immediate post-Soviet period, Finland opened

immigration for those Russian citizens able to demonstrate their heritage as ethnic Finns, creating a minority population of Russian-speaking immigrants. Today, with 5.5 million citizens, Finland's population is just over a third of that of the Moscow metro area. While Finland was once a region of the Russian Empire, and today is an independent nation state, the neighboring Karelian Republic - with shared historical and cultural ties - is an administrative unit of the Russia Federation. The population of the Karelian Republic, according to 2010 Russian census data, was 643,548.

The Karelian Republic both geographically and culturally inhabits a border territory between Finland and the Russian Federation. The location and sanctity of the political border is a tenuous one, and has shifted numerous times since Finnish Independence (Korpela 2008). Even so, an imaginary line has real impacts on the built environment, infrastructure, public memory and identity, and guarantees of citizenship (see: Kurki 2013; Marin 2006).

Karelia, in Russian, refers to one of the Northwestern most provinces of the Russian Federation. Also called The Karelian Republic, or *Respublika Karelia* in Russian, it borders Finland to the West, Murmansk Oblast' to the North; the White Sea and Arkhangelsk Oblast' to the east; and Vologda Oblast' and Leningrad Oblast' (the Greater Saint Petersburg administrative district) to the south. Karelia is named for a historic ethnic group. The Karelian people are categorized by archaeologists and Soviet ethnographers³² as an indigenous population, speaking a language related to Finnish, and historically living a lifestyle characterized by hunting and fishing in northern forests, an animist mysticism, and a

³² The history of pre-Soviet and Soviet Ethnography is a topic in its own right, with configurations of colonialism and scientific knowledge production that objectified indigenous people that followed patterns somewhat distinct from that of Euroamerican anthropology. Interesting work on this history can be found in the work of as well as Eugene Golomshtok, Francine Hirsch, and Stephen and Ethel Dunn.

traditional national costume distinguished by red cross-stitching on white fabric. Their cultural heritage is well-documented in regional cultural heritage sites and public museums³³.

In Finnish, *Karelia* refers to the Southeastern territory of Finland as well as sections of the Russian province of Karelia. *Karelian*, as an adjective in Finnish, can refer to the language - considered by many Finns to be an ancient or Eastern dialect of the Finnish language. Or, it can refer to a particular design aesthetic, characterized by a curling pattern adorning pottery, and a style of building furniture (which are both apparently considered indigenous to the Southeastern region of Finland, the *Finnish Karelian territory*)³⁴.

This misalignment about what the word *Karelia* refers to, and about who is *Karelian*, is indicative of a much deeper history of conflict and migration around the Russo-Finnish border.

Figure 13: Map of Karelian Border Region This map shows the contested region of the Russian Karelian border during the and immediately following the second World War.

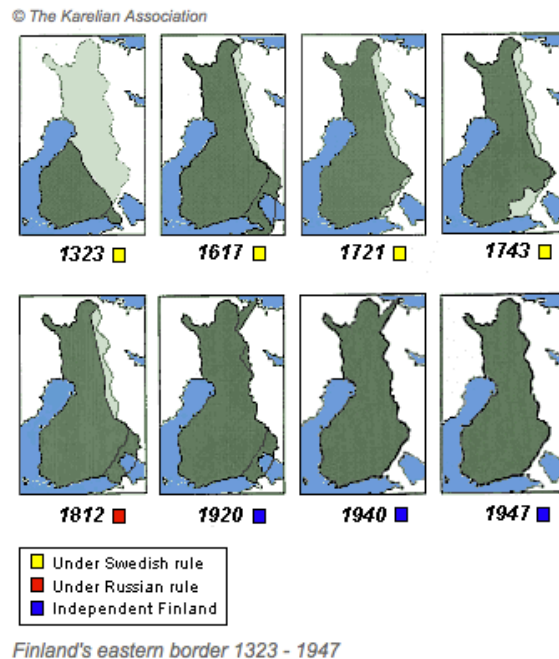
³³ The Karelian ethnic group for which the Russian Republic is named also share the region with two other indigenous groups. In southern Karelia, the Veps people, whose language resembles neither Finnish nor Russian, maintain an indigenous identity, although today's population is small, and the community impoverished (Nilov 2009). In popular Russian cultural history representations, the Veps people are known for traditional dress that is characterized by a unique technique of bending birch bark into clothing and jewelry. Farther from Petrozavodsk, in the northernmost reaches of Karelia and into Russia's Murmansk Province, the Sami people are known for their nomadic tradition as reindeer herders. The Sami today maintain a degree of indigenous independence, crossing the forested northern peninsula between Russia, Finland, Sweden and Norway. Cultural history destinations in Karelia portray Veps and Sami as timeless indigenous minority groups, and also document the presence of pre-Christian Russian tribes and early Russian Orthodox sites, such as the island of Kizhi, a popular tourist destination accessible by ferry from Petrozavodsk, home to a historic Orthodox church built with only wood and no metal nails. A popular mysticism about the region's prehistoric peoples foregrounds an idealized relationship with the natural world, and the region is known for a series of ancient etchings of animal figures in lakeside boulders, known as the Karelian Petroglyphs, the forms of which are frequently reproduced on tourism souvenirs from key chains to t-shirts.

³⁴ I draw this information from exhibitions on display at the archaeological and design museums in Helsinki, August-September 2012.

Because this map was created by a scholar using Finnish sources, Lake Onego is called by its Finnish name, Lake Ääninen. Map adapted from Tolvanen 2008.



Figure 14: Shifting Borders of Finland. A series of small maps represent the shifting boundaries of present day Finland between 1323 and 1947. Graphic adapted from Korpela 2008.



Following the 1917 Revolution, the new Soviets and Finland were in a state of war. Finland emerged as an independent state following the signing of a treaty at Tartu (Estonia),

which ceded two regions of Finnish Karelia to the Soviet Union (Korpela 2008). Ethnic Finns whose homes fell on the Russian side of the new border became Soviet citizens. Following the conference of the Soviets in 1922, the Karelian SSR was created.

Throughout the twentieth century, Soviet Union worked to absorb non-Russian ethnic groups in the region - including Finns, Karelians, and Veps, into Soviet culture through multiple processes of Russification. All residents were given Soviet citizenship. The Karelian language was eradicated except in ceremonial contexts, such as folk songs on appropriate holidays. School lesson and commerce were to be conducted in Russia (Melnikova 2009:90). In the post-war period internal migration strategies moved ethnic Russians from other Soviet regions, especially the war torn areas of Ukraine and Russian-Ukrainian border territories, to Petrozavodsk, bringing a large population of native Russian speakers to inhabit the city. Today, it is rare to hear the Karelian language spoken in the region; young people in Petrozavodsk who come from village regions might volunteer that they have a grandparent who still speaks the language.

A further chapter in the complicated history of the region unfolded with the Second World War. The Russian front with Finland is called by its own name, The Winter War, and included several shifts in borders (see: Tolvanen 2008; Trotter 2000). Most notably, Finnish troops advanced and captured of the city of Petrozavodsk in 1941, an offensive known as the Continuation War. The population of Petrozavodsk recalls this time as an era of grave hardship. Stories of Finnish-run concentration camps in the city, starvation, and cruelty circulate in popular memory amongst present day Russian residents of Petrozavodsk. At the same time, Finnish ethnic populations recall fleeing Russian Karelia for Finland in the pre-

war period, leaving behind family homesteads that were subsequently occupied by resettled Soviet migrant populations in the post-War era (Armstrong 2004).

Soviet migration in the post-War era further contributed to the Russification of the region. The migrants to rural Karelia were

mostly rural [collective farm workers, *kolhozniki*] from Ukraine and Byelorussia and other regions including Mordovia and Chuvash. Migrants were usually young families with children, and moved independently, rather than with community groups, but *kolhoz* [collective farm] groups were established with people from similar regions. [...] No one was native or able to call the territory their homeland; rather, they were settlers.
[Melnikova 2009:87-89]

Only in the Post-Soviet Period has the relationship with Finland begun to be repaired.

"Following the opening of the border in the 1990s, Finnish nostalgia tourism became an important industry to the region" writes Melnikova, an ethnographer of the region in the post-soviet era. "And, local and regional administrative governments cooperated on joint projects to develop the transnational history of the region" (2009:93). Joint government projects helped to develop Russian Karelia in the 1990s and 2000s. Finnish charity groups, churches, and cultural exchange programs brought Finns and citizens of Russian Karelia together. Finnish researchers and social workers reached out to their colleagues in post-soviet Karelia (Kulmala 2010; 2011). Many of the NGO projects and disability rehabilitation work in the late 1990s and early 2000s was funded or supported in part by Finnish governmental or non-profit organizations.

A particular characteristic of the new relationship with Finland is the unique status of citizens of Russian Karelia to travel to Finland. While most Russian citizens have a great deal of difficulty obtaining visas to travel to Europe, residents of the Karelia Republic are permitted a special relationship with Finland. Therefore, the status of Karelia as a border territory quality lends the experience of citizenship in Petrozavodsk a unique character.

Unlike those Russian citizens living in other parts of Russia, the reality of what life is like across the border is real and tangible. Residents of Karelia have special visa privileges for international travel: anyone without a criminal record and possessing an international passport will likely receive a visa for up to six months of travel in Finland.

Figure 15: Photo of the Petrozavodsk Train Station. The train station in Petrozavodsk, here viewed from a bridge over the tracks, the city obscured behind it, is labeled in Russian and in Finnish (Petroskoi). In the above image, the Finnish signage is visible (the Russian, in identical style but in Cyrillic, is on the other side of the cupola, here blocked from view by a tree). The train station remains the main artery by which people travel to and from the city, although the renovation of the federal highway that runs from Saint Petersburg to Murmansk via Petrozavodsk in 200? has facilitated more automobile travel (and significantly cut the travel time by car between the cities). Photo credit: Cassandra Hartblay, 2013.

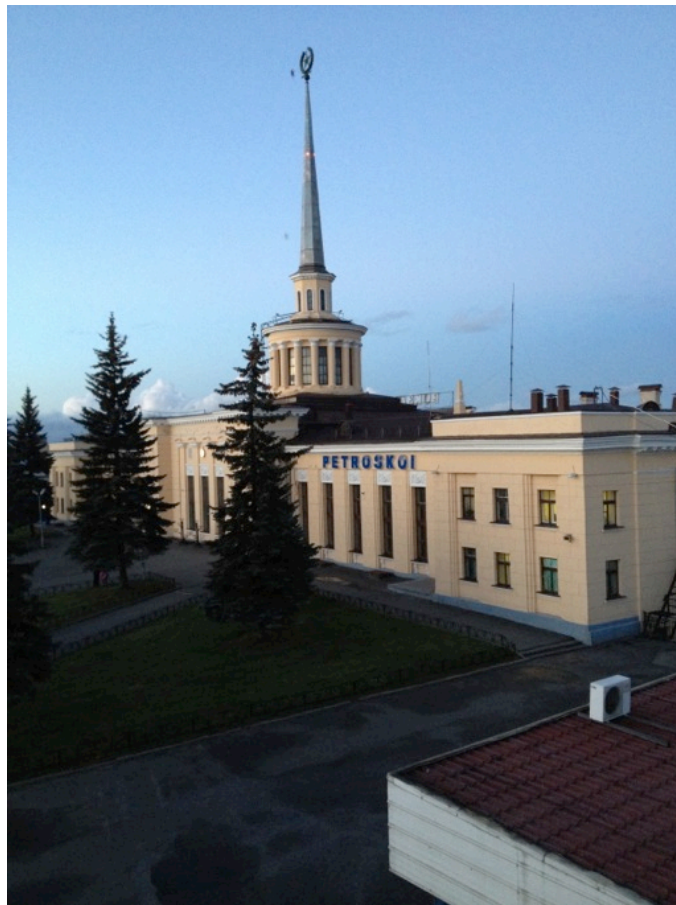


Figure 16: Photo of Petrozavodsk neighborhoods. A view of a central residential neighborhood of old Petrozavodsk, with industry, the city center, and Lake Onego in the background. The photo was taken from the roof of a Soviet-built 11-story apartment building. Many of the houses in the foreground of the image are the old-style wooden houses in which

the majority population lived before Khrushchev's push to build modern housing in the post-war era. Photo credit: Cassandra Hartblay, 2012.



Figure 17: View of Petrozavodsk from across the Lake. With the sprawl of the outlying regions of Petrozavodsk in the background, a cow munches on sweet clover, snap dragons, and thistle in Salommenoye, a northern district of the city set on the shore of Lake Onego (35 minutes from the center by bus). The Salommenoye region, although essentially a village - with cows, chickens and vegetable gardens cluster around tiny wooden peasant house along

dirt roads, is administratively part of the city of Petrozavodsk, in order to maintain municipal control of the Salommenoye bridge. The northern tip of Lake Onego at the Salommenoye bridge passes into a straight connecting it to another body of water, which extends north to the next nearest city, K (pop: 20,000 people) one hour to the north by highway. Photo credit: Cassandra Hartblay, 2012.



As such, unlike many other Russians, many in Petrozavodsk have visited Finland several times, thus experiencing a European lifestyle firsthand. A healthy black and grey market economy in Finnish goods exists in the city. Those traveling to Finland often take cash from friends to make large purchases that are cheaper abroad: IKEA furniture, winter coats, or baby formula. Underground grocery stores sell organic Finnish dish soap and cleaning products, t-shirts and other commonplace goods that are not legally distributed to Russian retailers or which are prohibitively expensive with import taxes. The reality of Russian supply chains mean that even the cheapest goods manufactured in China - whether

furniture or clothing - are very expensive in Petrozavodsk. Although the availability of high quality goods in the city has improved in recent years as full-scale shopping malls and chain retailers have come to town, the midrange products at midrange prices that are a staple of Finnish life are hard to find in Russian markets.

Additionally, because Finland is a part of the European Union, those residents of Petrozavodsk who can afford it can easily travel throughout the EU, vacationing in Spain, or spending a long weekend in Stockholm. While getting a visa to visit the Eiffel Tower or Venice seem like impossible dreams to residents of other Russian regions, the visa barrier is removed for many to residents of the Karelian Republic, and those with the financial means (upper classes and upper middle urban classes) frequently travel in Scandinavia and the EU (while lower class middle-aged folks complain that during Soviet times vacations to other regions of the Soviet Union were comparatively more affordable than now).

Postsoviet Karelian Imaginaries

In popular conversation in Petrozavodsk, the Russian status quo is frequently presented in contrast to the imagined global "normal" - which exists, in popular Russian imagination, throughout Western and Northern Europe, as well as in the US, Canada, and Japan. The postsoviet context, often invoked in conversation with a reference to how things are "here" or "*u nas*," for us here in Russia, is constructed in opposition to these imaginaries of other cultural conjectures. In Petrozavodsk, this practice is especially present, and is usually presented in relation to Finland. In one interview, Sergei deployed this comparative perspective to tell me about his relationship to Russian politics:

I keep a distance from politics. Or, maybe it's that I somehow don't take what's happening very seriously. **Of course, we're never going to measure up to Finland, our neighbor.** I've been there several times on a guest visa. And we can't compare, of course. There everything is totally different. But, what can you do? It's just that our country is big, and so, like, it's really hard to get things on track

in every region, so that everything would be good. So we go along and do what we can when it's possible, they patch things up [*vosstanavlivaiut*] as much as possible, as money will allow.

In this example, Sergei observes that Russia cannot be run the way that Finland is governed. The perception of Finland as totally different from Russian Karelia is felt symbolically, in terms of governance and politics, as Sergei's comment suggests. But it is also felt materially, through historical configurations of infrastructure. While the entire course of twentieth century architectural and infrastructural development in Petrozavodsk was executed by Soviet *gorodstroitel'svo* or city planning, Finland maintained a system of private property, and the central regions that abut the borderlands near Petrozavodsk are characterized by small towns surrounded by family farms studded with homesteads and red wooden barns. The Finnish side of the border region looks much like the American upper Midwest (also settled and developed by ethnic Finns (see: Golubev and Takala 2014; Harpelle et al 2004; Hokkanen 1991)).

While citizens in Russian Karelia live in large apartment buildings, built quickly in the 1970s and 1980s to respond to a Soviet housing crunch, Finns live in single family residences, or modern townhouse apartments. Public transportation on the Russian side of the border is made up of fleets of aging minibuses and buses, while Finnish public transit is well-funded and includes late model accessible buses and well-maintained busstops and sidewalks. Finnish public infrastructure and businesses are frequently renovated and constructed according to the latest European standards, and buildings like schools and hospitals are retrofitted or rebuilt to be fully accessible according to international standards. In contrast, people with mobility impairments in Petrozavodsk find none of these modern conveniences in their city, where public transportation offers no wheelchair lifts, hospitals, schools, and businesses rarely have functioning ramps. The social attitudes toward disability

in Finland are starkly different from those in Russia, as well: the Finnish education system, widely recognized as one of the best in the world, operates on a model of radical inclusion for students with disabilities (Hautamäki and Jahnukainen, personal communication), disability advocates hold positions in the national government, the social welfare apparatus offers superior benefits and standards of living, and the opportunities to find employment for adults with disabilities are greater, given a lower level of social discrimination.

Tania, my interlocutor who has dwarfism and works as a textile artisan, talked at length about visiting a friend, who also has a disability, who moved to Finland. In Tania's telling, her friend who moved after high school, has had an experience of adulthood with a disability that is starkly different from Tania's own in Petrozavodsk.

So in Finland, I've only been to Finland, I haven't been anywhere else, in Helsinki. And so the thing is that I can say that I was *really* [*ia voobshche*]... But Olya, she was in my class at the internat, and she [has] DTsP, [...] and she lived here for a time. So. Here she is, and she has no perspective at all, it just worked out for her mom to move to Finland, and so they have already been living there for a while. Olga lives apart [otdel'no] from her mom, she got married, she had a child, she gets herself around with a wheelchair [*nositsia s etoi koliaskoi*], here and there. She is a totally independent person [*absolutno samosotiatel'nyi chelovek*]. If she were here she would have been, well, not someone who -- she wouldn't have had --- She's still a really emotional person, and it would have gotten to her, if like, if she had wanted to go to university and it didn't work out, it would have just worn her down and worn her down, and she would have thrown up her hands. But there she feels as if she is a person, like, like I said. And she says to me, "Come on, learn the language, move here!" And so I say, "Well, so, the grass is always greener" [*vezde khorosho, gde nas net*]. And I sort of, in general, I wouldn't want to move anywhere if it wasn't going to be [close to my extended family].

In this passage, Tania articulates through a description of her friend Olya's life in Finland what she perceives to be her own hardships as a person with a disability on the Russian side of the border. Her consideration of moving suggests an attitude that seemed common amongst residents of Petrozavodsk in this age group - that if they really wanted to move to Finland it would be possible, but that doing so would be somehow unfair to family members who stayed behind, and that they would be abdicating a sort of moral responsibility to endure the injustices of Russian life.

In terms of disability, Tania's description of her friend Olya's experience reveals that in Tania's experience, it is difficult to achieve certain aspects of a "normal life" as a person with a disability in Russia, which might be taken for granted in Finland: to live independently from one's parents, to move through the city freely on one's own with a mobility impairment, to attend university as a right and foregone conclusion, to form a family of one's own. These elements that remain just out of reach for a person with a disability in Petrozavodsk - but that Tania suggests are the elements of a "normal life" offer an important insight. Where many nondisabled Russians consider certain elements of the Finnish built environment and social and political context more desirable than the Russian conjecture, for adults with mobility impairments, the elements of life that remain out of reach are things that most nondisabled Russians can achieve: an education, a family, freedom of movement in public space. In this sense, while my able-bodied interlocutors also waxed poetic about how much better life could be in Finland, their dreams of a new and more affordable apartment, a prettier public infrastructure, better access to consumer goods, and a more just governmental system were felt differently from the material and social horizons of disabled interlocutors.

Disabling Postsoviet Karelia

How does the political and material infrastructure of Petrozavodsk intrinsically creating barriers and concerns about access and a "normal life" for *invalidi* and for nondisabled citizens? Postsoviet ethnography has written at length about the habit of citizens in postsoviet Russia and other postsocialist countries of Eastern Europe to imagine life elsewhere, as consumer-citizens in a European society, where access to consumer goods and services, housing and transportation, culture and education are imagined to be different, and politics offer possibility rather than constant crisis. This imaginary is frequently posited as

more "normal" than a (post)socialist configuration, summed up by the Russian phrase *zhit' normal'no* (Zavisca; Fehervary; Yurchak). How does the idea of a normal life developed in the literature of postsoviet ethnography implicitly posit a nondisabled body? How does an attention to the parameters of an imagined normal life for Russians with disabilities shift our understanding of what Russians mean when they employ this phrase?

In order to unpack this question, in the coming chapters, I explore the ways that the built environment of postsoviet Petrozavodsk create particular modes of reproducing disability as a socially marginalizing identity. Could the notion of access or *bez barer'niye sredi* - a barrier-free environment - extend from the disability advocacy community to the broader citizenry in Russia in a different way than in the American context? How do the claims that Russians make about what was at stake in infrastructural insufficiency align disability advocates in Petrozavodsk with broader social dialogues about state-citizen relations, government incompetence, and civil society or the public sphere?

As I began to consider these questions, I turned to several specific bodies of literature. These included Feminist disability studies, design theory, the anthropology of infrastructure and materiality, the geography of disability, the politics of space and critical geography, and the ethnography of post-soviet public space and civil society.

Before proceeding with the ethnographic account, let me briefly review what I mean by each of these theories, and how I see them fitting together. In the follow chapters, I will explain how I see them coming into play in Petrozavodsk.

Locating Post-Soviet Public Space

In order to fully unpack the ways in which a ramp moves as not only a tool but as a cultural symbol - in friction and contested meaning - we need to return to the question of the public sphere.

The public sphere in Russia since the fall of the Soviet Union has been a particularly heated subject for debate and interpretation in both Anglophone and Russian scholarship.

Primarily, here, has been the assertion that the Soviet Union "had no civil society" and as such the physical space of the public arena was not considered to be a space of free association in the liberal paradigm imagined by Western scholars (Parsons 2011). Rather, the *prostor* or *prostranstvo* of the Soviet city - the town square or the agora - was a space of non-communion, where a panopticon-esque state watched over the action of individuals, preventing free association. Moreover, the character of postsoviet public space has changed over the past twenty-five years, as new elements of capitalist markets trading in consumer services and goods enter the residual infrastructure of state socialism.

As a result, the character of postsoviet public space has been contested. Some argue that free association developed throughout the years of the 1990s (cite) in the form of all the markers of civil society that western liberals (Kymlicka) like to cite: third sector organizations, peaceful protest, conversations with strangers, voluntary alliances. Others argue that the devastation of the post shock therapy era left Russians shell-shocked in such a way that coming to trust one another in public space was nearly impossible (Caldwell); moreover, the symbolic language and meaning of the postsoviet *prostor* was mutated in complex and difficult to track ways that left citizens confused and disoriented in their own cities (Parsons). At the same time that some elements of the built environment of soviet life

remained (Collier 2013), the logic of what was preserved and what was dismantled was unpredictable and seemingly random (Vitebsky).

CHAPTER V
"LIFE IN FOUR WALLS":
POST-SOVIET APARTMENT COMPLEXES AS MATERIAL AND SOCIAL
BARRIERS

A common refrain in interviews with and about people with disabilities in Petrozavodsk was the phrase "*zhizn' v chetrikh stenakh*" - or, "life in four walls." The expression is meant to denote the sort of mundane lack of stimuli that someone who is housebound experiences. It could, for example, also apply to a prison cell, referencing the confinement of someone whose day is spent within four walls. In this case, the "four walls" were the walls of one's room or apartment.

As Alina told me one day, "You see, [in the US] all of the *invalidi* are out and about in plain sight, but here they all sit, each in their own home."³⁵

Many sources have considered this trope in their discussion of the lives of people with disabilities in Russia and the Soviet Union. For example, a recent Human Rights Watch report, based on interviews with activists and people with disabilities themselves in Russia, suggests that physical confinement to homes is the primary barrier that Russians with disabilities face in their environment, ahead of, if compounded by inaccessible sidewalks and street crossings, public transportation, and entrances to public spaces, businesses and government buildings (2013: 20-32). This assertion resonates with Svetlana's findings about young adults with mobility impairments in Karelia (Driakhlitsina 2009), and with other

³⁵ "Видишь, у вас все инвалиды перед глазами, а у нас сидят по домам."

accounts of Soviet and postsoviet disability experience (Kikkas; Phillips 2011; Romanov and Iarskaia-Smirnova 2006).

Romanov and Iarskaia-Smirnova made a similar observation in their 2006 treatise on disability theory - one of the most complete such works existing in Russian.

Certainly, "there are so many *invalidov*" is a phrase often heard from our [Russian] tourists who have travelled to Western countries and quickly got used to the convenient entrances in train stations, the automatic doors at stores, libraries, and universities, and the comfortable elevators in public buildings. One can enter these places hassle free with a child's stroller, and an *invalid* can also go just as easily, and no one takes him or her to be sick or in need of help. Thus, a person in a wheelchair gets around independently (*samostoyatel'no*), and even travels, confidently using these mechanisms and accommodations (*prisposobleniya*), showing up in a store or a school, at a stadium or a government office, at the train station or the theater, or goes to the airport or the court building. So, if people in wheelchairs in Russia are currently not visible to anyone, this is not all thanks to them not being able to participate in an active life, but because our streets, systems of transportation, and buildings are not only inconvenient or unsafe for them, but because they are actually just inaccessible (*nedostupny*).

I quote this passage in full (in translation), because I think the tone of patient explanation, indignant, and matter of fact observation nicely demonstrate the anticipated attitudes of their fellow sociologists in 2006. Specifically, Russians are less accustomed than peers abroad to seeing people with visible disabilities in public space, a status quo also described by Sarah Phillips in her ethnography of disability in Ukraine (2011). Romanov and Iarskaia-Smirnova conclude the passage by observing that *especially* in the Russian case, the social invisibility or marginalization of people with disabilities is deeply tied to the physical structures of infrastructure, barriers, and inaccessibility. While the argument that physical barriers produce social isolation is often recited in introduction to disability studies courses in the US, it is not a sentiment that circulates far beyond those circles; nor has scholarship explored how the postsoviet Russian built environment and cultural conjecture is, as Romanov and Iarskaia-Smirnova argue, specifically disabling. When Romanov and Iarskaia-Smirnova make this appeal in their Russian-language text, they do so in a cadence and tone that is already

established in the Russian popular vocabulary: one of bemoaning a social failure to create adequate infrastructure for a "normal" life.

Given that a central argument of this dissertation is that understanding the ways in which disability is enacted and reproduced as a category in culturally specific ways in contemporary Russia, it is important to consider how the elements of the postsoviet material and built environment that contribute to the marginalization of people with disabilities.

Marginalization is frequently conceptualized as a spatial metaphor that alludes to a condition of social stigma and exclusion. However, frequently the spatial metaphor is not only a metaphor, but a metonym for social and political exclusion. It is my argument that this is the case in terms of the ways in which the postsoviet apartment building - as a material object - contributes to and reproduces conditions of isolation and marginalization for people with disabilities living in Petrozavodsk today.

In the first place, the material and the social are coemergent, and patterns of social isolation and exclusion continually impact one another, as attitudes about the renovation of buildings or who might be entitled to new living arrangements routinely exclude people with disabilities. In the second place, the politics of space are always local and always specific. There particular characteristics of the Russian postsoviet built environment - especially housing illiquidity and the aging infrastructure and habits of repair - that are unique, local, and have real impacts on the lives of people with mobility impairments as spatial and social actors.

That is - this is not a general argument about how disability and apartments *in general* are coemergent. Rather, this is a specific argument about the particular conditions of the built environment in Petrozavodsk in the 2010s. Because we understand the category of disability

to be culturally, historically, and **spatially and materially contingent**, we cannot assume that *invalidnost'* as a social category in Russia is reproduced in the same way that *disability* is reproduced in Britain (Gleeson; Shakespeare), or *canji* China (Kohrman 2005); likewise, the built environment of Petrozavodsk might be specific in ways that distinguishes it from Moscow or other Russian cities. And, furthermore, the divergences in the reproduction of these seeming synonyms can be instructive for both disability theory and for how we as anthropologists understand the formation and reproduction of stigmatizing social categories.

In order to develop this line of thinking, I will first discuss a cultural history of the Soviet apartment building as a material object. This is partially a history of the housing infrastructure in contemporary Russia, and partially an exploration of the postsoviet apartment building as a disabling object. The Soviet housing project has recently been the subject of several studies on the built environment of the former Soviet Union (Fehervary; Collier; Zavisca). However, with the exception of Phillips's discussion of mobility in Ukraine, there is little ethnographic literature exploring how this built environment relates to critical disability theory, which has frequently been spatially conceptualized in Western scholarship (e.g. Imrie and Hall; Gleeson). Secondly, I will draw on ethnographic data to discuss the history of Soviet infrastructure and how postsoviet housing illiquidity contributes to the reproduction of barriers to social participation for people with disabilities in Petrozavodsk. Finally, I will present interview data demonstrating how within the "four walls" of a room or apartment, my interlocutors make sense of and narrate their experiences, sometimes bemoaning their confinement, and sometimes contesting the implication that life in four walls is socially isolating. They have formed habits, routines, and adaptations that remake that immediate material environment as a nondisabling space. Access, in this sense,

is partially about the built environment and partially about routinized choreographies (Moser and Law). As a result, venturing "out" may mean leaving behind well-rehearsed choreographies and leaving oneself vulnerable - thereby reinforcing incentives to stay "in". This removal of the disabled self from public space in turn contributes to the reproduction of disability stigma, both in cultural attitudes (to be disabled is to be weak and reliant on family) and in literal marginalization, as people with disabilities are pushed to the "edges" or to the confined spaces of the apartment.

In particular, my interlocutor's stories about how they came to live in the apartments they inhabit suggest some of the specific ways that housing options in Petrozavodsk are especially disabling. Their stories illustrate the scarcity of apartments and market illiquidity, and a variety of strategies for obtaining better living spaces - many of which operate outside logics of the housing market as a sphere of monetary exchange (much like the subjects of Zavisca's study on Russian apartments). These tales of a lack of available options to move to a different apartment produce a situation in which people with disabilities are limited not only by the four walls of their apartments, but also by an inflexible and unaffordable system of housing distribution which prevents many families from moving to a more accessible apartment.

To think about disability in terms of infrastructure is a move that has several antecedents. One is the above mentioned notion of choreography that comes from intersections of disability studies and science and technology studies. Another recent focus amongst sociocultural anthropologists on "anthropology of infrastructure," which blends the longstanding ethnographic interest with how material elements of culture are bound up in the social to ongoing developments in information science and STS. In this sphere of unfolding

scholarly investigation, infrastructure becomes an object of ethnographic investigation.

Infrastructures are built networks that facilitate the flow of goods, people, or ideas and allow for their exchange over space. As physical forms they shape the nature of a network, the speed and direction of its movement, its temporalities, and its vulnerability to breakdown. They comprise the architecture for circulation, literally providing the undergirding of modern societies, and they generate the ambient environment of everyday life. ... Infrastructures [are] interesting because they reveal forms of political rationality that underlie technological projects and which give rise to an “apparatus of governmentality” (Foucault 2010, p. 70).

[Larkin 2013:328]

This chapter seeks to knit together this concern for *infrastructure* as a material network that, while frequently fading into the background, actually plays an active role in the organization of social life, and, in the reproduction of particular social processes, here, the marginalization of people with mobility impairments.

That is, I am offering a consideration of the postsoviet infrastructure of urban life, and, especially, housing, as an *infrastructure of ableism*. While disability theory as long postulated an *architecture* of ableism, as the antithesis of accessible design, and in many ways the two phrases might be interchangeable, I focus on *infrastructure* both to align this work with the current anthropological literature, and because the municipal, civic, or public implication of *infrastructure* (built by the state for the common good) is suitably opposed to the patronage implication of architecture as designed for a client-capitalist. By using Larkin's definition of *infrastructure*, as well, we can find that an *infrastructure of ableism* might refer not only metaphorically to information networks (as an architecture would), but quite literally to the material and physical forms of those information networks.

Home Alone

One afternoon over tea, Valya [Alina's mother] recalled a time when Alina was still a child. The work of caring for her daughter - who needed assistance to go to the bathroom - made it difficult for her to work.

Valya: A lot of the parents didn't work, but I worked. [...] So I would lock her in the apartment and walk to work [as a janitor] for three hours. ... After a year and a half I was going into the city to [work at] the medical clinic. I would leave keys with the neighbors, and they would feed her, change her, and sometimes they brought her over to their place -- that was when we were renting an apartment in a house. But when we moved here [to a bigger apartment building], I would lock her in... they didn't give me medical leave, even when she was in a cast after an operation... I walked to work, and locked her in...

C: (to Alina, with empathy) You must have been lonely in a cast and not able to move...

Alina: You didn't say it right, I wasn't alone, I always had a lot of people around... there were always people around me.

Valya: I would leave the keys and the neighbors would come, it was simpler then.

Alina: I would play with the kids and no one picked on me. It was only when they grew up a little that they realized that I couldn't get around... Even now, everyone in the building can't believe that I go places, that I do things.³⁶

In Valya's account, the moral dilemma that she faced as a mother who both had to work and care for a child with intense physical needs weighed on her. She portrayed her decision to work as one that required her to leave Alina alone in the family's rooms of their communal apartment. Alina, in this exchange, challenges this perspective. She doesn't want her mother to present a story of her childhood that would induce pity. "I always had lots of people around me," she counters, and goes on to assert her capabilities and array of experiences outside of the apartment. In Alina's perception, an *invalid* who stays alone in an apartment is truly disabled, in that that person has no social value. Alina asserts her own social worth and

³⁶ С. С2 тебе наверное лучше меня всё объяснит. В те времена, когда я родилась, вообще такого не было, чтобы нас по телевизору показывали. У нас эта тема инвалидности была закрыта очень много лет. Честно тебе скажу.

С2 У нас в основном родители не работали, а я работала.

К. А большинство родителей не работают, а сидят с детьми...

С2. Вот её одну закрывала и шла убирать на 3 часа... Через полтора года я вообще ездила в город в поликлинику. Соседям оставляла ключи, они её там накормят, переоденут, а иногда к себе брали – это когда в частном доме квартиру снимали. А когда сюда переехали я её закрывала... И так больничных не давали, а она была после операции с гипсом... Шла на работу, её закрывала...

К. (сожалеет) Ты, одинокая девочка, в гипсе совсем не двигалась...

С. Ты не так сказала, я не одинокая, у меня всегда было народу много... Вокруг меня всегда люди.

С2 Я ключи оставляла и соседи когда проще были – приходили.

С. Мы играли с детьми и никто пальцем не показывал. Это потом уже взрослыми поняли, что я скакать не могу... До сих пор весь дом удивляется, что я куда-то хожу, что-то делаю.

diversity of experiences. Although, in fact, she does spend many days in her apartment, she often has visitors, and has relationships with neighborhood children, neighbors, and with peers who she sometimes meets weekly during periods when non-profits or the social work agency are running programs.

Alina is sure to assert that her social world reaches beyond the walls of her family apartment, and to contrast that fact with the culturally expected situation for people with severe physical disabilities like hers. "Even now," she says, "everyone in the building can't believe that I go places, that I do things." In her conversation with her mother, Alina contests this dominant perspective that to be an *invalid* and to stay at home renders her socially isolated, or, "needed by nobody." Rather, she suggests that her social relationships are both fulfilling and cast her as a friend and peer to others.

At the same time that people with disabilities may be at home, popular attitudes in contemporary Petrozavodsk do not imagine them as such - rather they simply do not imagine people with disabilities at all. The seclusion of people with disabilities in their family apartments or institutions contributes to a lack of visibility surrounding the hardships that the built environment presents for mobility. Because fellow citizens do not see people with disabilities navigating unruly terrain, they are, in turn, untroubled by the inaccessibility of the surroundings. For instance, I asked a group of high school students to tell me where in the city they thought that people with disabilities might be, not a single one replied, "at home". The students had quite a bit of difficulty with this question. They had a hard time imagining disability places, because they had so little experience seeing people with disabilities using public spaces. The hospital or clinic, someone always volunteered. In short, the identification of *disability places* was overwhelmingly medicalized. It was non-intuitive for students to

realize that most people with disabilities were probably just in the apartments next door to their own.

The Cultural History of the Soviet Apartment Building

Each New Year's Eve in Russia, a 1976 romantic comedy, titled "The Irony of Fate, or, Enjoy your Sauna!" (*S Lyekim Parom ili Ironiya Sudby*), streams into living rooms across the country. The film - a sort of Russian "It's a Wonderful Life" for its holiday season ubiquity - hinges on a peculiarly Soviet plot point: across the Soviet Union, each city had streets with the same name, and block after block of apartment buildings built using the same design. The film's protagonist, drunk after a particularly adventurous New Year's Eve, fails to notice that his friend has dragged him from Moscow to Leningrad, and, finding his way home, locates his street, his apartment building, and his apartment number, enters the apartment, and falls asleep on the couch. He awakens not much later to find the true owner of his identical apartment (albeit in Leningrad instead of Moscow) in a state of panic about the strange man sleeping on her couch. You already know how it ends - with the two falling in love, succumbing to the irony of fate.

The premise of the film itself hinges on a nuance of the architecture of Soviet life, which has since become the architecture of post-Soviet life: the Soviet apartment building. The opening credits of the film display an animated parade of these ubiquitous rectangular Soviet apartment buildings, shown marching in of their own accord - on iron legs - and planting themselves in various unsuspecting landscapes - from the warm seas (of southwestern Russia), to the peaceful snow (of the north), to the deserts of Central Asia. The animated scene shifts to a sketch of the globe, a single apartment building taking it over, then multiplying, becoming ubiquitous and manifold. The opening animation sequence is quickly

followed by a wide-angle scan surveying the apartment blocks of outer Moscow, where building after building melts into a repetitive pattern of concrete cubes.

Far from the miserable automatons that inhabit American Cold War depictions of Russians, the characters - and, indeed, the authors - of *The Irony of Fate* are colorful, endowed with a sense of humor, and fully human. They just happen to live in a social environment that has been engineered in a peculiarly uniform way. Even as the movie itself pokes fun at the absurdity of the vast geographic expanse of the Soviet Union that the opening cartoon illustrates as suffering an invasion of concrete apartment blocks, the characters find lightness, life, and complexity in an architecture of uniformity.

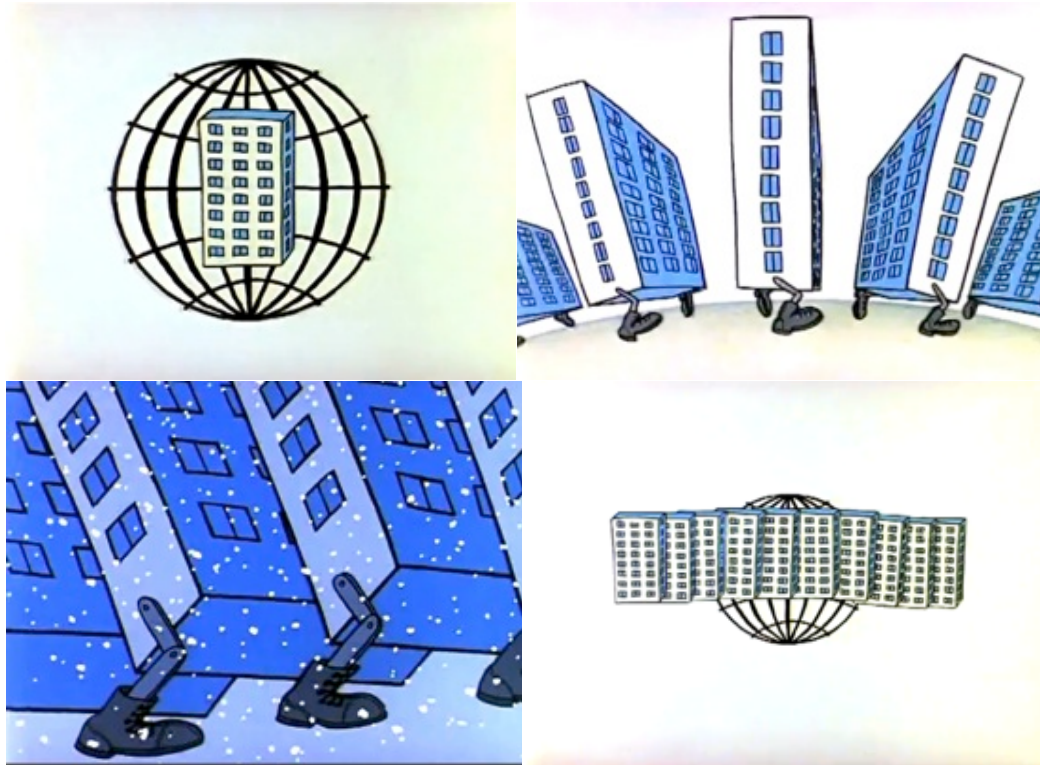
This is significant, given that in American popular imagination, Soviet-era uniformity is frequently represented as a repression of individuality or. Soviet citizens were imagined by US press depictions as always victims of the oppression of centralized planning; binary logics of oppressed/free led to a totalized view of the Soviet person as a person deprived of choice and self-expression humanism (Yurchak 2005). This imaginary could easily extend to the Soviet apartment building as a cultural object that eschewed originality and improvisation - the bricoleur or connoisseur - in favor of mass-produced perfunctory design.

Current ethnographic literature reimagines postsoviet apartment life not as a purely limiting or enabling factor, but rather eschews binary assessments of Russian citizens' agency in the given environmental circumstances in favor of a more nuanced view that reimagines the contemporary Russian citizen as a bricoleur, making do and deploying creative, but culturally-rooted solutions to the problems presented by the postsoviet built environment³⁷.

³⁷ However, recent scholarly attention to the Soviet and postsoviet built environment suggests a potential different interpretation of the post-Soviet *parti*. Stephen Collier has explored the ways in which the built

In this chapter, I take a similar stance, imagining the built environment of the housing options in Petrozavodsk and the corresponding infrastructure not simply as a purely disabling element, but as a material configuration that is coemergent with constantly contested social assemblages.

Figure 18: Images of replicating Soviet Apartment Buildings from the opening sequence animation of S Lyokhim Parom.



environment of the Soviet infrastructure has led to very particular and culturally-located configurations of public infrastructure, which are now repurposed into privatized and state-owned infrastructures that follow logics and arrangements of responsibility unique to postsoviet space. Jane Zavisca has argued that the spatial confines of the Soviet family apartment, and the limited availability of housing in those now aging apartment units in Russia today, creates very particular constraints on kinship and reproduction.

Figure 19: Film Still from The Irony of Fate. An opening shot from the film, showing newly constructed Moscow apartment blocks



The proliferation of housing projects represented in the opening credits of *The Irony of Fate* - large concrete and brick apartment blocks - correspond to the historical launch of a USSR project in the 1950s. The projects built in the first wave of this effort are colloquially known as *khrushchevki*, named for Khrushchev himself, who led the initiative. The project was launched in an effort to meet a dire need for functional housing following World War II. The Soviet concept of city planning postulated an ideal ratio of people to square footage of apartment space in the urban environment. Such a ratio was designed by the planners in the early Soviet era as part of the Soviet constructivist principle that a perfect social environment could engineer a perfect social order (Collier 2011:93; Zavisca 2012; Fehervary 2013). Soviet cities were designed to maximize productivity by providing the Soviet workers with

everything that they needed to move effortlessly between home, work, leisure, and civic life (Collier 2011). Khrushchev's directive was to quickly build large quantities of new urban apartments - not only were many cities in Western Russia raised by war, but revised cultural standards meant that postwar Soviet citizens imagined a good life that included an apartment for each family (in contrast to early Soviet experiments with communal housing) (Zavisca 2012; Fehervary 2012).

Soviet central planners created series after series of building designs, variations on a theme. Each series adapted the minimum square footage requirements to the needs of particular geographical or meteorological features of different regions, or the needs of residents of a particular part of a city. Building plans included both blue prints and building construction guidelines. After all, in a centralized economy, a building plan also required the distribution of building materials. A contemporary Russian wiki page historicizes this record with a public archive - a list of residential structure plans and the years in which they were issued. Without capitalist distribution, it is safe to say that a broad majority of living quarters built between the 1950s and 1980s in the Soviet Union were apartment complexes following the design of one of these plans (exception: the Russian summer house and vegetable plot, or *dacha*, see Ries 2009; Caldwell 2010).

But still, these buildings aren't precisely identical. The same human element that has underwear hanging in one balcony window, herbs drying in the next, and vodka bottles lining a third produced a "sameness" of form that is never precisely "identical". Even as the viewer accepts the premise of *The Irony of Fate* in order to enjoy the plot device, the fateful twist remains just that - a plot device : it's absurdist and unthinkable that a person could actually be lost in the wrong city and think he was in his own neighborhood. The human geographies

of each neighborhood lend local texture and specificities that a socialized Soviet or postsoviet can immediately recognize.

Soviet housing projects³⁸ may be identical in design, but at most similar in execution. Idiosyncratic touches and additions - the architectural vernacular of the region - differentiate neighborhoods from one another. Here, the paneling on balconies is a tiled pink; there, a textured orange. Here, balcony windows are covered with a geometric iron grating; there, a peculiar modernist concrete rain shield connects neighboring buildings to create cozy courtyards. In Petrozavodsk, for example, even when the design of apartment buildings are identical in terms of floor plan, numerous elements of human execution mark one given region from another. In one neighborhood, front stoops are made of worn, poured concrete that hasn't been replaced recently, while in another, the stoops are newly poured and painted bright green and wooden railings have been installed. Or, the buildings - although "identical" in form, are laid out over the terrain in a particular pattern that is specific to the neighborhood. Likewise, the history of the neighborhood, and who has lived there marks some regions against others - here, near the center of the city, the residents are mostly bureaucrats and teachers, the streets nearby are lined with shops and wide sidewalks, and the stairwells are filled with bicycles and strollers. In another neighborhood, far from the center, the streets are without sidewalks, lined by narrow muddy shoulders, private dwellings behind high walls, and a series of apartments set across a hillside inhabited by factory workers have entrance roofs in disrepair, and only a single corner store by the bus stop.

³⁸ Yes, we are talking about an entire subcontinent of humanity that literally lived and continues to live in "the projects". I asked a Slovakian friend in Petrozavodsk (teaching English on an EU program) what he thought of the apartment he lived in in Petrozavodsk. Cassandra, he replied, all of Europe - at least all of Eastern Europe - lives in these buildings.

Figure 20: Photos of housing in the Drevlyanka region of Petrozavodsk.
*Buildings in this region are from the series built in the 1980s;
Notice the graphic element of design in the balcony paneling that is specific to this region of
the city. My photo.*



Today, the Soviet-built apartment building remains central to every aspect of Russian life. One illustration of the vast uniformity of contemporary housing options is the ubiquity of the conceptual category of "khrushchevka" (the original series of postwar buildings). The word is so pervasive, as is the architectural form, that today a Google search for "khrushchevka" will immediately suggest "khrushchevka planirovka" (blueprints) and "khrushchevka remont" (renovation), as so many throughout the former Soviet Union are constantly negotiating ways to fit the complexity of their lives into the crowded, aging concrete boxes. Web searches turn up precise names for particular architectural solutions - the angled two room, the classic two room, the open plan - are posted online with detailed floor plans, with notations for the square kilometers the division allots to each room.

Aside from *khrushchevki*, other series of Soviet apartment buildings named similarly, for the era in which they were built, or some characteristic of the structural design, from the shape of structure to the number of floors, to the type of material used on the exterior of the structure (e.g. *panelki*), making these forms similarly recognizable in their proliferation. Some of these characteristics are useful in describing the nature of one's space and the size of one's apartment very quickly to others who haven't been there, or in giving directions to one's residence (e.g. it's five-story building; or, when you get off the bus, go past the orange *panelki*, and across the yard you will see a nine-story brick apartment house).

The logics of renovation epitomized by the strategies for revising the layout of *khrushchevki*, of attempting to update the Soviet apartment for contemporary life, are embedded in a discourse that posits Russia as always already behind and chasing after a Western European or American modernity (Fehervary 2013). Khrushchev in the 1950s famously planned a consumer goods summit, in which Americans showcased the housewares - from cook stoves to electric irons that signaled the bright future of American consumer home space. The material stuff of consumer lifestyles remain an important valence by which postsocialist citizens index a normal, desirable, or comfortable life (Fehervary 2013). In an oddly disjointed extrapolation of this rhetoric, any renovation to the Soviet-era apartment space done in the postsoviet era is colloquially referred to as a *yevroremont*, or *Euro-renovation*. A single word, the concept of Euro-renovation is used across the board for any apartment renovation - even if the materials used are derived from commodity chains that source from China or Vietnam, and the interior decorator, the designer and architect are Russian. As one friend put it, when you walk into your friend's apartment, even if it had been previously renovated, but they've wallpapered a room and put in new lighting, socially, there

is nothing absurd about saying, "Oh, you've done a *yevroremont!*" Which is to say, *redecorated*, or, modernized. A desired European modern imaginary is thus posited in this colloquialism as always indicated in any expression of domestic change. The materiality of European of domesticity is here opposed to the limited nature of Soviet supply chains: everyone had the same furniture. Indeed, in the film discussed above, the characters have both ordered the same furniture from Poland for their identical apartments in different cities. Today in Petrozavodsk, friends recall going over to friends' apartments after school, and finding the same furniture they had at home: everyone had the same shelf, the same two sofa beds.

In Petrozavodsk, a two-room apartment is considered a comfortably-sized space for a family with one or two children. It is considered uncomfortable when circumstances bring the owner of the apartment or the primary resident to have to rent out one of the rooms to another family, so that each family lives in one room, and shares the kitchen and the bathroom. Families often hope to build their own houses, or move to a bigger apartment, but frequently cannot afford to do so. Depending on a family's background, a young couple with a small child may live with a parent or pair of parents in order to save money.

While few postsoviet Russians would call these Soviet apartments convenient or comfortable³⁹, they occupy a particular realm of normalcy, the nostalgia of the familiar, a

³⁹ In more remote areas of the Russian frontier, however, *Khrushchevki* are considered desirable. The centralized heating and running water, paid for primarily by the state, make the apartments significantly more comfortable in the winter than the prewar stand alone house, frequently without running water, indoor toilets, or a heating system besides a woodstove. Many Russians, especially outside of urban centers, but also within them, live this way to this day. In Petrozavodsk, I had only one friend who lived in a prewar building, one of many three-story wooden constructions that stand nestled together in various neighborhoods of the city. These apartments are notoriously drafty, the plumbing is frequently the original slapdash plumbing installed in the 1930s (or, even, in some places, toilets are outdoors), the pipes and electrical connections are more sensitive to weather, given that they run along the outside of the buildings, and the living space is very tight. My friend, having grown up in a

shared fact of daily life. Jane Zavisca has documented the ways in which contemporary Russians struggle to *zhit' normal'no* - to create a comfortable life - in a situation of scarcity in which adequate housing is nearly impossible to come by. What distinguishes the Russian case from the American conjecture is the way in which a much broader swath of the population lives in these aging apartment blocks, rather than in *otdel'niye*, separate, houses. Russians also tend to live in apartment buildings with neighbors who represent a greater variation of class and social circumstance than is customary in American neighborhoods (beyond, perhaps, a few unusual sections of the biggest US cities) (Utekhin et al 2008).

Strategies for Obtaining Living Quarters

As anywhere, in Petrozavodsk, some apartments are more desirable and present fewer barriers than others. However, compared with the West, the work of obtaining a different place to live unfolds according to wholly different systems of exchange and logics of entitlements. Where do apartments come from? How does one come to inhabit them?

Alina and Valya: Waiting and Sharing -- Government Distribution

Some Russians hold out hope that their disability status entitles them to a socially-distributed apartment. Alina and Valya first explained the waiting list for a government apartment to me. Alina (in her early thirties, a wheelchair user with Cerebral Palsy or DTsP in Russian) lives with her mother Valya in an apartment 20-30 minutes by car from the city center (or, 35 minutes by bus, or, 1.5-2 hours walking, which is how Alina and Valya usually travel in the summer, because it is free and Alina's wheelchair is so difficult to get on the old buses that serve their neighborhood). Their building is in a factory region. There are only the

village and moved to the city for university and subsequent employment, found the accommodations in a two-room apartment which she shared with a "grandmother" to be no worse than other options, and the lower rent than a shared apartment in a similar region of the city desirable.

minimum local amenities - a small convenience and grocery shop, an elementary school, and a bus stop, and a 15 minute walk to a nearby factory. Although their apartment is only on the second floor, given that Alina's severe form of DTsP means that she can't walk or stand independently, they need to call on a friend or neighbor to help carry Alina, and then her wheelchair, downstairs in order to go out. Often, when Alina would attend a social group for young adults with disabilities, she would rely on the driver of the minibus that picked up the group's participants to carry her up the two and a half flights of stairs.

Alina and Valya's experience of apartment destiny was perhaps the most starkly distressing - or at least, they were the most forthcoming of my interlocutors with their complaints. Unlike other families that I knew, they had no breadwinner. Alina received a month disability pension, and her mother received a monthly retirement pension. Alina's brother, in his early twenties, was by most accounts good for very little, and only showed up occasionally to eat and sleep. They had moved into the current apartment when Alina was a small child from a previous worse one, which although it was in the center of the city was too small for a family of four (her father was alive then) and was in one of the poorly heated old wooden houses. The apartment that they were moved into, based on a waiting list of those who have social reasons to await an apartment, is actually a communal apartment, and their family has three rooms, while they share a bathroom and kitchen and entrance way with whomever is living in another room. I hadn't realized the apartment was so divided - I assumed that the family had chosen to rent out a room in order to get some extra income. "oh, no no no!" Valya told me, with the particular gleam in her eye reserved for moments of reveal injustice. "It might be technically illegal, officially communal apartments no longer exist, but WE live in one!" For the past seventeen years, the family has been on a waiting list

to receive a new apartment. When Valya scurried off to find the latest letter that they had received stating their place in the queue, Alina waived her hand in an expression of disgust. "It's barely moved in seventeen years!"

Marina: Making the Best of Things -- Inherited Apartments

Even as families worked to obtain their own apartments, throughout the twentieth century, and now in the 21st, scarcity remained the primary manner through which Russians experiences living space. Russians since mid-century on to today describe having "*svoia*" or one's own/one's family's apartment emerged as a primary element of what as a critical element of basic living standards (*zhit' normal'no*) (Zavisca 2012). Yet, throughout the twentieth century and the following decades, the availability and cost of actual housing has remained illiquid, and most young Russian families today do not have enough living space to *zhit' normal'no* or the financial resources or available housing to make such a thing possible. Further, the scarcity of housing makes families hesitant to give up apartments that they do not need. This in turn contributes to illiquidity: not only are there not enough empty or unused apartments on the market, very few unused apartments enter the market, as they are instead rented, or farmed out to family members who "officially" live elsewhere (Zavisca 2012).

Marina and her ten-year-old son live with her boyfriend in her inherited family apartment. For some time they lived in a different apartment, but in the same region of the city. They moved during the time that I was doing research, so that I visited them in one apartment tin October, and in a different apartment after that, further out from the center of the city, and run down.

Marina's son, who has *DTsP* (Cerebral Palsy), attends the specialized school for children with disabilities. He attends a vigorous course of physical therapy supplemented by Marina's own implementation of various elements of physical therapy gleaned from internet research or talking to other parents. She managed, even living on a meager pension, to acquire a "home-gym" for her son, a sort of indoor gymnastics apparatus. Frequently when I would visit the family in the evening, she would be enforcing a daily regime of "standing" for her son. Although he is ten, he looked quite a bit younger, small for his age. Propped up between the kitchen table and the wall, he was made to stand for 40 minutes at a time, although he much preferred to sit. The family held on to hope that with continued physical therapy, his tense muscles could be trained into the capacity to walk. This goal was not achieved during my research, though the therapy regimes continued with vigor. Instead, family members carried him up and down the four flights of steps, under an arm, like a much younger child of four or five, just on the cusp of being too big to be carried. His tricycle and wheel chairs were stored on the staircase landing just outside of the apartment, for safe-keeping, therefore requiring a second trip, or two adults, in order to take him outside or to school.

As a way of explaining how she could stand to live in such a far out, run-down apartment, Marina told me a story as she prepared tea in the kitchen on my first visit after the family had moved. She recalled living throughout her childhood in a barracks - emergency housing constructed by the Soviet government in the immediate postwar period. With families clustered around bedding areas in undivided warehouses, outdoor toilets, and shared kerosene stoves, the barracks were very much stop-gap measures. Our family, she told me,

really couldn't wait, and we were ecstatic to get a three-room apartment with a kitchen and indoor plumbing.

The apartment that her family eventually received was in a top-floor walk-up of a four story building in the Klyuchareva region of the city. Far from the center, the area was developed around two factories - a bread factory and a shipbuilding factory. Although the factories no longer work at the same capacity now that they have been privatized, and although the region is far from the center, the apparatus of residential life - most importantly, including public transportation - still services the region, making it a livable option. Today, numerous new housing projects are being built in the area, and the amenities and available apartments attract young families.

Thus, the very same apartment that felt so modern when it was given to the family in the 1950s was already a disabling structure. This was so in more ways than one. The gas stove lines and indoor plumbing that were once cutting edge amenities 60 years later are markers of outdated modernity, causing Marina to remark on them to me as a visitor. "This stove was the best thing we had ever seen when we moved into this apartment," she recalled fondly, as she lit the pilot light while we talked in her kitchen one evening. At the same time, the financial possibility that the apartment afforded a family surviving on a low income was an enabling factor that made living there preferable to other options.

These anecdotes illustrate the way in which the local personal histories of housing and inheritance shape the life chances of young people with disabilities in Petrozavodsk today. The irony of fate indeed, that Marina was able to inherit the family apartment, but, that with a son with a mobility impairment, that apartment was on the top floor of an elevatorless building. The kind of housing liquidity and flexibility that many middleclass westerners take

for granted simply isn't present in Petrozavodsk; for many, moving isn't an option.

Opportunities to choose where one might live are few and far between.

Vera: Renting, Trading Up, and Making Renovations

Vera, who lived at the time in a three-room apartment with her parents, her husband, and her two young children, told her own story of her family's journey to their current living situation.

V: So where we live... When I first became disabled (*poluchila invalidnostu*), we were living in a dormitory. And after that, my parents waited in line for a long time until... I think they even wrote a request. So. They got a two-room apartment. But, a two room apartment in a regular building, a five-story building, on the second floor, that's what we had. As long as I was little, and my parents could still carry me up the stairs well enough, because there wasn't an elevator... so. But, when I got a little bigger and became a teenager, like up to seventeen years old, I got heavier, and at the same time my parents were getting older. So, we moved to a different apartment on the first floor, but there wasn't a ramp there either, so it was a long time, um, that we were petitioning our administration with the ministry of health and human services, so that they would build a ramp for us. So, they finally did it all, it took probably seven years to get it together. But - it worked out, I mean, I have my own ramp at home, and inside we remodeled so that, because the passageways were really narrow everywhere, there were really narrow doors.

So, then, we thought everything was really set up. I can get through the doors without a problem, I can get outside on my own. I mean, the problem that most people in wheelchairs have is that they can't get out of their house, and, thankfully, I don't have that problem.

C: Yes, a lot of people can't get out of their homes.

V: Yes, REALLY a lot of people.⁴⁰

⁴⁰ Вот, дома по-своему, значит --- аа-- когда у меня - когда я получила инвалидность, мы жили в общежитии. А-а-а, после этого, родители стояли на очереди, долго, до того, еще... думаю, вораждение даже писали. Вот. И, они получились двух-комнатную квартиру. Но, двух-комнатная квартира обычно в домах, в пяти-этажки, на втором этаже, у нас была. Когда пока я была маленькая, еще родители мои меня поднимали нормально по лестницу, потому что, лифта не было... вот. А-а, когда я подросталась там, до семнадцати лети, повесить меня стало тяжелее, и родители как бы старее. Вот, мы переехали в другую квартиру на первом этаже, но там тоже не было не пандуса ничего, вот, мы очень долго, м-мм, вделились нашей администрации, с министерством здравоохранением, чтобы сделали нам пандус. Вои и это все сделали, заняла наверно, лет семь, чтобы соврать. Но - по достатки, имеем, что у меня дома пандус отдельный, и дома сделанно перепланировка, чтобы, потому что, проходы очень узкие везде, двери узкие были.

#00:08:56-1# К: Ну, да.

#00:08:56-1# Ж: Вот, а теперь, как бы, подумали абсолютно нормально. Спокойно у двери двигаться, могу сама на улицу вспуткаться. То есть, проблема, которая у большинства людей на колясках - м-м-м - что они не могут выйти из дома, у меня, в счастье, нет.

#00:09:12-9# К: Да, многие не могут выйти из дома.

Vera was glad that the apartment her parents had, through years of work and organizing, obtained for their family offered her the possibility to come and go via a ramp. At the same time, she was saving money and hoping that if her husband sold an apartment that he owned in Saint Petersburg, they might be able to afford a mortgage to purchase another apartment, leaving her parents to their own apartment.

Without the capacity to move to a different home when one becomes a barrier, Russian citizens are more disabled by their environment than their counterparts in Western Europe or the US, where liquid housing markets make finding a new place to live a real possibility for middle and upper classes.

Inaccessible Ins and Outs

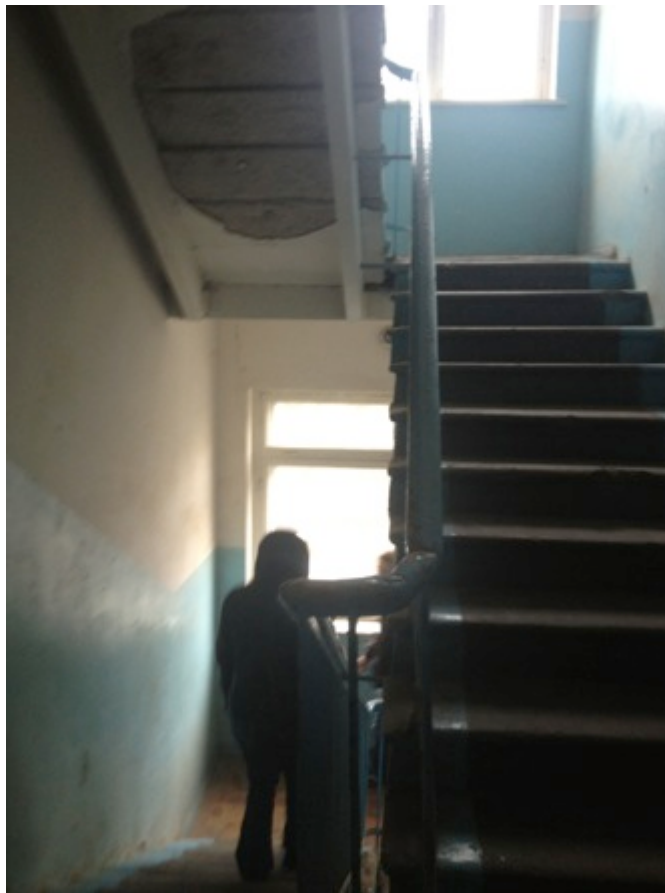
As Vera points out, and as the other cases related above also demonstrate, a central concern for *invalidi* is how they will get in and out of their family apartments. The architectural design of the entryway or shared staircase that leads to the individual apartment doors in all of the various Soviet-designed apartment complexes are patently inaccessible.

Ethnographers have documented the peculiar nature of the stairways in postsoviet buildings: they occupy a certain kind of spatial category that is neither public nor private in the American sense (Utekhin et al 2008). When the buildings were privatized in the 1990s, the staircases remained *obshchestvenniye*, while the apartments became private property. As a result, apartments were renovated internally, even doors to apartments look different within the same staircase, as apartment owners purchased their own security doors in several

#00:09:12-9# Ж: Да, ОЧЕНЬ много.

different styles. The space of the stairway becomes a particular kind of place, colored by smokers whose wives banish them to the stairwell to smoke and ash into coffee cans or empty jars, a neighbor with a green thumb who keeps well-tended houseplants on one windowsill, children's tricycles or sleds in one stairwell, another which is clean but empty, still another which reeks of urine and spilt vodka.

Figure 21: A typical apartment building staircase in Petrozavodsk. My photo.



This shared nature of parts of the building create hassles when it comes time to make renovations; this can be particularly frustrating for people with disabilities who want to renovate entranceways for accessibility purposes. Alina and Valya described one such occurrence:

Valya: Did you see how they redid the roof above our entranceway?

Cassandra: I didn't notice.

V: They put the announcements up, but didn't take them down...

Alina: The neighbors around here aren't all happy with the renovation...

V: Well, I say to them, "Say thank you that they did anything at all!" So that the awning wouldn't be crumbling down on anyone who was going in and out... how many kids does it have to kill before they fix it...

C: It's good they redid them.

V: People are so dissatisfied around here. [impersonating a dissatisfied neighbor] "They didn't do it right!" Well, I say: "Then you do it better!" The neighbor's son as asking me [mocking voice] : "Are you satisfied with how they did the new entranceway roofing?" And I told him that I'm satisfied with everything. And he goes to me, "Well what for, you're not signing any documents." And I say that I'll sign whatever, and if he doesn't like it, he can go and fix it himself.

They're saying that they spent the money for nothing, but I say, they're not just doing the awnings, soon they'll do the driveway as well. And of course this comes out of the general housing fund. Soon they're going to fix the second driveway.⁴¹

Generally some arrangement exists in which a resident acts as the custodian of all the stairwells for a block, collecting money from residents to keep the stairwells swept and washed, to repair the outdoor stoops, keep light bulbs changed, to clear ice and snow from the doorway. But, as with anything, there are variable levels of functionality here, often erring toward the mismanaged.

Some apartment blocks in Petrozavodsk have elevators. However, the function of these elevators - at least to Western visitors - seems somewhat obtuse. Elevators in these

⁴¹ С2. Видела, у нас козырьки над подъездом поменяли?

К. Не обратила внимания.

С2. Своё объявление так и не снимают.

С. Соседи у нас не все довольны, что обновили...

С2 Я им говорю: «Скажите спасибо, что нам что-то сделали». А так на голову козырёк бы свалился тому, кто на улицу вышел... Сколько уже под ними детей детей погибло...

К. Хорошо, что переделали.

С2. Так не доволен у нас народ... "Не так сделали"... Я говорю: «Тогда сделайте лучше».

Сын соседки спрашивает меня:(парадирует голосом с издёвкой) «Вы довольны, что нам козырьки сделали?» Я отвечаю, что всем довольна... А он мне: «Ну и зря, не подписывайте документов» Я говорю, что всё подпишу, а если вам не нравится – возьмитесь и переделайте.

Говорят, что деньги зря потратили. А я отвечаю: «Не только же козырьки же делать... Вот сейчас подъезд будут делать – это ведь с общедомовых денег оплата идёт. Скоро второй подъезд будут ремонтировать».

buildings are notoriously tiny. Barely wide enough across for one person to enter the door on foot, there's no chance for a wheelchair (or even a large suitcase) to squeeze in. More than two or three passengers inside the tiny car quickly becomes uncomfortable, as the car is so narrow that for riders to stand two abreast they must be arm-in-arm.

Figure 22: A typical entrance doorway in the Drevlyanka region of Petrozavodsk. Notice the uneven ground and disrepair of the stoop, and the idiosyncratic paint on the metal doorway.



Moreover, from an accessibility standpoint, there are additional barriers to using the elevator, either for someone carrying an awkward or heavy object, or for someone using a wheelchair, or with poor mobility. Entering the buildings, for instance, the 1980s era apartments in the Drevlyanka region of Petrozavodsk, one must first mount a small step onto a front stoop. Having entered a code on a metal storm door, one must pull open the door (stepping off the stoop to do so), and then step over a half-inch lower lip of this exterior door. An identical interior metal door set back three feet into the entranceway is usually propped

open, but again has the same lower door jamb (which many an American who has visited Russia will recall tripping on). Straight ahead, one will find a short flight of eight steps, fairly wide and with a railing. If one manages to mount these steps, and arrive on the first floor of the building, passing the flight of stairs curving upward, the tiny elevator is directly to the left. This arrangement of barriers ensures that even highly active and athletic wheelchair users would have difficulty getting in and out of even the first floor apartments.

Safe Spaces: Four walls as comfort

For Sergei, his family's apartment was both a refuge from the complexity of the world in which he is made "disabled" and a barrier to participation. In an interview, Sergei told me that he prefers to stay at home, unless he is going somewhere in particular. Of course, he pointed out, he could go to the store in the neighborhood, but why should he do that, when his mother can stop into the store on the way home from work, and it's much easier and faster for her. Sergei walks slowly, with a limp and bent-in ankles. His mind is sharp, but still he spends most of his days in his bedroom, watching movies and playing guitar. He likes to talk about movies and sing, but getting to a space that he can share with peers is difficult. He described the sense of ease that he feels when he is home alone and his parents are out:

S: [...] when I am home alone, I feel really at ease. When [my parents] go off to the dacha, or somewhere, that's kind of nice for me. I feel good home alone - totally normal. Everyone is surprised, "What aren't you bored? Why --" [can't think of the wording] well, in general people expect that I would be somehow uneasy (*diskomfort*). But it's not boring for me, [smiling] I love when I'm alone. [quietly] Really often.

C: What do you do?

S: Um, I --- ?? In life, you mean?

C: No, I mean, when you're alone at home for awhile. Do you read? Play guitar?

S: Play guitar. I play guitar, yes, I play guitar a lot. As soon as I'm alone, I play guitar, and sing with my whole voice. ... So, I mean, it's like -- in general when my parents are at home I also sing with my whole voice occasionally, but not always. It depends on my mood. Sort of. So. So yes, I play. Just for myself. Really well. Well, I have to practice. Learn some new songs, some old ones that I've already let go, repeat them. I like that. So, what else. It's really nice when -- well ... it just happens that - we

have to take a break from each other. Right? To have some personal time. because when you're together all the time, when you do everything, it builds up (thinking, then quietly)... yes. (anew) You have to consider that with someone you're close to that for example -- for example if I watch television, then, you come along, maybe you'll bother me. In general, everything pretty much works out like that. I usually get up at a proper time, but ... when I'm home alone... how nice it is to... I do whatever is that I need to, what I want to do. I don't have to keep a schedule, or stay on track at all, when they leave. Nothing in particular. ... I can... have breakfast now, I can have breakfast later. At whatever time I feel like it, always. So. So you can just sit, and do what ever you want, your favorite thing, and forget all about everything else. Even to have breakfast. So -- (quietly) like that.

[Or,] I mostly watch videos on the internet. Movies, and my internet is set up without limit, and I've had unlimited internet access for a long time already. [...] I look for films online depending on my mood. You can pretty much find whatever you want.

Sergei's family apartment is in the Kukkova district of the city. He lives on the 2nd floor of a walk-up building that is part of a large complex of nearly identical apartment buildings (another friend, who is a neighbor once explained to me how to get to her house: go to Sergei's apartment, and then go two buildings over and one building up, and my apartment will be at the same entrance as his family's but in that building). Sergei could make it down the stairs on his own holding on to the railing, but he prefers having a hand or arm to lean on. If he is going somewhere, he likes to take a taxi that picks him up outside the doorway of his entranceway, or have his mother drive him, or very rarely he will travel on public transportation with the help of his parents or someone else.

Vakas shared a similar perspective. After suffering from a traumatic brain injury before he finished the third grade, he never regained his previous sense of self, and continues to speak with severely slowed speech. His balance is off, and as a result of his long convalescence following his accident and the subsequent confinement from his peers, his social skills aren't up to par. His parents are much more protective than Sergei's, and although he is 32 years old, Vakas isn't allowed out of the apartment without a family member or a social worker.

In the context of his apartment, however, he was simply himself. As an adult living with his family, his room was his refuge - in his bedroom, he was able to do what he liked

(usually spend his day making friends in online communities). His family had renovated their apartment in a manner that left it with three bedrooms, a hallway, and the kitchen as the only common room. This left enough room for his mother and father to share a room, for his brother to have a room, and for him to have a room.

Vakas explained to me that he much prefers to spend his time in his room. He often waits to leave his bedroom in the morning until the very last possible moment; after drinking tea in the kitchen with his mother and brother before they leave for the day, he then retreats to his room. He does his best to avoid his father, who also spends most of the day at home. In his room, Vakas told me, he can do whatever he wants, and so he feels a sense of ease.

Conclusion

Thus, conditions of illiquidity, avoidance of market tactics to obtain housing (usually because markets are prohibitively expensive), an overall scarcity of housing, aging and inaccessible Soviet architecture, and a history of communal systems that makes accessibility renovations to common areas difficult all combine to make the typical apartment in Petrozavodsk a disabling structure. In this way, inaccess emerges through a particular historical configuration of material objects, and socially-coordinated infrastructure design and planning. The Russian patterns of dwellings and the manner in which housing is distributed creates a particular infrastructure of ableism. The following chapter extends this question of postsoviet infrastructures of ableism to examine accessibility in public space.

CHAPTER VI
"IT'S JUST FOR THE CHECK MARK":
MINIMUM REQUIREMENTS, GLOBAL FRICTION, AND INACCESSIBLE
ACCESSIBILITY RAMPS

One afternoon in the fall of 2012, I was sitting in my fourth floor walk-up apartment in Petrozavodsk⁴², editing fieldnotes on my laptop. A Facebook alert pinged. A colleague from the US, halfway across Russia conducting his own fieldwork, had sent me a link. I clicked.

The link led to an Imgur⁴³ thread - an image gallery of 17 photos, all showing inaccessible accessibility ramps. Here was one ramp in which the railing to the adjoining steps actually cut off access between the stoop and the ramp. Here was another - in my experience ubiquitous in Saint Petersburg and Moscow metro entrances - which consisted of nothing more than a pair of inch-and-a-half wide metal rails, screwed into the granite steps, and descending at the same steep angle. The spaces pictured in the image gallery are marked as Russian by Cyrillic signs in the background and by architectural vernacular.

Another version of the same meme had circulated first on the Russian-speaking internet. In this case, the images were presented on a blog as an amassed body of evidence

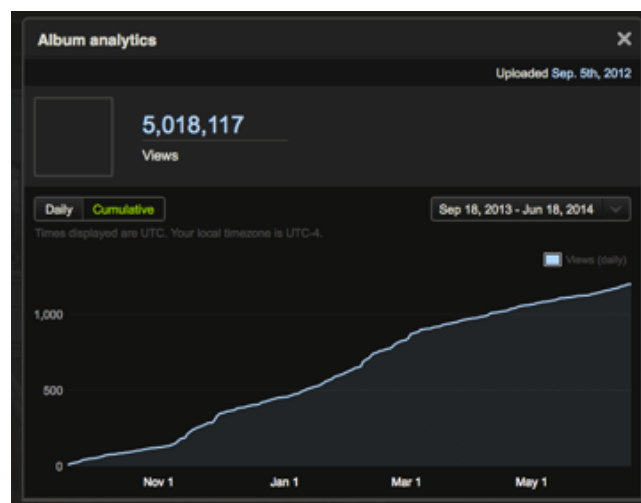
⁴² Petrozavodsk is a city in the Northwest of Russia. It is the administrative capital of the Karelian Republic, which borders Finland. The populations native to the region share ethnic, linguistic and prehistoric archaeological evidence of cultural ties with Eastern Finland; however, since the migration that occurred during the Soviet 20th century, the region is majority ethnic Russian, and primarily Russian-speaking (only a very few people in rural regions continue to use the native Karelian language outside of folksongs and festivals).

⁴³ Imgur is an online image aggregating site that allows readers to give a news item an *up* or *down* vote to signify whether a given content item should be promoted or get buried. By processing the massive algorithm, the site provides constant new content to its readers. Imgur was designed to generate viral image memes and draws an international user base (Garber 2014).

that the Russian authorities fail to provide an accessible environment for citizens with disabilities. A popular subject with Russian journalists interested in uncovering government incompetence, a Russian-language Google image search for further images of inaccessible ramps (*nedostupnyi pandus*) produces numerous examples. On the Anglophone internet, the meme circulated as an example of irony (inaccessible accessibility!) and Russian incompetence.

The Imgur thread, as a meme, quickly replicated on the English-language internet. Web analytics show that the image has been successively shared at a steady rate since it was posted in September 2012, with a slight surge around the time when I first viewed it [see image below], again shortly after, and again around the time of the Sochi Olympic Games, when a similar meme (#SochiProblems) highlighting shoddy construction in the Olympic Village also circulated.

Figure 23: Meme Analytics. This image shows a graph documenting the continuous spread of the Imgur photo gallery showcasing the 17 photos of inaccessible Russian accessibility ramps. It lists the overall number of gallery views between September 18, 2013 and June 18 2014 at 5,018,117. Source: Imgur (retrieved June 18, 2014).



The digital photo collection offered a popular illustration of a phenomenon that my research participants - people with disabilities and their family members - had been telling me about since at least 2010: the inaccessible accessibility ramp.

In the summer of 2010, a Russian woman whom I call Nina Anatolievna, a school teacher whose daughter, 22 at the time of the interview, has Cerebral Palsy and uses a wheelchair, told me about such a ramp in an interview. Describing for me the kinds of frustration that she and her daughter had faced over the years, Nina Anatolievna offered several anecdotes - from only being able to enter a theater through a service entrance in the back, to her daughter's experience as a student at a local university that had a ramp to the first floor classrooms, but no accessible bathrooms. She then turned to the example of a corner store near her apartment, in order to explain that often, ramps do not actually function to provide access.

In a lot of cases it's just for the check mark. Is there a ramp?! [mimes checking something off on a list] It's like, this nearby store, where they also *built a ramp* [sarcastic emphasis].

So Sveta says, "Oh!! They built a RAMP!"

And I say, "Sveta, you know, you can go up the ramp but that's it - you'll stay right there!"

Because she can't go into the store itself. Because there's -- it's only about [shows the width of the door with her hands] that's it! You get it?! She can't even go through the aisles at all. Oh, there's a ramp - a ramp. So something here is *equipped* [sarcastic emphasis] [*oborudovano*]. So for now that's what we've got...

In this utterance, Nina Anatolievna stressed a sarcastic emphasis on the word *equipped*, expressing the contradiction between the purported intent of access, and the real result of a retrofitted environment that, while "equipped" with a ramp, was not actually accessible. Like the online meme, her comment served to draw attention to the ways in which elements of the built environment in Russia, recognizably designated as objects intended to provide

access, or, *disability things*⁴⁴, failed to actually facilitate access to public space for people with mobility impairments. Nina Anatolievna's commentary fits into broader Russian narratives about the material results of economic and moral corruption in Russian public life, specifically, that the government and wealthy business owners - those performing "official" functions (whom she refers to *en masse*, as is common in Russian, using the third person pronoun) - cannot be relied upon to carry out their tasks in such a way as to actually benefit the intended recipients (e.g. Rivkin-Fish 2005: 6-9).

After revisiting this interview, I had come to think of these inaccessible accessibility ramps as "check-mark ramps," following Nina Anatolievna's assertion that "it's just for the check mark." Her comment suggests that inaccessible ramps come into being when someone tasked with building a ramp in order to fulfill a requirement on a checklist, without attending to the actual intended functionality of the ramp. An accessibility ramp that is inaccessible for a wheelchair-user has no use for that user, but apparently offers some kind of benefit for the person who built it.

This evokes what Martha Lampland and Susan Leigh Star have described as the "slippage between a standard and its realization in action" (2009:15). Presumably, whoever ordered the ramp built might check off the word "ramp" on some checklist of items required for renovations; or, he might want a ramp in front of his store in order to convey some quality that a ramp evoked. That is, an accessibility ramp might have multiple uses beyond

⁴⁴ The phrase "disability things" is one coined by Katherine Ott, a curator at the National Museum of American History of the Smithsonian Institute (See the project *Everybody: An Artifact History of Disability in America* for an example of how her work uses material culture and technology to discuss the complexity of disability). The phrase has been a point of departure for a series of panels at the Society for Disability Studies conference for two years running (2013 and 2014), at which disability studies and design scholars have unpacked the cultural associations in a given object that is often characterized as a *disability thing* but does not necessarily have to be (prosthetic limbs), or is not usually considered a *disability thing*, but may in fact be (the iPhone). Thanks to Aimi Hamraie for their help with tracking the origin of this concept.

its titular intention. This idea echoed a theme that is familiar both in stories about Russia and in ethnography: a gap between intended and actual use or meaning, the emic and the etic. In the Russian case, the concept of "Potemkin villages" offers a shorthand for something that appears to exist, but turns out only to be a facade (e.g. Bernstein 2014:42-66).

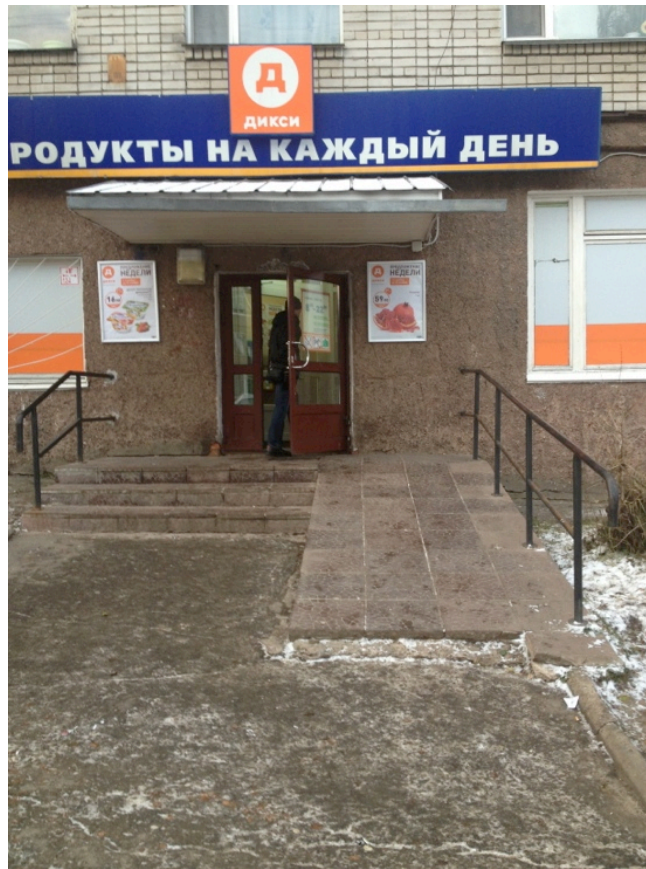
Yet, inaccessible accessibility ramps are familiar to wheelchair users everywhere, and not just in Russia: because ramps are often constructed by people who are not wheelchair-users or mobility-impaired themselves, often to comply with legal requirements, those who use ramps in the US and Britain often find that ramps have dead ends, gaps, or sharp turns that make ascending or descending difficult (Imrie 1995; Linton 1998).

In this light, the comedic effect of the Russian inaccessible accessibility ramp meme seemed to get stranger the more I considered it. When I started walking around the city looking for examples of inaccessible accessibility ramps, I found very few, or, the ways in which they were inaccessible were not so immediately obvious, so as to pack the visual punch as those in the online photo collection managed to do (see image: grocery store ramp & caption). And certainly the inaccessible accessibility ramps in other countries were not funny in the same way that the Russian check-mark ramps were. Moreover, in Petrozavodsk, there were many examples of storefronts and important elements of public infrastructure with no ramp at all, but those certainly weren't funny.

Figure 24: Neighborhood Ramp in Petrozavodsk. A ramp in front of a neighborhood grocery store in Petrozavodsk looks well constructed at first glance. But, a second look shows that the final lip of the ramp is in disrepair. The door at the top of the ramp opens at an angle awkward for a wheelchair user to navigate. Upon entering the store one finds the tight turns in the vestibule too narrow for a wheelchair or stroller, and inch-high thresholds.

At first glance, this storefront, unlike many others in the city, is accessible. But Sveta, a wheelchair-user who lives in a neighboring building, can only enter the store with great difficulty: she relies on the help of her husband to hold doors, push her through tight spots, and lift her wheelchair over high thresholds. As a result, she rarely goes grocery shopping.

Photo Credit: Cassandra Hartblay 2012.



Thinking through these elements, I wondered: What were the reasons that someone might build such a ramp? What checklist? Who was enforcing it? If these ramps weren't working for people with mobility impairments, for whom were they working?

Considering these questions in relation to ethnographic material and critical theory, I will argue that, indeed, the symbolic function of a ramp and the actual work that the

production of ramped entrances *does* in contemporary Russia is decoupled. Specifically, I identify the following ways that ramps or their images work "for" social processes other than facilitating access: (1) online images of inaccessible accessibility ramps serve a discursive purpose related more to widely circulating narratives (in Russia) about a Russian distrust for the execution of public or official resources, and (in the US) about Russian incompetence, than to debates about disability and access, (2) in contemporary Russia, the symbolic function of an access ramp as an architectural form may have more to do with performances of professionalism and Europeanness than with a desire for an inclusive public sphere, and (3) the design and construction of ramps plays out through the logic of checklists, a modernist technology which replaces the concern for function of a given form with a list of decontextualized norms. As the concept of "accessible design" circulates globally, the accessibility ramp becomes an object that exists in global friction, taking up different, but interlocking, local meanings.

By attending to friction around disability access in contemporary Russia, this chapter contributes to a rich literature in anthropology chronicling the ways in which discourses making claims for social and political inclusion of minority groups, such as feminism, LGBT activism, and so on, take on different meanings and spark different debates in the postsoviet context (Phillips 1999, 2008; Rivkin-Fish 2005; Hemment 2000, 2004; Kay 2000; Sperling 1999; Essig 1999). By unpacking the ways in which accessibility ramps move as objects or disability things, and accessible design moves as a conceptual category and technology of modernity, this chapter also contributes to important debates in disability studies, feminist design theory, information science, and the anthropology of infrastructure about the tension between universal categories and norms as a strategy for institutionalizing access, or, as a

modernist mode of discipline that obscures and marginalizes difference and ignores local context (Bowker & Star 1999; Garland-Thompson 2006; Hamraie 2014).

Access in the Russian Built Environment

The Russian built environment is strikingly inaccessible. For instance, a 2004 survey conducted amongst citizens of the cities of Saratov and surrounding regions found that public roadways and sidewalks are particularly inaccessible, and other public spaces are only slightly better (Romanov and Iarskaia-Smirnova 2006:109-110). While private spaces might be renovated or retrofitted, and businesses or government offices might have some gestures toward accessible design.

Similarly, Human Rights Watch and the Russian disability advocacy NGO Perspektiva have documented the egregious degree to which the so-called social marginalization of people with disabilities is related to material elements of the built environment. International NGOs play important and varied roles in translating international human rights discourses about disability into Russian, in disseminating these ideas to Russian advocates, and in advocating for elements of the international concepts of disability access (such as accessible buses, inclusive public education, and social service programming beyond monthly pensions) to be adopted by the Russian federal government.

Although attention to ramps in particular does not fully encompass the relationship of social attitudes and stigma toward people with the broad diversity of impairments that fall under the category of disability (e.g. Deafness, blindness, autism, Down Syndrome), examining what ramps symbolize can tell us much about how disability or minority access gets prioritized or deprioritized, negotiated, and imbued with meaning in the Russian context.

In Petrozavodsk, ramps began to appear in new shopping centers built in the 2000s; shiny mall-like facilities, these new spaces also had large, western-style elevators, escalators, indoor atriums and food courts - elements unusual in the centrally-planned, utilitarian logic of Soviet architecture. But most apartment buildings, shops, grocery stores, schools, offices, and public parks had no elements of accessible architecture - most visibly represented by the ramp. Private citizens and disability NGOs installed makeshift ramps in homes and office spaces. Hospitals lacked even accessible bathrooms, but sometimes had ramps at a main entrance, or elevators.

A Sociocultural Approach to Disability

Anthropologists have long observed that categories often taken to be universal - such as race and gender - when studied in ethnographic context, turn out to be contingent and contested. An anthropology of disability treats the concept of *disability* as such. As we have seen, categories of disability do not match up cross-culturally, and definitions of disability within cultures and nation states are often hotly contested (Kohrman 2005). Accepting this approach to disability requires dismantling a dominant paradigm, "the medical model" in the parlance of critical disability studies, which attributes disablement to inherent, pathological characteristics of individual bodies. In contrast, a critical sociocultural model understands disability and disability stigma to be (re)produced through social, cultural, legal, and transnational processes that privilege particular kinds of human bodies and minds (Linton 1998; Imrie 1996; Davis 2006; Ingstad and Whyte 1995 and 2007; Ginsberg and Rapp 2013). Furthermore, because *disability status* is a category bestowed on citizens by the welfare state, and *disability rights* and *social welfare for people with disabilities* are valences by which countries are assessed by their international peers, attention to the ways in which

ideas and definitions of disability, and accessibility measures for people with disabilities move and circulate transnationally can uncover much about contemporary global processes and governmentality (see, for example: Kohrman 2005, Petryna 2002, Phillips 2011; Katsui 2014; Wengle and Rasell 2008). This chapter addresses the latter issue, that is, how elements of access are or are not implemented in one Russian city. By paying attention to the socio-spatial reproduction of barriers and access in the built environment, this work begins to describe one way in which marginalization and exclusion of people with disabilities gets reproduced in contemporary Russia (Imrie 1996:11), while also suggesting a synthesis of disability theory with theories of global friction.

The Physics of Friction: The Ramp in global motion

To most American readers *the ramp*, as an architectural feature, has a very particular meaning: it is a "disability thing" (Orr n.d.). That is, a ramp as an architectural feature is already linked to the thing that we call "disability". A ramp abutting an entranceway in a building or near a short flight of stairs is an object which at a glance is immediately legible as serving a specific purpose: it facilitates access for people with disabilities. Unlike stairs, a ramp can be navigated by a person in a wheelchair; it can also be a preferable route for people with an unsteady gait, poor balance, or an injured or lesser-functioning leg (stairs require balancing on one leg to lift the other). Or, while steps assume that people are a certain height, a well-proportioned ramp can make mounting a vertical divide more hospitable for people with short legs. Along with people with a broad range of disabilities, children and elderly people often prefer ramps to stairs; in this sense, it is nondisabled adults who prefer stairs.

This meaning of the ramp has not always been present. In fact, the ramp as a tool for accessibility in public space emerged as part of the Universal Design (UD) or Accessible Design (AD) movement. Certain elements of UD were incorporated as minimum standards in the ADA (1991). In turn, they became elements of the legal infrastructure of the US building code. Like feminist design theory that preceded it, accessibility by design starts from the premise that "design is never ideologically neutral. Whether explicitly or implicitly, built environments always reference and imagine bodies and spatial inhabitants. ... both the presumed body *and* the marginalized body are always implied in, structurally incorporated into, or actively excluded from, physical environments" (Hamraie 2013:no page). Aimi Hamraie argues that the look or visual vocabulary of an architectural mode, called *parti*, can be at once both *aesthetic*, and *imply use by particular kinds of bodies using particular kinds of technological assistance* (2013:no page). In this sense, while ramps at the entrances to buildings or between floors or levels can serve all members of an urban population, the accessibility ramp is often imagined as being "for" a wheelchair user - perhaps the white stick figure of the international "handicap" sign.

But what is a *ramp* actually? A ramp is a machine. In fact, a ramp, called an *inclined plane* in physics, is one of the five simple machines that make up the basic building blocks of mechanical engineering (Hendren 2012). Along with the screw, the lever, and the pulley, the ramp is one of the most basic mechanical tools. Each of these simple machines redirects energy or force in a particular way; designers and engineers put them together and in combination to form the tools that make up our world (Asimov 1966:88). In a classic popular physics book, physicist Isaac Asimov describes how a ramp "works" with the example how one might use a ramp to aide in loading a barrel onto a truck; the ramp "dilutes" the amount

of force used to raise the barrel to the height of the truck bed, in proportion the slope and length of the ramp (a longer ramp will dilute the force more, but require transporting the barrel across a longer distance) (91-92). In introductory physics, in order to consider this relationship of slope, length, and force, *students are often instructed to discount friction*. Physicists consider friction to be an "imperfection" in the environment, which inhibits the flow of kinetic energy (Asimov 98). But *friction* is also a factor in allowing for passage up and down an incline - only by calculating the friction can a physicist or engineer know how difficult it will really be to move an object up and down a ramp. And in the real world, not the imagined world of physical modeling, humans *need* a certain amount of friction to move up and down an incline plane without slipping and simply sliding to the bottom.

In contemporary ethnography, Anna Tsing has proposed that we may think of *friction* metaphorically, as a productive force that occurs and produces heat or complexity. Things and ideas, Tsing argues, do not flow freely from one context to another. Like the imaginary ramp in the mechanical physics of Galileo, which exists in a universe free of the "imperfections" that cause mechanical friction, economists and globalization theorists often imagine supply chains and human rights concepts flowing freely from one cultural space into another. Tsing suggests that rather than think of cultural differences or the mismatches in the ways that given objects or ideas are passed from one cultural sphere to another as an impediment or imperfection, it may be useful to think as these mismatches and tensions of interpretation or meaning as productive friction. Or rather, where conventional wisdom reads mismatches or misunderstandings as troublesome, Tsing takes a more neutral perspective: the friction generated by the mismatch may be useful. This is one of many ways that contemporary ethnographers talk about conflicting ontologies (e.g. Ries 2009; Mol 2002).

Extending Tsing's concept of friction by combining it with the physics of ramps might point ethnology in an interesting direction. In many ways, the ramp as a design element or architectural feature has moved through multiple cultural or ontological spheres to arrive on the streets of Petrozavodsk and in pixelated images on my internet browser. What are the tensions and incongruences of meaning and interpretation that have aided the accessibility ramp in spreading and replicating across multiple global contexts? At what points are students of access or purveyors of human rights instructed, like physics students to "ignore friction"?

Checklists as smooth passage

The checklist, as well as the ramp, is a particular kind of technology. Bowker and Star discuss the *list* as a particular tool of modern bureaucracy and civilization (137). Foucault (1970), they argue, conceptualizes *the list* as key to the development of modern science - e.g. the elaboration of *kinds of* animals or plants in the elevation of biology from a rich-man's hobby to a science. Latour (1981) has highlighted lists as physical objects that can be shuffled and compared, moved across space, and held as proof of protocol by a bureaucrat. In this way, Bowker and Star note, list making is "foundational for coordinating activity distributed in time and space" (138). It attempts to streamline, coordinate, or make congruent a decision-making process that occurs across space and time. The list also produces a certain expectation of reality, in that it presupposes a bureaucratic action that might be applied "in response to a recurrent situation" (138).

In this sense, list-making technology becomes an important tool in the execution of the infrastructure of modernity. As particular ideas, forms, or norms are disseminated through a geographical territory, lists serve to normalize and standardize practices of design

and implementation. As power has taken different forms, so too has the reach of the list and its norms. The monarch created particular kinds of lists, as did the twentieth century state (Scott 1995). Now as the flows of global capital distribute ideas and technologies across uneven cultural settings, lists and norms attempting to reproduce infrastructures of modernity get taken up and implemented in a diversity of cultural settings where the meanings of the products they presuppose are heterogeneous and contested. That is, precisely because lists attempt to standardize across time and space, they operate as a system for managing the heterogeneity and disagreements of global friction (Bowker and Star 1999:139).

A suspicion of norms, and of modernity's obsession with the mean or average body, is central to disability studies (Canguilhem 2009; Davis 2006; McRuer 2006). Yet, disability rights activists working in global contexts rely on norms or standards as central technologies of list-making, in order to disseminate the principles of accessible design to diverse global contexts (Djumbaeva; Kohrman; DPI; Abilis). Concerns with material and environmental inaccessibility as bound up in the social exclusion of people with disabilities are central to both the theoretical debates unfolding in disability studies (Imrie 1996; Charlton 2010) and international development and human rights discourses. Standardized modes of constructing accessible infrastructure, characterized by specific norms in the form of measurements and materials - the architectural building codes that make up accessible design - are considered to offer potentially universal solutions (even as many disability scholars and activists rebuke the very idea of "universal"). In this way building standards, or norms, already occupy a place of tension in relation to accessible infrastructures. Even as disability studies is wary of norms, or norming, when it comes to disseminating elements of the built environment, disability advocates may choose to "ignore friction". Even as list-making is a tool to smooth difference,

and therefore checklists always function in friction, individual components of the list - the aesthetic look of a ramp, the check mark itself - may become fetishized, and sought after as ends in themselves.

What happens when we apply these problems to the checkmark list and ramp-building habits in Petrozavodsk? If we consider checklists as universal standards that are developed in relation to international building code standards, a checklist could be a functional tool for implementing accessible design principles in Petrozavodsk. However, if checklists are haphazardly implemented, or the details are not upheld, something that "looks like" a ramp may come to stand in for an actual tool for accessibility. By exploring some of the actual anecdotes and tensions on the ground in Petrozavodsk, we can see how these frictions play out in the logic of check-mark ramps.

Friction in Function and Form

In the spring of 2013, I recorded an interview with Anya, the psychologist and a power wheelchair user. Anya is a compelling person to interview. Not only does she frequently talk for long stretches at a time with only minimal prompting, but she is a keen observer, and has sharp sense of humor is highly entertaining. She often deploys her sarcastic wit to drive home the absurdity of a particularly element of inaccessibility - a tactic that many disability activists in the West will find familiar.

For some reason they are trying to make the buildings of certain social services, or medical facilities, or the town hall and mayor's office, accessible. Like, they did something with the grounds of the pension office, and then something else. But how useful is building a ramp to the town hall, if I can't get down the stairs from my apartment?! [laughing] How am I supposed to use a ramp to the town hall? I think that in the first place, they need to adapt the entranceways (*pod"ezdi*) of the buildings where people with disabilities live. To start from there and work on out. To make public transportation accessible! ... Like in Finland -- I showed up, I stood at the bus stop, a bus came, laid down a ramp, I got on, the doors closed, and we were off. What's so bad about that?! ... I don't need a ramp at the pharmacy if I can't get out of my house!

...if we *do* have a ramp, it's covered in snow and no one shovels it!

But who ever said life would be easy? No one promised an easy life! [pause; then, sarcastically, thinking of how hard it is to get around in the winter] It's our little way of doing rehab!"

In this quote, Anya observes that recent construction in the city has seemed to prioritize making accessible particular buildings that have some official function related to the state - the post office, the court house, or the town hall and mayor's office (*meioria*). These isolated islands of accessible passages remain disconnected from the broader network of transportation and passageways. Without the broader grid of the city undergoing similar renovations, a ramp to the town hall, to Anya, seems an empty gesture, or a cruel joke.

Anya imagines an alternate universe in which people-centered design would consider her homespace - which she has adapted herself - as ground zero, and work out from there. Instead, accessibility starts at points of state power, as a symbolic expression of the Russian Federation's compliance with the minimum standards of international norms of access, Anya drives home this point by drawing a comparison between her own city and cities in neighboring Finland.

Anya's monologue reminds us that in order for an accessibility ramp to function, a person must have already arrived at the bottom (or top) of the ramp. If a wheelchair-user can't get out of her house, or across town on public transportation, she will not be able to make use of a perfectly executed design element in the new shopping mall downtown. Ramps as tools to facilitate access to public space in Russia, even if perfectly executed as discrete architectural elements, often do not function fully, as a ramp presumes certain other technological minimums, which may not be met. As part of a heterogeneous network of sociotechnological actors (Callon 1991), ramps may or may not find convergence with other elements.

That is, a ramp alone is only an indicator of access; the ramp requires numerous other elements of the infrastructure to converge in order to actually function for access. Ideally, a

ramp functions as an enabling device or technology, allowing a smooth passage⁴⁵, where otherwise social boundaries might need to be broken - requests for help getting over a threshold or up a set of steps. Yet, as Anya's narrative illustrates, there are multiple ways in which the diverse elements or sociotechnological actors in the infrastructure may not align to promote the function of the ramp. In these cases, the form of the ramp, and its symbolic function as a "disability thing" and element of global design culture remain, but its active function as a technology of access is lost⁴⁶.

Another example: for wheelchair users, the usefulness of a ramp presupposes a wheelchair. If there are no wheelchairs, or if wheelchairs are broken, a ramp is not a useful tool (of course, a well-built ramp can still be a preferable option to stairs for ambulatory people with chronic fatigue or impaired mobility). An unevenness in the distribution of wheelchair technology is a significant problem for access both in Petrozavodsk and in the former Soviet Union more broadly. Sarah Phillips has documented the ways in which wheelchair-users in postsoviet Ukraine worked to form complex alliances to convince business owners and government agencies to support the manufacture, purchase and distribution of well-designed wheelchairs in the 1990s and early 2000s (2012). Wheelchairs are expensive, usually manufactured abroad, and difficult to obtain. Because the supply and

⁴⁵ The notion of smooth passage is one that I carry over from the article "Good Passages, Bad Passages" in which Ingunn Moser and John Law blend science studies and disability theory to argue that as cyborgs, humans rely on the confluence of a variety of technologies and material and human factors to facilitate smooth communication or passage from one state, stage, or place to another. But often for those of us negotiating non-normative bodies, the linkages between the elements in these exchanges and passages do not align; and passage is rocky, incomplete, tumultuous, slow, or difficult. In crip culture, the choreography of discrete design elements and social factors into a "good passage" is a goal rather than an expected occurrence. Here I have used the phrase "smooth passage" to emphasize the concept of unevenness and friction.

⁴⁶ Robert McRuer reported a similar phenomenon regarding a lone curb cut installed in a sidewalk outside of the British Embassy in Mexico City - although installed with much fanfare, McRuer argued that the curb cut did little to facilitate access in the city, nor to assuage the disabling and debilitating conditions of life in the city more broadly ("Crippling Development" Seminar Presentation, Prague, 2013).

distribution of wheelchairs is slow and unreliable, if a part breaks or wears out, they can be difficult to fix. In Petrozavodsk, Anya complained that the frequently encountered rail ramp design (a ramp that is not a flat incline plane but two rails which wheels must fit into installed over a staircase), tends wear out the treads on her automatic chair's tires as they rub the sides of the railings. This causes problems, because the tires are expensive and a hassle to replace.

My friend Alina waited six months of 2012 for the replacement part for her broken manual wheelchair. She was able to borrow another chair to get around in, though it didn't fit her as well. We laughed when I came to visit, because the broken wheelchair took up so much space in her room that she had taken to using it as a desk chair while she waited for a replacement part. In another interview, she told me that when she was taking courses at a community college three miles from home, she would often “walk” (her mother Valya pushing her chair), because it was too difficult to get lifted on and off of the city bus. Like Anya's comment, this story illustrates the ways in which particular elements of the sociotechnological infrastructure of Petrozavodsk were inaccessible; this led wheelchair users to create alternative networks or pathways that facilitated smooth passages.

These objects - wheelchairs, ramps, and other design elements (or their absence) - can be understood as part of a sociotechnological network, in that they are always embedded in social relations. It is not only an object itself that facilitates access, but also social attitudes that foster or dismiss the implementation of design elements for their intended use.

When ramps, wheelchairs, and other technologies of access and elements of accessible design move into postsoviet spaces unevenly, their function is compromised by gaps in the network of sociotechnological actors. This means that whether or not a ramp is a

check-mark ramp, or visibly non-adherent to the formal design principles that facilitate good passages, from the perspective of the wheelchair-user, the ramp may not be fully functional.

Friction Two: minimum requirements and the logic of checklists

During one interview, I asked Anya to tell me what she thought about the concept of accessibility in the built environment. I used the phrase *bezbariarnaia sreda* (literally, a barrier-free area or surrounding environment), a conceptual and linguistic translation from international disability activism. Disability activists in Petrozavodsk used this term when talking to the media about accessibility in the downtown area, drawing on examples from ongoing activism in Moscow (facilitated by internationally-connected disability rights organizations), which they followed online. In this sense, Anya's response to my question was to immediately situate *bezbariarnaia sreda* in the Russian context, as a traveling term that had to be distinguished from the Western contexts that it was adapted from.

Accessible space - *bezbariarnaia sreda*? It's a painful question. The law on accessible space, well... last year they rewrote it several times, so that in the end they could implement it. I was following one particular point in the law. [...] there's this word, "minimum conditions of a barrier-free environment." I thought about that and realized that the word *minimum* is the key word. That someone could just argue that *this* word - *here* is the standard. I'd be saying, "You understand, that we have a right, as everywhere else, to the minimum standards of a barrier-free environment." And they'd answer, "Sure, our ramp is set at the wrong angle of incline - that's nothing, because the main thing is that a ramp is there! So, take a look, here are your minimum conditions." And I'd say that this is wrong, but I can't prove that it's wrong. There's no way to beat it. So, in this sense, I guess you could say that [the law] is written exactly how they wanted it.

In this quotation, Anya expressed the sense of frustration that she feels about the notion of accessible public space. Although the phrase for the concept - *bezbariarnaia sreda* - is now standardized in Russian, the real world work of implementing the concept, through a system of legal right seems to her to apply to some *other* place, and to have been adopted in Russia only symbolically. On the one hand, she is making a joke - in Russia, she implies, we define things (like accessibility) in order to wiggle around them. On the other hand, she is speaking

seriously. As a powerchair user, whose mobility device is too heavy to be easily lifted, she very much counts on ramps to be able to get in and out of buildings. She has personally overseen the installation of a ramp outside of her apartment building, and of several at a previous place of employment - never without significant hassle (a story that will be familiar to power chair users both in Russia and elsewhere). While this latter experience could be part of a litany of complaint from a wheelchair-user anywhere in the world, the particular cadence of her interpellation of legal code as difficult to enforce aligns with broader Russian conversations about government accountability, and lip service rather than integrity in implementation.

In Anya's experience, a "minimum requirement" is the requirement that *might* have a chance of being met (but only after a long process of complaint, threats, incorrect or unacceptable half-hearted stop-gap measures). Anything above and beyond a minimum requirement simply will not be considered, she insinuates. In her description of these *minimum standards*, Anya used the common Russian construction of assigning actions to an unnamed "they" - the faceless mass of government bureaucracy or the powers that be. Who, I wondered, were "they"? Who was actually responsible for designing, building, and assessing the implementation of accessibility ramps?

Anya and our mutual friend Rudak, also a wheelchair-user and activist, had some guesses. Anya had experience in the spring of 2013 trying to get a ramp built in the entranceway to her new apartment. Unfortunately, no one from the building management knew what she was talking about, and no one was convinced that it was their job to build such a ramp. In Anya's telling, she left several messages for her building manager over the course of two months; she joked that they began simply answering the phone and hanging up

to get rid of her when they saw her number on the caller ID. Finally, she announced that she was calling the local media to do a story on the fact that no one was responding to her request; a handyman showed up shortly, and in Anya's estimation, spent about fifteen minutes laying an asphalt wedge along half of the single step in front of her apartment building entrance. The work isn't great, but it allows her to get on and off the stoop daily on her way to work and back without ruining her tires. Haphazard, off-the-cuff ramps like this are frequently built onto storefronts and homes as afterthoughts, by workmen with little or no training and little attention to building codes.

Figure 25: "Don't Park here, 8am-8pm!" A screenshot from a local TV news spot about the ramp in front of Anya's apartment shows the unstudied concrete construction, and a hand-painted notice not to park cars in front of the entrance. Image from online video: http://vk.com/im?sel=5865389&z=video5865389_168244542%2F843d901b04a66ab013



In another scenario, the duo, along with another local activist, worked to find out who in the town administration was responsible for enforcing building codes. The train station in the center of town was scheduled to be renovated, and they wanted to make sure that the renovation would include ramps and elevators to facilitate wheelchair access to the platforms (currently only accessible by stairway). Having narrowed down responsibility to one of two possible offices, they were curtly informed by bureaucratic workers in each department that

the question of enforcing building codes was out of their respective jurisdictions. The activists then obtained a letter from a federal agency, which stated that, according to federal law, an office in the city administration must accept responsibility for this role. But, having obtained this letter, and presented it to the same offices to no avail, the activists were stumped. Aside from the state, they could think of no organization with the authority to enforce the building codes.

In this sense, my interlocutors who are wheelchair users have a fairly good sense of how these unstudied ramps get built at apartment buildings, and limited ideas of how to enforce a standard of access. This makes other type of ramps that exist in the city -- the architecturally-designed, professionally-built ramps that can be found in front of government buildings or in shopping malls -- somewhat of a mystery. I asked Rudak how he thought that these ramps came to be built according to standards of accessible design, and he suggested that the reason that these well-designed ramps can only be found in such buildings is that shopping malls are simply built according to existing modular plans adapted from European cities, and the ramps happen to come along with the design. That is, in his estimation, a well-designed and well-executed accessibility ramp, by definition is not Russian, and could not have originated in a Russian context.

"Lots of lists - really a lot!": Building professionalism

In the fall of 2012, I brought my questions about architecture and accessibility to a friend who works as an assistant in a Petrozavodsk architectural firm. At the time she already had completed most of a four-year degree in civil engineering, and was preparing to take licensing exams. We had known each other already for several years, and she knew that my research was on *invalidi*.

Thinking of the check-mark ramps, I asked Olya to repeat for my digital recorder what she had explained to me in an earlier conversation about checklists. Olya explained that using checklists to ensure that draft plans for new buildings are in agreement with building codes (*normi* in Russian) is a key element of her job.

O: I work in a company that does contracting for residential buildings, public buildings, sports complexes, and so on. And, I work in the architectural division. And - mostly our work is to see to it that all the building codes are fulfilled. And, included in those are norms for -- [pausing to emphasize or recall the official term] accommodations for low-mobility groups in the population.

C: What are some of the other codes?

O: Other codes? Well, for example, mmm. There are codes to make sure that there is good natural lighting in a room. [...] There are codes, for example, so that the toilet in your apartment isn't next to the living room of a neighboring apartment. That's against regulations. Because it would be bad if there were a leak -- it wouldn't be very pleasant! There are lots of codes, in general. Really a lot. You have to set the thickness of the walls, the thickness of roofing, so that people will be warm, and -- so that it will be comfortable, and you won't hear your neighbors, and so on. So, among all of those, now these last few years, they've really been actively following up with implementing codes for people with limited mobility (*malomobil'nikh grupp*).[...] in the population. That is -- this goes for wheelchair users (*invalidi kolyaskochniki*), and, also for pregnant women, women with strollers, mothers... like, there are a lot of these people.

Olya went on to explain to me that her work is made up of verifying numerous, seemingly unrelated measurable elements of a building plan with established norms. While she intellectually recognizes that each norm is based on a particular corresponding function, e.g. thick walls and roofs so that people will stay warm, her job is not to establish the norms, or work out the norms, but to verify that the architects who have laid out the plans have met the existing norms. And, in her telling she made sure to demonstrate to me that the work of meeting standards regarding access is not set apart from the other elements of her job, but rather included in the same manner and importance as light, heat, and sound. She emphasized repeatedly that there are "a lot of norms - really a lot!" Later in the interview, she elaborated:

it's an interesting job, of course, but sometimes it can be -- tedious to work out. Like, when you're like, [adopts a sarcastically delighted voice] "I'll come in! I will draw a building! I'll add staircases! Oh, it's so pretty!!"[returning to her normal voice and cadence] But, in reality, you are sitting there with all these building codes (*normom*). And you spend a lot of time on it.

Olya contrasts her vision of architecture as a romanticized, exciting career and a chance to change her environment by building her world, with the much more mundane reality of

checking figures. *This*, she emphasizes, is the actual content of her work: endless verification. Checking that the elements of a given design meet the standards established for accessibility for "people with limited mobility" in Olya's telling is not an afterthought or chore, but rather a routinized element of her work, seamlessly integrated with others.

I asked Olya how it was that the norms for MG came to be instituted.

O: I don't know exactly what year it started. But, when I started with this work, the first job, well, it was like four years about. And -- it was already, like -- well, they were trying. To implement it. Lately, they're *really* strict that we follow up on this.

C: What does *strict* mean?

O: That - it means that - we *have to* do it, so that there's a *ramp*, with the right incline. So that we can't just - you know, how a lot are done, like lean some kind of board up against something, and say, so there it is - a ramp. We are obligated to do it so that it has a comfortable incline [--] so that a person can get in and out. We are obligated, like I said, to make a nice big bathroom stall. An elevator. Et cetera.

In this exchange, Olya contrasts the work of using checklists with non-expert vernacular design, like the ramp outside of Anya's apartment, which she implies is haphazard and unprofessional. In Olya's estimation, it seems that part of the utility of a strict building code is a more beautiful and well-executed public space. Without professional norms and standards to follow, ramps and other elements of the built environment might be poorly executed. In other conversations, like Anya, Olya described the jolt of jealousy she feels every time she crosses the border of the Russian Federation into Europe. Immediately, she said, the roads are smoother. The sidewalks are not only well designed, but also well executed, and the bus stop shelters are new. I have often heard her joke with friends about how poorly the infrastructure of the city stacks up to other cities they have visited abroad. While Olya is busily making plans to continue to live in Petrozavodsk - she recently married and bought an apartment - she would like to live in a Petrozavodsk that looks more like Helsinki or Stockholm.

Olya's "obligation" to make sure her bosses' drawings meet building code standards is therefore, for her, not only busy work, but actually linked to a real world outcome: a built environment to be proud of, that functions well. And, to the expression of her own professional expertise. She went on to explain how the building code is enforced.

O: [...] So, it's not *just* that we have to follow up on all of this. There's a regulating body (*kontroliruyushaia organizatsiya*) that then checks over all the projects, and says, well, *orders* corrections on mistakes. And, then we fix them. It's not only -- it's not just about accommodating the movements of people with limited mobilities. It's also about all the other regulations in general, too. [...then,] when we finish a project we give it to the expert review panel - [it's called] *ekspertiza*. It's made up of educated people, who sit on the panel and look out for everyone. For compliance with all the regulations (*sobludenyem vsyekh normy*). When they say, yes, you have it all correct, *theoretically*, only then can work start on the project. Like, construction on the project can go ahead and begin. But, more *often* (laughs), it construction is already underway while the plan is still being worked out (both laugh). So then it's going on in parallel sort of, so the work is coordinating it all, and moreover, then to make it all match up, to finish building peacefully, and so on. So, like, in order to not have to throw out the final construction, we'll start to build the building. [The project financier] could, at any moment, on his judgment, take his resources and leave.

Olya's description of the role of checklists in ensuring accessibility standards reveals a Russian design expert culture that is concerned with executing their work according to the highest European professional standards. In Olya's perception, civil engineering in Petrozavodsk is not comparable to that in other Russian cities, so much as to geographically comparable international cities.

In contrast to Rudak's supposition that ramps in shopping malls come about because a building plan has been stolen from a European shopping mall, in Olya's telling, each building and each renovation is designed carefully by trained Russian professionals. As professionals, she and her colleagues execute the elements of design laid out in checklists, including the checklist for *malmobil'nikh gruppov*.

That is, in contrast to Anya and Volodya's guesses, according to Olya's insider's perspective, it's not at the architectural stage that plans for accessibility standards break down, but rather in the hands of the building contractor. This is not about Soviet bureaucracy, but the precarity of public/private and negotiations of capital in neoliberalism. Olya went on

to retell a story that she had told me once before. She recalled it, in particular, because it represented a moment of ethical conflict for her, and because she had recognized it as a point when the execution of accessibility norms broke down.

There was this big building (*dom*). It was divided into two floors. And, they needed to make some kind of way to get to the second floor. They made this giant, enormous ramp. It was for cars and people and everything else. And, along the edge of the ramp, they made a handrail. There were high ones - according to the regulations they have to be [something like] 100 centimeters - and a lower one. It could be for children, or for wheelchair users (*invalidov-kolyasnichkov*). That is, we do all of this. We drafted everything. When these railings or handrails went - to the people who - well, who make them, from metal, they calculated the cost, and they sent it to our boss, and said, *That's expensive. Take out the handrail for invalidi (invalidov)*. So [the project underwriter] took it upon himself and just got rid of it. I don't know, how it all happened --- [but in the end when I visited the building, there was only one railing].

When I asked her to elaborate, Olya explained that the project foreman proposed some changes to cut costs. When the revised plans were presented to her, she refused to sign-off on changes that didn't meet the building code. But, she shrugged, embarrassed, someone else must have signed off.

In these tellings, both the architect and the ramp-users fail to imagine one another as individuals, and disregard one another's expertise. Olya's story suggests that the architects would point fingers at the builders for being at fault in moments when norms are not upheld. Yet, they would not think to reach out to ramp-users to raise a fuss about an oversight in execution. In Olya's telling, wheelchair-users are recipients of a built environment, not co-designers. And, as a mere employee, Olya herself, and the sanctity of her checklists, were ineffectual in the face of the logic of the bottom line. In an economy of capitalism, scarcity, and every-man-for-himself, if the one footing the bill wants to take out a handrail, that's his gamble to make, regardless of how well Olya's drawing executed the elements of the checklist.

Anya, the powerchair user, also described a scenario when building norms were subverted at the hands of builders. In her case, however, it wasn't the boss overriding a well-

designed plan, but rather, day laborers following orders and guessing what a ramp should look like.

At the Martial Springs retreat center (*Martialniye Vody*) they made a ramp, so that you could get [from the main building] down to the spring. The springs with the healing waters⁴⁷ are down the hill and leading down to them is a long staircase. And last year, the good people [sarcasm] decided to build a ramp down to the springs. And it ended up, that at the same time that they were doing the renovation work, my mom happened to be driving in to the resort. She saw what they were up to and stopped and asked, "What are we doing?" and they answered her, "We're making a ramp." And mom says, "You're not building a ramp, because I can already see that a wheelchair won't be able to get through there." They started to wave some documents around, they go, 'we have the regulations (*normy*), we have the standards (*standarty*)!' And so, Mama says, "I don't need your standards, I am talking to you as a person who has spent 35 years of my life with an invalid, and I am saying that a wheelchair won't be able to get through here.

So, what do you think happened? They erected the ramp all the same. And ... so then it ended up that I started to bug them to redo the ramp. I chipped away at them and in the end they redid it.

In this telling, the fault for an inaccessible accessibility ramp falls on the day laborers tasked with building it. Again, a barrier of class or identity separates the executor of the ramp design from the user. The user's perspective is subverted to the laborer's own informal checklist: use the materials we were given, build something that looks like something else we've seen, according to the instructions we've been given, get paid, go home. The black and white of the norms and instructions override Anya's mother's lived experience as a source of expertise. Operating in conditions of scarcity, and as laborers, the workers had instructions to follow that aligned with hierarchies of command, and could not be interrupted by horizontal avenues of advice from a passerby. In these cases, the purpose of the ramp and its meaning existed in friction between each set of parties involved.

Conclusion: the ramp as modernity

⁴⁷ People drink the water from the springs, which is also gathered and used for mineral baths. Each of the three springs has a its own composition of minerals, which are said to be healing for specific ailments.

The non-functional ramp fails as a tool for accessibility for wheelchair users or other members of the *malomobil'naia grupp*a (those with strollers, children, the elderly and others with poor balance or compromised mobility). However, it is functional as a symbolic element of the visual public sphere. The ramp, as a cultural icon, references access and social democracy, as well as aesthetics of European society. A ramp is not just a requirement of meeting building standards (after all, with the right kind of bribes and lack of oversight, these might be overlooked altogether) - it is a vessel for a particular kind of cultural flagging. This is a place of modernity, a ramp is imagined to indicate. A ramp carries with it the mark of modernity, a standardization of the built environment, that, through the logic of checklists and norms, bit by bit, overtakes local vernaculars.

Checkmark ramps continue to spring up, as they are implemented by architectural firms in new constructions or executed by workmen following orders. Anya's insight that by establishing a norm, a process also establishes a de facto minimum level of satisfactory execution, begins to circulate in interesting ways, as we watch the manipulation of "minimum" come into negotiation between different parties with different interests. A norm operates as a necessary and useful tool of modernity - offering the possibility of sharing potential measurements for a well-functioning ramp between different locales. Yet, the establishment of a norm also creates a fundamental situation of friction, by decoupling design process from function. From the perspective of centralized planning, the shortcut of creating a checklist or instructions prevents the kind of mistakes that vernacular architecture might make, or the replication of costly design process through trial and error, assessing the properties of various materials and measurements. However, by centralizing expertise, the checklist prevents fellow citizens from recognizing that knowledge of what counts as a

working accessibility ramp can be found in ramp-users themselves. The check mark reveals itself as fundamentally belonging to systems of centralized, hierarchical design and planning. Materials and energy may actually be wasted when checklists are incorrectly interpreted, elements are left off to save on costs, or design elements are added without integrating them fully with the overall environment. The check-mark ramp appears where universal design travels in friction. The form of the ramp implies the invisible presence of the checklist, and the power relations facilitate the execution of the checklist's guidelines.

In this way, we might return to Rudak's (ultimately untrue) comment that ramps most likely come to Russia not as individual elements, but as part of plans for shopping malls that are imported wholesale from Europe. The logic of this statement underlines his certainty that accessibility ramps, as an element of material design, are patently not Russian in origin. That is, the concept is one that is imported, and moreover, that the import of the accessibility ramp is something that travels into Russian infrastructures not as an independent unit, or as a design element actually intended to facilitate the access of minority populations, but *as part of a larger imported infrastructure*.

Rather than part of the plans for a specific building, the accessibility ramp is continually being imported to Russia as part of a series of plans for the new Russian nation. The ramp as a technology, and the checklist of architectural accommodations for *malomobil'nikh grupp*, travels within Russia as part of an infrastructure of illiberal democracy (as described by Zakaria), which, on the one hand, reconsolidates centralized power of in an autocratic, modernist state, and on the other hand, privileges profit-making and economic growth in private industry as an end to itself, as the social good from which other social goods might follow. In this mode of logic, ramps are built in the most

symbolically important government buildings as a way of asserting lip service to internationally disseminated democratic principles of human rights and minority inclusion: in this incarnation the ramp symbolizes the egalitarian access to the tools of governance that characterizes democracy in the global imaginary. In shopping malls, the ramps play into an aesthetic of access that has to do with luxury, comfort, and ease, with technology and Europeanness. That is, these ramps are tied up in a global politics of development, wherein a symbolic inclusion of minority groups is not an end in itself, but leverage toward entrance or membership in Western systems of governance that privilege minority inclusion as a precept of modernity. The aesthetic work of the ramp as evidence of dissemination of the varied value systems appeals to a heterogeneous array of stakeholders - most of whom are not members of the *malomobil'nikh grupp*.

Standards and norms - elements of design or infrastructure, and their implementation - are always already engaged in an ontological presupposition about what kinds of human bodies count. Do Russian human bodies count? Do disabled, poor, or racialized bodies count? Which bodies "deserve" access to the symbolic capital of a ramp-laden public space? Does Olya? Does Anya? As Arturo Escobar has pointed out, when designers describe "design for the real world," anthropologists must ask, "which world? what design? what real?" (2012). Or even, Who designs? Who builds? These are questions that must be posed if ethnography insists that friction is not an imperfection of physics, but rather, the unevenness that drives intentional motion. When worlds are built and rebuilt, when norms travel, power and exclusion are built in. Power relations do not operate as nested binaries of exclusion or domination - Russia/West, Able/Disabled. Rather, valences of power move through, across,

and with one another, producing frictions that propel unexpected relationships or objects - like the inaccessible accessibility ramp - into existence and prominence.

Figure 26: Dictionary definitions of the word accessible in English.

accessible, adj. Text size: A

View as: [Outline](#) | [Full entry](#) Quotations: [Show all](#) | [Hide](#)

Pronunciation: Brit. /ək'sesɪbl̩/ , /ak'sesɪbl̩/ , U.S. /ək'sesəb(ə)/ , /æk'sesəb(ə)/

Forms: LME *accessyble*, 15- *accessible*.

Etymology: < Middle French *accessible* (French *accessible*) that can be reached or entered (14th cent.), available, obtainable (15th cent.) and its etymon post-classical Latin *accessibilis* approachable, easily approached (early 3rd cent. in Tertullian) < classical Latin *accēss-*, past participial stem of *accēdere* *ACCEDE* *U.* + *-ibilis* *-IBLE* *suffix*.

In the case of quot. *a1425* at *sense 1a*, the text of the Vulgate in the same manuscript (Cambridge, Corpus Christi College, MS Parker 32) has post-classical Latin *accessibilem* (probably by confusion with *accessistis* 'you have not approached'), hence giving rise to the reading in the English version, but the correct reading is *accessibilem* 'burning' (compare Hellenistic Greek *κεκαυμένω* 'burning' in the corresponding Greek text). [\(Show Less\)](#)

1.

a. Capable of being entered or approached; easy of access; readily reached or got hold of. Also with *to*. [Thesaurus »](#)

a1425 († *a1400*) *Northern Pauline Epist.* Hebr. xii. 18 *3ee han not neghed to þat tretable fyr and accessyble [L. *accessibilem*].*

1568 T. HACKER tr. A. Thevet *New Found Worlde* xiv. 22^v. This herbe groweth on the tops of high and accessible rockes without any earthe.

1642 J. HOWELL *Instr. Forreine Travell* ix. 116 She [*sc.* Spain] hath bold accessible coasts.

1727 J. WESLEY *Let.* 19 Mar. (1931) I. 43 The town..lies in a little vale, so pent up between two hills that it is scarce accessible on any side.

1779 T. FORREST *Voy. New Guinea* i. v. 56 Here all hands bathed, which we generally did when fresh water was accessible.

2.

a. Capable of being used as an access; affording entrance or a means of approach. Also in figurative contexts. [Thesaurus »](#)

1602 T. LODGE tr. Josephus *Wks.* viii. ii. 204 He..caused the hie waies that led to Ierusalem..to be paved with blacke stone..to the intent to make them more accessible for those that traualled to and fro.

a1616 SHAKESPEARE *Cymbeline* (1623) iii. ii. 82 Accessible is none but Milford way.

1667 MILTON *Paradise Lost* iv. 546 With one ascent Accessible from Earth.

1737 R. GLOVER *Leonidas* vii. 238 If the Greeks Arrang'd within Thermopylæ, a pass Accessible and spacious, could repel With such destruction their unnumber'd foes.

1761 L. STERNE *Life Tristram Shandy* IV. xxv. 125 Had I found the declivity easy, or the ascent accessible—certes I had been outwitted..but it was so perpendicular a precipice [etc.].

1835 J. HARRIS *Great Teacher* (1837) 347 All the paths of human ambition were open and accessible to him.

1869 J. PHILLIPS *Vesuvius* iv. 105 The crater now became a funnel which was accessible to the bottom.

1912 *Bull. U.S. Geol. Surv.* 510 151 The opening was accessible until about two years ago.

1998 *Log Home Living* June 20/2 The Denali Park Road is accessible by private vehicles for 14 miles to the Savage River bridge.

b. orig. *U.S.* Capable of being conveniently used or accessed by people with disabilities; of or designating goods, services, or facilities designed to meet the needs of the disabled. [Thesaurus »](#)
[Categories »](#)

1970 *Amer. Jnl. Nursing* 70 43/1 Symbol for identifying accessible buildings and facilities.

1985 *N.Y. Times* 8 June x. 3/1 Tour buses have lifts to get wheelchairs aboard..and restrooms that are readily accessible.

1991 *House Beautiful Kitchens/Baths* Winter 20/1 Accessible design meets everyone's needs—those who use a wheelchair or have limited sight.

2000 C. CASSERLY in J. Cooper *Laws, Rights & Disability* vi. 157 The Code of Practice gives detailed guidance on different types of auxiliary aids and services, including accessible websites and subtitles.

2008 *N.Y. Times Mag.* 6 Jan. 43/1 At the behest of groups representing the disabled, HAVA required each poll station to have at least one 'accessible' machine.

CHAPTER VII
KAKAIA VLAST', TAKIE I DOROGI:
RUSSIAN TALK AND TERRITORIES OF IN/ACCESS

How do people with disabilities in Petrozavodsk talk about inaccessible infrastructures? How do their discursive strategies align with and fit into broader Russian performative practices of citizenship?

In this dissertation, I approach the question of what disability is - what it does, what it means, and how disabled identity is performed and conceptualized by people with disabilities themselves - through two major lenses: material infrastructure and performance or enactment. In this chapter, I work to bring these two lenses together. And, I highlight one keyword of the global lexicon of disability rights, *access*, and its particular meanings as it circulated as a concept in Petrozavodsk during my fieldwork.

In this chapter, I move back and forth between disability theory, and ethnographic attention to the stories that people with disabilities tell about inaccess in their city. I further examine these narrations in relation to the broader discursive practices by which Russians performed citizenship and dissatisfaction with the Russian government. In this way, I hope to map out some of the ways that talk about inaccessibility generally, and talk about inaccess specifically related to disability, can be understood in terms of existing rubrics of Russian discourse. In particular, I draw on Nancy Ries's concept of the litany and "the Russian tale" as popular modes of discursive performance with specific performative as well as constitutive meanings.

This strategy offers a contribution to the ethnography of Russia by tracing the concept of inaccess as a way to extend existing frameworks for thinking about Russian discursive forms and political subjectivity. I also seek to offer disability studies a case study that situates notions of in/access in local context, and to show the important ways that the lexicon of the transnational disability rights movement takes on particular meanings as it travels globally. In this case, I suggest, the manner in which the idea of inaccessible infrastructure resonates locally also offers an extension for how disability studies theorizes access. That is, that in global contexts, in/access always already indexes infrastructure, which carries with it sentiments about development, modernity, and governance.

I argue that Russian discursive practice often involves descriptions of absurdities or injustices that might also be described as complaints about inaccess. As Ries documents, Russians often end these litanies of complaint with a statement that, given the Russian condition, nothing is to be done. While to a Western listener, such a conclusion seems to be a statement of hopelessness and futility, I argue, on the contrary, that such comments do not necessarily mean that the speakers actually *believe* that nothing is to be done. My research suggests that Russian complaints about disability and access may serve a rather different performative purpose. In fact, it was the disabled activists who "do" the most who most often talked about how nothing is to be done and nothing changes. Following Ries, I argue that these statements serve to align the interests of Russians with disabilities with their non-disabled fellow citizens; by voicing litanies, they assert themselves as part of an imagined Russian public, sharing in an experience of suffering common woes at the hand of a morally ineffectual government.

In the fall of 2012, the gear up for the Sochi Olympics of 2014 had just begun in Russia. The Olympic committee had promised to make the Olympic village "the most accessible ever." However, this goal came up short, according to disability activists (Andrea Mazzarino, personal communication). But the inaccessibility of the Olympic Village infrastructure became a footnote in a much larger story about infrastructure and inaccess: in the week before the games, foreign journalists arrived to find a barely-finished, slap-dash infrastructure rife with awkward mistakes and indications of rushed, haphazard construction. The news media around the globe tweeted and blogged about half-finished sidewalks, oddly installed bathroom fixtures, and faulty hotel doorknobs. As the Olympics opened (although one ring did not) the Russian predilection for constructing subpar infrastructure paraded as a touchstone in both Western and Russian comedy. When the Paralympics opened several weeks later, the media in both Russia and the West largely overlooked the immense changes in the ways that Russian official discourse has recognized disability issues since the collapse of the Soviet Union. As Sarah Phillips has documented, the last time the Olympics were held in Russia, in 1980, the official statement about Paralympic athletes was quite different:

a Western journalist inquired whether the Soviet Union would participate in the first Paralympic games, scheduled to take place in Great Britain later that year. The reply from a Soviet representative was swift, firm, and puzzling: "There are no invalids in the USSR!" (Fefelov 1986).

[Phillips 2009:1]

By 2014, not only did Russia host the Paralympics, support Paralympic teams, and pay lipservice to infrastructural accessibility in the Olympic village, the country also ratified the UN Convention on the Rights of People with Disabilities⁴⁸. Putin met with a group of

⁴⁸ Whether the ratification of the treaty holds an meaning for disabled Russians, or represents a manner by which the Russian government sought an easy acknowledgement and legitimization as the sole entity of justice

select Paralympic athletes in the lead up to the games, and children with disabilities across Russia had the opportunity to participate in adaptive sports. In this way, adults with disabilities in Russia, having seen enormous change in the course of their lifetimes in terms of the state's relationship to disability and the public visibility of access, now had the dubious distinction of being able to join in and share with the rest of Russia a collective embarrassment over the gap between what was promised and what the government and its contractors actually delivered.⁴⁹

In my attention to how Russians with disabilities in Petrozavodsk talked about access, I noticed a similar trend. On the one hand, Western conversations about disability and access assume that the disabled, encountering barriers in the built environment, are a minority group facing hurdles that majority groups need not reckon with. On the other hand, the situation in Russia is such that infrastructural inadequacy and limits to social access present problems for most in the majority culture of nondisabled Russians, and, indeed, are a frequent topic of conversation. As part of this problem, I also set out to unpack how it is that the English word *access* might differ from the semantic domains indicated by its Russian translation, *dostupnost'*.

As I began to consider infrastructure and access during my time in the field, I started paying attention not only to the ways that people with disabilities talked about infrastructure and public space in Russia, but also to the ways that other residents of Petrozavodsk did so.

in the territory of the Russian Federation is another story. For a critique of the role of the UNCRPD in non-Western contexts, see Meekosha and Soldatic 2011.

⁴⁹ A state of affairs that is highlighted in an online article, published in 2015, in which wheelchair users in Sochi concertedly align their complaints about barriers in the built environment with more mainstream conversations about the failure to construct a public space that served the actual public in Sochi. <http://neinvalid.ru/spustya-god-posle-paralimpiadyi-v-sochi-ne-rabotaet-ni-odin-gorodskoy-podemnik-dlya-invalidov/>

And, I found that nondisabled residents frequently complained about their own experiences with infrastructural barriers that prevented ease of movement through public space. What were the performative and constitutive meanings of these comments⁵⁰?

Locating *Accessible Public Space* in Global Discourse

Since the collapse of the Soviet Union and the entrance of transnational actors into the Russian and the Russophone public sphere, the use of translated Anglophone phrases for describing services, goods, and habits have become a common part of daily Russian life. Russians read and write emails on *mobilniki* (mobile phones) or *noutbuki* (notebook computers), aspire to live not in apartments but in *kottezhi* (cottages, or single family homes), discuss the merits of a particular *pi-er* (PR or public relations) strategy, and are likely to *postavit' laik* ("like") a humorous photo on a friend's Facebook wall. In previous chapters, I have described the ways that new lexicons for disability have entered contemporary Russian usage patterns in ways that contrast with the category or social identity of *invalid*. In order to unpack the ways that ableism operates as a system of oppression in the postsoviet context, and particularly in postsoviet space, it is important to also trace the semantic locations and synonyms of the word *access*. This requires first locating access as a term with a particular origin in Euroamerican disability rights discourse, and a subsequent dissemination through the global disability advocacy and human rights apparatus.

⁵⁰ Although I am making use of Nancy Ries' observations of styles of Russian speech, I do not rely strictly on her modes of analysis. Where Ries describes types Russian talk as *discursive genres*, I find that Alexei Yurchak's formulation of *performative* and *constitutive* meanings of an utterance or enacted, embodied action (2006:22-23) to be helpful in understanding how speech and communication can work simultaneously on multiple planes. I do not think that Ries makes a functionalist argument, but I think the clear designation of performative and constitutive meanings helps us as social theorists to avoid the accidental implication that those we observe are somehow duped or unaware of their own social intents.

In the word *access* is an implied relationship between people and things, between human bodyminds and the surrounding environment, and the ways that that environment has been designed to fit particular bodyminds. *Accessibility* "is an interpretive relation between bodies" (Titchkosky 2011, 3; cited in Hamraie 2012). That is, in access is already an implicit concept of infrastructure and social relations. Because it implicates infrastructure – e.g. state projects – it also relates to citizen-government relations.

So, I am curious about the ways that notions of access map onto Russian discussions of disability. If access implies sociopolitical material relationships, what ways do ideas of access in Russia differ from ideas of access in English?

The origins of *access* as a disability justice concept

The word *access* seems to have been taken up in relation to disability in English in the second half of the twentieth century in North American disability advocacy circles. As activists agitated for universal design and wheelchair-friendly spaces, they began conversations with city planners and architects about what a public infrastructure that supported different kinds of bodies would look like (Fritsch 2014; Hamraie 2012; Serlin 2012; Williamson 2012). Wheelchair-users in the 1970s and 1980s used the idea of “barrier-free design” to advocate locally, nationally, and internationally for design elements like curb cuts, ramps, and elevators. Barrier-free design could apply not only to infrastructure or architectural elements, which eventually were regulated by statutes and building codes related to disability access, but also to consumer products, like can-openers, which are not regulated by statutes (Hamraie, personal correspondence).

Subsequent and simultaneous advocacy proposed the idea of “universal design” as a phrase that might refer not only to designing for bodies which do not fit a physical standard,

but also for creating inclusive environments through social means to be inclusive of vision, hearing, and mental impairments (see: Mace 1985; Zola 1989). International lobbying around barrier-free design has been ongoing since at least the 1980s, when design practices attempted to take on new social issues related to the deinstitutionalization of people with disabilities in the United States (Hamraie 2012 and personal correspondence; e.g. see The Institute for Human Centered Design in Boston).

The Oxford English Dictionary (OED online 2014) includes an entry under the adjective *accessible* that relates specifically to design and disability, which specifies this usage as originating in the US, and states, “Capable of being conveniently used or accessed by people with disabilities; of or designating goods, services, or facilities designed to meet the needs of the disabled.” The general definition of accessible is “Capable of being entered or approached; easy of access; readily reached or got hold of.,” deriving from the Latin *accedere*, to approach. Meanwhile, the entry for *barrier*, *n.* does not have specific mention of disability, but is defined as

1. *gen.* A fence or material obstruction of any kind erected (or serving) to bar the advance of persons or things, or to prevent access to a place.
[...]
3. **a.** Any natural obstacle which stops or obstructs passage, defends from foes, prevents access, or produces separation; a separating boundary-line.
[..]
4. **a.** Anything immaterial that stops advance hostile or friendly, that defends from attack, prevents intercourse or union, or keeps separate and apart.

In this sense, “barrier-free” and “accessible” function as synonyms in contemporary English.

Meanwhile, the Russian translation of the word access, *dostupnyi*, does not necessarily carry the same possibility of indexing disability access, although it may be used in this manner. While disability advocates and advocacy organizations use this word to describe disability access, its conceptual domains in general discourse is less readily related to disability than its English counterpart.

For instance, a search of the Universal Database of Russian Central Newspapers shows that today most uses of the words *dostupno* and *dostupnyi* (adverb and adjectival forms of all genders and cases) in print news stories still refer not to disability but to especially the affordability of goods and services, or the capacity of average citizens to obtain said goods or services. It is a common word, with 116,575 entries between 1980 and 2015. For example, the sentence in relation to healthcare for women and children, “*A glavnoe, chto eto dostupno vsem,*” “The main thing is that it be accessible [available] to everyone.” The database searches as far back as 1980, and by date, the majority of deployments of words with the root *dostup* relate to this concept of availability or practical capacity to obtain to a resource. The use of *dostupnost'* in relation to disability is much scarcer. In this way, the concept of access as a subdefinition of the general definition that specifically relates to barriers affecting people with disabilities seems to have only a limited circulation in journalistic discourse; that is, I would expect an average adult Russian-speaker to understand the concept of *dostupnost'* for *invalidov* not as a conceptual domain in and of itself, but as an appropriate extension of the general meaning of the word *dostupnost'*.

Similarly, the phrase *bezbar'ernaia sreda*, or barrier-free environment, is one that I learned from disability advocates in various regions of Russia. It is the standard phrase used by the organization Perspektiva to describe material conditions that facilitate access. Svetlana - my colleague and interlocutor who wrote her dissertation on the socialization of young adults with disabilities in Karelia - also used this phrase in her academic work. She organized an *aktsiia* - a demonstration or happening - in downtown Petrozavodsk, in which several advocates and wheelchair users conducted an accessibility audit of business on the train station and businesses main street, following a model that Perspektiva advocates had

used in Moscow. She described the *aktsiia* to me in terms of *bezbar'ernaia sreda*, and so I began to use the phrase in my conversations and interviews with my interlocutors. It was only upon reading the transcribed interviews later that I realized that my interlocutors sometimes used the phrase in direct response to a question that I asked using the phrase, but rarely did so on their own accord. Perhaps sensing this, I tended to use the phrase with those interlocutors - Anya and Rudak - who were more tuned in to transnational disability rights discourse.

Later, curious about the way in which the term moved into the Russian language, I wrote to a disability advocate I know, Galina Gorbatykh, who lives in a different region of Russia. Galina received her Masters degree in Francophone Canada in the 1990s, and is a lawyer and a local politician (as well as a wheelchair-user), so, I thought, might have a particular awareness of the term as one that had moved into Russian discourse from abroad, because I suspected that the derivation was a technical one related to legal provisions or architectural standards. In response to a short online inquiry that I sent to her (in polite but colloquial Russian), Galina sent back a several paragraph long response, in which she cited numerous laws and provisions in which the phrase had appeared, frequently slipping into the highly technical jargon of official or legal Russian. While she may have copied and pasted some segments of this response from some of the advocacy materials she uses in her work, it is also possible that, given her professional area of expertise, this is simply the register of language in which she describes the question of accessibility.

For instance, she opened her response with a definition of the term as it operates in Russian, and then immediately situated vis-à-vis transnational disability advocacy concerns.

The term 'dostupnaia' or 'bezbar'ernaia' sreda is called up on many legal acts in the Russian Federation and in various sources has different shades of meaning. In most contexts, the term '*dostupnaia sreda*' can appear in the sense of: a barrier free environment [*bezbariarnaia sreda*] - that is, those elements of

the surroundings [*okruzhaushchei sredi*] through which people can enter and move freely and which people with physical, sensory or intellectual impairments can use.

A setting [*sreda*] for the activities of daily living [*zhinedeiatel'nosti*], that is accessible [*dostupnaia*] for the disabled [*dlia invalidov*] is usually an environment [*sreda*] that has been renovated [*dooborudovannaia*] with consideration for the needs that arise in connection with disability [*invalidnost'u*], and that in using, the disabled may carry out an independent way of life.

Galina's response is quite long. She confirmed my suspicion that both the phrases '*dostupnaia*' or '*bezbar'ernaia*' *sreda* are primarily located as part of legal definitions, and offered that they entered the Russian language through legal doctrine beginning in the 1990s.

The first legal acts that named *dostupnaia sreda* were the Presidential Decree of the RF from October 2, 1992 number 1156 "On measures for the creation of access for invalidovs in daily surroundings" [*O merakh po formirovaniu dostupnoi dlia invalidov sredi zhiznedeiatel'nosti*] and in Legal Act of the RF from March 25 1993 Number 245 with an identical name. These were strengthened and further developed in the Federal Law Number 181 from November 24, 1995, with changes and amendments from August 8 2001, "on the social protection of *invalidov* in the Russian Federation." In articles 14, 15, 16 the state declared the creation of accessible infrastructures and the necessity of free access of *invalidov* to information and related measures of responsibility for realization of the items laid out in the Law in 1990 starting with that they translate books, such as Kalmet Kh. U. "Living surroundings for the disabled" 1990. [...]

In this sense, we can understand the derivation of the terms as located in an official register of speech related to Russian legal doctrine. Galina also specified that the origin of the terms is related to a global context in which accessibility in public space for people disability is a concern that circulates transnationally. She wrote:

It is worth noting that the understanding of problems of creating [*sozdaniia*] accessible environments [*dostupnoi sredi*] for all is also a global problem [*obshchemirovoi*]. Addressing and solving the issue of eliminating barriers begins first of all with architecture. Starting from the end of the 1950s, steps have been taken to create accessible environments for all, beginning with proposals from disabled people's organizations in the countries of Western Europe and North America including practical recommendations for city planners and designers [*proektirovshchikov*] and architects. The first standards [*normy*] for the implementation of accessibility [*obespecheniu dostupnosti*] in elements of infrastructure [*infrastruktura*] appeared in the USA at the start of the 1970s. Fairly soon after many other countries have made it mandatory to agree with accessibility standards [*trebovaniia dostupnosti*] for elements of the built environment [*ob'ektov sredovogo okruzheniia*] for individuals with limitations [*lits, imeushchikh ogranicheniia*]. The first standards [*normativom*] for barrier-free construction [*bezbar'ernogo stroitel'stva*] to appear were RSN 70-90, which have existed [*deistvovavshii*] since 1991. It follows to note that the law "on the social protection of invalid" from 1991 prohibited the development and building of venues not equipped with elements of access for *invalidov*.

Galina's language is pitched toward legal advocacy. It has the forceful tone of someone accustomed to writing so as to enforce the weight of the law.

None of my interlocutors in Petrozavodsk used the language of access in this way. While Anya and Rudak were both aware of, and at times, read legal provisions for their own advocacy purpose, they were unlikely to speak or write in the official tone that Galina's letter exhibits. Instead, Anya and Rudak frequently mentioned legal provisions as a way of gesturing to their failure or absurdity. Meanwhile, Svetlana, as a sociologist, deployed the terminology of access somewhat differently still: while in spoken language she might use the phrase as a shorthand when talking to other advocates - as a rallying objective around which action might be taken, in her academic writing she also deployed the phrase as a way of theorizing and naming a social problem that she observed in her research (see: Driakhlitsina 2009). That is, for Svetlana, the term was not an emic category that her research subjects used, but a scientific or theoretical concept that was useful in describing her findings.

In this way, it becomes clear that the terminology of accessibility - that is, the direct translations of the terms access and barrier-free environment that circulate globally - in Russian remain tied to formal registers of language.

Pothole Talk: Infrastructures of In/access for nondisabled residents of Petrozavodsk

In conversations about infrastructural barriers amongst the nondisabled population of the city, one element seemed to attract the most attention: potholes. In the first few months of my fieldwork researching disability and social exclusion in Petrozavodsk, Russia, I noticed that I couldn't escape them.

If I wasn't stepping around them as I hurried across a street, or being jostled over them in a taxi or *marshrutka*, friends, acquaintances, and taxi drivers were talking about them. Like the weather, potholes were the favored conversation for small talk and idle conversation. Potholes were a part of the shared conditions of life to which chit chat might

always turn, either in moments of forging passing solidarity with strangers, or bemoaning the status quo between gossip and catching up with friends or colleagues.

People remarked on and complained about potholes. Taxi drivers, noticing my accent, made wry jokes and apologies about the "state of our roads." Friends updated one another about what they had heard about the schedule of public works projects: *this fall they will repave Nevskii, next spring they are scheduled to do Kirovskii*. By the time the spring rolled around, I found that I was the one cracking pothole jokes to cab drivers, who would guffaw and turn to look at me with raised eyebrows, as if to say, you might be a foreigner, but if you're in on pothole talk, you're in on something much larger.

One summer afternoon in 2012, not long after arriving in the field but long before I had become fluent in pothole chitchat, I was cutting through a courtyard on my way to a neighborhood grocery. The courtyard itself was dusty and dirty, with large, shallow, dried-up "lakes" - less pothole than wide craters. Another time, when my friend Masha and I passed through the same courtyard on the way to walk along the embankment of Lake Onego, the large, forest-lined lake that defines the city's perch in the Karelian wilderness, six hours on the 2009 highway from St. Petersburg, we joked, "Oh, here we are - Lake Onego is much smaller than I pictured it. I didn't realize it was so close to my house!"

But that afternoon on the way to the grocery store, I paused, noticing a decal sticker on the rear window of a nearby Lada:

Kakaia Vlast', Takie i Dorogi

Like many short phrases, its meaning was clear, but resisted adequate translation. As I continued my walk, I filtered through possible renditions of the phrase in English.

"Such power, and such roads"

"As is the government, so are the roads"

"What a government, and what roads"

The word *vlast'* in Russian references both sovereign power of a ruler or system of government. It indicates a power that emanates from the center in a political science sense, or in common usage, regime, or, simply, "the government." In the plural, *vlasti* could mean, "the ones in power" or "the authorities." This was complicated by the grammatical structure of the comparative clause "*kakaia... takie...*" which doesn't have a clear counterpart in English, making translations inevitably awkward.

"However the _____, so is the _____"

"What _____, and what _____"

"As is the _____, so goes the _____"

"Such _____, and such _____"

Significantly, the phrase leaves the judgment about what the state of the roads are to the reader, a rare quality in English language comparative sentence structure.

But to any Russian reading the bumper sticker, the implication is clear: *Bad roads, bad government*. Later in the fall, the bumper sticker would appear affixed to cars around the city.

When people in Petrozavodsk talk about potholes, they frequently used the word *iama*, meaning *hole, pit* or *wallow*. Without a word like the English pothole, dedicated to the particularity of holes in the road needing repair, the synonyms for *iama* include *rytvina* (rut,

groove, gulch), or *vyboina* (dent, corrugation, or the pot-shaped forms in river rocks, usually called potholes in English). This array of Russian synonyms belies a condition of permanency that is quite different from the American understanding of the word "pothole," which implies a temporary problem that will be fixed. In Petrozavodsk, when people talk about *iamy*, they are talking about the municipal lack of attention to roads. They are describing a situation in which nothing could go smoothly, both literally and metaphorically.

This pothole talk amounts to a discursive register that is reserved for sharing woes, principally, complaints that may not have an answerable response. These are complaints that are posed as a manner of gesturing to a gap between a lived reality and an imagined good life (Chua 2014). In writing about Russia, many scholars have described a "culture of complaint," observing that "complaining is a popular form of communication in present-day Russian society" (Murayeva 2014). In many cases scholarly discussion of a Russian culture of complaint refers to an array of habits of written complaint that address the inadequacies of the state to representatives of the state (Murayeva 2014:94). But in thinking about pothole talk, I am interested in performative complaint, voiced grievances, the purpose of which is not always a resulting change but rather a bond of commiseration. Specifically, this is not a complaint to authorities, but rather, a voicing of dissatisfaction to another citizen (Ries 1997).

Talk, Complaint, and the Russian Nation

Pothole talk is related to the discursive performances that Nancy Ries describes in her ethnography of the perestroika period, *Russian Talk*. Pothole talk in Petrozavodsk often took a form that resembles the speech genre that Ries called a *litany*. As described by Ries, in Russian discursive practice, the litany is a recitation of individual woes that relates an instance of personal suffering to a broader social theme that is endured by the social

collective, the *narod*⁵¹ (1997). Alternatively, as in the case of wry jokes exchanged in a taxicab, pothole talk might take the form of a joke or ironic tale that is meant to say something quintessential about Russianness, a related genre which Ries calls "Russian Tales" (49-51).

As Ries observed when she described these genres, pothole talk offers a recitation of suffering, of absurdism and futility, and posits a powerful "they" that is opposed to the speaker or disempowered collective. Russian litanies of complaint are "part of a larger cultural ritual" of narrative performance (Ries 1997:18). Ries writes,

litanies were those passages in conversation in which a speaker would enunciate a series of complaints, grievances, or worries about problems, troubles, afflictions, tribulations, or losses, and then often comment on these enumerations with a poignant rhetorical question ('Why is everything so bad with us?'), a sweeping, fatalistic lament about the hopelessness of the situation, or an expressive Russian sigh of disappointment and resignation. [84]

Ries argues that the customary habit of ending complaints with an exclamation of hopeless fatalism is a discursive pattern, characterizing the genre, rather than a purely literal claim. She suggests that this mode of closing a long complaint can feel, to an American ear, rife with a sense of futility. Russian litanies anticipate no solution. And, Russian litanies prompt a response of empathy or agreement about the situation being described, either in the form of a short exclamation of woe (How awful! What a nightmare!), or an exclamation of woe followed shortly by contributing a similar lament. This discursive pattern, Ries argues, creates a stark contrast with American patterns of complaint, which often indicate an expectation of a problem-solving response (Ries 1997:35-37;115).

⁵¹ Ries uses this word, *narod*, but it should be noted that she means a social collective to which the general Russian public - those who are not in power - are thought to belong. *Narod* in other contexts could be interpreted in many ways, to mean, for instance, a folk or ethnic group, those who share a homeland, or, the masses.

While to an American ear, the genres of complaint that Ries documents, and that I observe, seem to offer no solution per se, they may also do important work of creating openings for other possibilities. Scholars have argued that complaint, including Russian patterns of complaint, say as much about a desired "ideal state" that is implicitly referenced, as a contrast to the undesirable circumstances described, as they do about the current state of affairs (Murayeva 2014:99; Weeks 2004). In my interlocutors' complaints, the imagined ideal state is often sketched as already in existence somewhere. That is, complaints are grounded in a diffuse sense that things are different elsewhere, abroad. Descriptions of Russian infrastructural inadequacy - ramps, potholes, or otherwise - are posited in relation to some imaginary West. The bumper sticker suggests that somewhere, because the government is good, so, too, are the roads.

Ries argues that these modes of Russian talk (she is talking about the perestroika era, but I find her definition of the genre helpful, even though a great deal of time has passed) offer not only the constitutive meaning of articulating claims about what is not right, or what has not been properly executed by those in power (e.g. the bumper sticker is a mode of activism in its own right), but also serves the function of bringing people together in moral objection to the status quo. Ries suggests that litany and Russian tales serve to create a "generalized social bond." The recitation of litanies and the telling of absurdist tales and ironic jokes is part of a cultural ritual of social communion. People gather around kitchen tables, in taxi cabs, in cafes or over cups of tea at the break room table, and share these stories. Through these enacted rituals of complaint, Ries argued, her interlocutor "identified herself with the moral community created through shared suffering and difficulty, thus effacing the boundaries between her social group and the Russian people as a whole" (91).

In fact, many Russians complaining about *iami* or potholes do so with no intention of pursuing an "official" resolution to the problem. Rather, the complaints function to build camaraderie, establishing a "we" who suffers while "they" - *vlasti* - *the ones in power* - do nothing. Ries suggests that suffering and tales that recount instances of suffering have special meaning in Russian discourse. She argues that talk about difficult social circumstances, of getting through a difficulty, had to do with "belonging in some kind of moral community – a community that shared suffering. As ritual recitations, litanies invoked and created access to that belonging" (87). While many rituals of complaint enacted in a wide variety of cultures might also serve to enhance social bonds, Ries argues that *suffering* has a specific moral meaning in the Russian context. Elaborating suffering, or the privations of negotiating inadequate infrastructures, might offer a discursive mode of establishing the moral personhood of a speaker, and of linking the speaker to a Russian *narod*. I don't think Ries means this in a wholly functionalist sense, nor do I mean to imply that here – rather, talk and performative interaction get enacted in culturally-specific ways, they follow patterns that are at once imitative and constitutive.

Considering this evidence, the postsoviet mode of complaint has an important consequence for how we understand assertions of access and inaccess in relation to disability rights in Russia. Specifically, litanies of complaint in Russia often follow patterns that seek to align the speaker as a member of a suffering *narod*, or national people, but to American listeners, these speech acts can be easily misinterpreted as not functioning to solve a problem of access. On the contrary, I argue that because litanies of complaint function to align a speaker with the collective, they are actually focused on an assimilationist strategy of aligning disability access issues with broader Russian collective desires. In this way, we will

see that attention to the lives of people with disabilities and to disability theory has much to add to conversations among western scholars about the anthropology of infrastructure, and about minority politics in Russia.

Infrastructure and Governance

Potholes, and the roads that they speckle, are part of - or interrupt - what development discourses, and lately, anthropologists, call *infrastructure*.

Infrastructures are built networks that facilitate the flow of goods, people, or ideas and allow for their exchange over space. As physical forms they shape the nature of a network, the speed and direction of its movement, its temporalities, and its vulnerability to breakdown.

[Larkin 2013:328]

Roads, as elements of the postsoviet infrastructure, facilitate flows of people. Or they fail to do so. And, the moments when they fail inevitably index a relationship of government.

Infrastructure as a term was invented and deployed as part of the twentieth century Euroamerican imperialist development project. Development theory, or modernization theory, and the attendant global economic models, conceptualized industry and infrastructure as precursors to the development of free market exchange and, in turn, liberal nation states. From dams to roads to electricity, the idea of infrastructure was created as a technical term for projects of modernity, for state-building enterprises and neocolonialism (Rankin 2009). At the same time, the Soviet Union developed its own project of imagining and building infrastructure, only this was infrastructure – from housing to public transportation – intended to build socialism (Collier 2011). In this way, infrastructure is always related to the obligation of a state to its citizens, and to imaginaries of modernity. This brings us back to our bumper sticker: As is the government, so are the roads.

Disability theory has long been concerned with issues of infrastructure, and the ways in which barriers in the built environment facilitate or impede access. Infrastructure studies

observe that when an infrastructure is working, it fades into the background. As we have seen in previous chapters, Disability Studies asks, *for whom* is an infrastructure working? Which bodies and ways of moving through space are not supported by a given infrastructure? (Hamraie 2013) Disability is, in a way, a prolonged experience of encountering a non-functioning infrastructure, one that fails to work for you, for your body and its technological prostheses. Moreover, disability studies points out something that cultural anthropology has long observed about material worlds: material environments and social forms are co-emergent. There is no infrastructure nor built environment that was not produced by social attitudes; and, in turn, social attitudes are enacted and reproduced in relation to the material environment.

Indeed, for my interlocutors, social attitudes and material barriers frequently appear in the same sentence as linked and irreducible to separate categories. For instance, the following comment from a Tania, a woman in her mid-thirties with dwarfism:

Well, about my own experience, I can say that there weren't any really major changes that happened in the 90s, like that people would look at me and point and laugh [*pal'tsem pokazivali*], that's still going on. The thing is that, like, the tolerance that we have in society, maybe, yes, somewhere in the big cities, or something, you can sort of feel that. But when I went to Finland and arrived at my friend's house, an old classmate, I went out in the streets, through the city and I felt like I was a person [*chuvstvovala sebia chelovekom*]. A regular person, who exists, I was walking through stores and they weren't following me with a sideways gaze, not at all. I, it was just like the difference between black and white, for real.⁵²

In Tanya's telling, elsewhere – abroad – outside of Russia, infrastructure, patterns of government, and social attitudes are altered all at once. Although Petrozavodsk, nestled on the lake shore in forested Russian Karelia is set in the same natural landscape as the Finnish

⁵² Ну, по себе что могу сказать, особо сильных изменений не произошло, что в 90х, как на меня смотрели и пальцем показывали, так это и продолжается. То есть, как, толерантность у нас в обществе, может быть, да, где-то там в больших городах или что-то, это как-то чувствуется. А, когда я в Финляндию приехала к подруге, к однокласснице, я ходила по улицам, по городу, и я чувствовала себя человеком. Обычным человеком, существом, ходила по магазинам, на меня не косились взглядом, никогда вообще. Я, у меня просто такое сравнение, "чёрное и белое", вот это да.

towns she visited, as a territory of governance, as a plane of infrastructural experience, and as a social realm, it is altogether different.

People with disabilities in Petrozavodsk, like Western disability advocates, ask for whom an infrastructure is constructed. And, when they do so, they frequently present their observations of inaccess in the genre of a litany, as described by Ries. For instance, in the following comment, Rudak, the activist, filmmaker, and rock musician who became a wheelchair user after a spinal injury, begins with a description of a situation regarding accessibility ramps that might exist anywhere, but concludes by asserting that the problem is a specifically Russian one.

The people who are building these ramps, they are doing this so that -- so that the ramp existed. So if they ask them, "Do you have a ramp?" - but not a person with a disability who will ask, but a person - let's say, from some kind of committee, or something like that. They will have documents, on which they will put a check mark [*galochka*]. That - access for invalidov is accounted for [*obespechen*]. But unfortunately, I don't know about other countries, but in Russia, when it comes to building ramps and entranceways, they don't invite [us] as consultants - no one who is a representative of organizations that work with people with mobility impairments [*invalidami pridvigayush'imi*], or people who are themselves wheelchair-users [*invalidy-kolyasnikov*]. They - create ramps that seem like, to them, to be what a ramp should be. They forget to install handrails, or they make a really steep incline, for example, or the ramp is just leaning up against a wall even. How else should they do it? "We'll make a ramp, but invalidi won't come here anyway" [*k nam zhe ne prikhodyat*]. "So, we'll just do it so that it's there." However is convenient for us. NOT so that it will be convenient for a person *s invalidnostu*, but, what's most convenient for me, the store manager. So it may as well be over off to the side, or some ramps come right up to a wall: "The most convenient ramp is one that doesn't interfere with anything."

Probably it's something like, as long as these aren't punished, as long as there are no examples of punishment -- because, unfortunately, in Russia it's not unusual that a law wouldn't work. And no one is afraid of this law. It happens. That's how it goes. Try and figure out for yourself to what extent this law gets enforced. Here is this law, and we follow it about 50% of the time. But for a person who doesn't understand how it should be, he comes along and someone tells him, So, check it out, we have a ramp here. And he says, yes. But no one ever suggests that he should sit in a wheelchair and try to actually use this ramp. And so the guy who made this ramp, he'll never test it. ... This way of doing things, it's every man for himself [*egoistichnyi*]. And - these people think that - it'll never happen to them. That, so, you're sitting in a wheelchair, that's obvious, it's how it's somehow supposed to be. But it's not something that could happen to him. Ever. Not to him, or to any of his family members. And then, when - as we say in Russia, as long as the roasted rooster doesn't bite you in the bum. People wave their hands and say, well nothing is equipped [*oborudovanye*] around here. The very same ones who are doing all of this. So, if there's a way to do it cheaply, to save a little money, then it seems to them that no one's ever going to show up and demand it [a well-equipped ramp].

Here, Rudak presents the case of the inaccessible accessibility ramp as a specifically Russian scenario – although disability advocates from abroad would recognize this tale of woe. Yet, Rudak suggests no resolution or solution. Instead, by gesturing to the temporary nature of the imagined store owner’s own able-bodiedness, Rudak is emphasizing that in spite of self-centered, penny-pinching logic, in fact, ramps are for everyone’s access. It is only ignorant social attitudes that prevent the temporarily able-bodied from understanding that. In this sense, he resolves his litany by aligning his own interests with those of the broader Russian population, bemoaning the bottom line thinking that leads to poorly equipped built environments. Yet, Rudak is one of the most active disability advocates in the city of Petrozavodsk; his ongoing efforts to shift public perception of disability and to pursue renovations are at odds with the constitutive meaning of the litany in question. If he really thought that efforts to change the Russian situation were futile, why would he pursue acts of activism? It may be that he pursues activism in spite of a sense of futility, as a moral commitment.

Infrastructure, Access, and Transnational Development

In the previous chapter and in a recent photo essay (Hartblay 2014), I discuss the proliferation online and in public space of inaccessible accessibility ramps, or, what I call "check-mark ramps". Like the ring that didn't open in the Sochi Olympics opening ceremony, check-mark ramps became a widely circulated internet meme, a way of indexing a deep-seated sense in both Russian and Western publics that there is something fundamentally awry in Russia's capacity to implement infrastructure.

This infrastructural inadequacy is both a joke and a pointed critique. What is it about Russia that seems to be so *backwards*? So goes mainstream discourse in both Russia and the

West about Russian infrastructure. In her account of Russian talk, Ries relates one litany that a speaker resolved with the line, "Russia will never be a civilized country" (101-102). This sentiment both succinctly characterizes the genre, and has important implications for how we understand Russian patterns of complaint to function in a postsocialist, global context.

If we understand infrastructure as always related to development discourses on one hand, and intrinsically to do with access and movement through space on the other, we might consider how these ideas come together. Thinking about access in terms of disability can shed light on ideas about transnational development in Russia.

Discourses of development propose to resolve inequity or "uneven access" to goods, services, ideas, and abstract concepts of the good life (Chua 2014: 15). By problematizing inequity and proposing to "fix" it, development discourse also works to produce the West, and particularly the United States, as a location of "developed" infrastructure in opposition to the "undeveloped" other (Escobar 2011). While much writing about development has focused on the ways in which this logic inscribed neocolonial relationships and hegemonies between the West and Latin America, Africa, and Asia, scholars of the postsoviet have argued that similar discourses produced similarly otherizing logics and internalized oppression amongst Eastern European subjects (Chari and Verdery 2008; Todorova 1997). Russian subjects with a global sensibility are constantly defining themselves around and in relation to a sense of the imaginary better life that is available to average citizens on the other side of the border. The notion of infrastructure as a prerequisite for economic growth come to bear in Russians own explanations for *why the good life has yet to arrive* (Chua 2014) in Petrozavodsk.

Talking about Access

Access, like infrastructure, is an intellectual artifact of a particular Euroamerican discourse that is continuously being exported and applied globally. In particular, it is tied to a global disability rights movement, which seeks to implore global bodies like the United Nations to encourage nation states to implement norms of accessibility. As such, even as my interlocutors spoke frequently in our interviews and in daily conversation about issues of access, they rarely used the terminology of this transnational rights discourse.

The dictionary definition of the global disability advocacy term *accessible* in Russian is *dostupnyi*. Yet Russian speakers rarely used this word in spoken language unless I had used it first; it remained in the realm of official language - reserved for printed text, or reference to regulations and legal frameworks. While an English speaker who is an active disability advocate might frequently use the word “access” or “inaccess” or the conceptual “accessibility” – I rarely heard these terms in Petrozavodsk - and not because people didn’t know what the words meant, but because they were considered to be part of an official vocabulary, reserved for signs, legal jargon, or journalism, and not used in daily conversation. Rather than words like *dostupnyi*, *nedostupnyi*, *oborudivan*, interlocutors tended to use more ubiquitous, simpler adjectives denoting ease of flow: *spokoinyi* or *normal'no*. Occasionally, these are supplanted with the words *udobno* or *komfortno*, meaning convenient, comfortable, easy to use. Even speakers with a great deal of technical expertise used these more colloquial describe conditions of access.

So - it's like halfway passable, we have, I mean at my house there is a separate ramp, and the apartment has been remodeled so that, because the hallways were really narrow everywhere, and the doorways were narrow. So, now everything is like, they planned it out so that it's just fine [*absolutno normal'no*]. I can move without a problem [*spokoino*] through the doors, I can get out to the street by

myself. The thing is that the problem that most people in a wheelchair have is --- umm, that they can't get out of the house, but, thankfully, I don't have that problem.⁵³

- Vera, mid-thirties, wheelchair-user following a childhood spinal injury, mother of two

Well -- look. So -- in general. In general in, for example, a public building, we have to work it out so that, for example, there are two floors in the building. On each of the floors there has to be toilet facilities for *invalidi*. An *invalid* should be able to get from the first floor to the second floor. In some way. So, this could be a ramp. Or, it could be an elevator. ... He -- the person in a wheelchair, or in general a person with limited mobility -- he should be able to easily [*spokoino*] enter any office that he needs to go to. That is, he needs to be able to take care of himself [*sam sledit' nado*]. So, it follows that there are two considerations. For -- like -- You have to figure out the turning radius of a wheelchair. That is, we can't make the bathroom facilities too narrow, because a person has to be able to go in, turn around however he needs to...[quieter] like, so that it would be convenient [*komfortno*] for him⁵⁴.

-Olya, able-bodied architect's assistant, late twenties

I think that, since there's nothing that can be done to fix my condition, in terms of my condition, I could have peacefully [*spokoino*] gone to school with all of the other kids. So.⁵⁵

-Tania, mid-thirties, seamstress and artisanal craft maker with dwarfism

There's this thing called a Sots-Taxi [a van that serves certain social groups, similar to what is called paratransit in the US]... I have a friend who was living in Petersburg and she used this Sots-Taxi all the time. But the conditions of the Sots-Taxi are that it only takes people to offices where you receive social services. ... But she wanted to go to a night club. They assigned her a route -- no, she went to the theater - that was it. So where she lived wasn't far from a medical clinic on one side, and not too far from a cemetery on the other side. So in order to get to the theater, she had to go from the clinic to some kind of social service destination. So my friend says to me, "Today I took a really fantastic trip to the theater... This was my route: clinic, graveyard, theater, and then on the way back, graveyard, clinic... [laughs] Not bad! [*Normal'no!*] ... But why can't she order a taxi to go straight from her

⁵³[Когда пока я была маленькая, еще родители мои меня поднимали **нормально** по лестницу, потому что, лифта не было... вот. А-а, когда я подрастёрлась там, до семнадцати лети, повесить меня стало тяжелее, и родители как бы старее.] [...]

Но - пол-доставки, имеем, что у меня дома пандус отдельный, и дома сделано перепланировка, чтобы, потому что, проходы очень узкие везде, двери узкие были.

Вот, а теперь, как бы, подумали абсолютно нормально. Спокойно у двери двигаться, могу сама на улицу впускаться. То есть, проблема, которая у большинства людей на колясках - м-м-м - что они не могут выйти из дома, у меня, в счастье, нет.

⁵⁴ "А -- в любом. В любом общественном например здании - мы должны учить, чтобы - например, в здании два этажа. На каждом из этажей должен быть санузел для инвалидов. Инвалид должен подняться с первой этажа на второй этаж. в каком том образом. И этот бы пандус. И этот бы лифт. ... Он -- человек на коляске, во обще маломобильный человек, он должен **спокойно** заезжать в любой кабинеты, куда ему нужно. То есть с этом сам следить надо. За очередной, получается - двоих проемов. За -- как? Нужно учитывать радиус поворота коляске. То есть, мы не можем сделать слишком тесный санузел, чтобы человек мог бы выехать туда, развернуться как ему нужно, ... [quieter] вот, чтобы ему было **комфортно.**"

⁵⁵ "По моему заболеванию исправить ничего невозможно, моё заболевание - я могла бы спокойно учиться со всеми детьми. Вот."

house to the theater? [imitating her friend] "Why would I need to go through the graveyard to get to the theater? Are you telling me that this is normal?!" So I ask my friend, "Well, so how was it?" And she goes, "Ohh, not bad [*normal'no*]..."⁵⁶

-*Anya, mid-thirties, psychologist, wheelchair-user*

In these examples, the word *spokoino* most frequently means "without a problem," in the sense that an experience or movement is free of barriers. The architect's assistant describes a wheelchair-user moving through an accessibly designed space *spokoino*, a woman looking back on her experience of segregation based solely on her short stature complains that she could have *spokoino* attended her neighborhood school. Frequently, in these examples and others, my interlocutors used the word *spokoino* - usually translated as meaning calmly or peacefully - to describe experiences of access, or to illustrate an oppositional image of imagined access as a counterpoint to an existing situation of inaccess.

As we have seen in previous chapters, access and infrastructure are not just the implementation of a particular technology. Rather, it is a complex network of heterogeneous actors that must come together to facilitate what Moser and Law call "good passages," moments when components and networks fit, and movement through space *works*. As Moser and Law write, addressing a disability studies audience, "to repeat the standard lesson from STS: if the networks are in place, if the prostheses are working, then there is ability. If they are not, well then, as is obvious, there is dis/ability. [...] Dis/ability is about specific passages

⁵⁶ "Соц-такси... У меня подруга жила в Питере и очень часто пользовалась этим соц-такси. А условия у этого соц-такси такие, что они возят людей только в учреждения социального обслуживания... А ей надо было уехать в ночной клуб. Составили ей маршрут... Нет, она в театр поехала – точно. Она с одной стороны жила недалеко от поликлиники, а с другой стороны она жила недалеко от кладбища. Чтобы поехать в театр, нужно было сначала от поликлиники доехать до какого-то социального объекта... Подруга мне говорит: « Я сегодня шикарно ехала в театр... Маршрут был таков: поликлиника – кладбище – театр (и обратно) – кладбище – поликлиника... (смеётся) Нормально!... А почему я не могу заказать такси сразу от дома до театра?... Зачем мне через кладбище ехать в театр?... Это нормально скажите?... Спрашиваю подругу: «Ну и как тебе?» Она мне отвечает: «О-о-о-о... Нормально...»"

between equally specific arrays of heterogeneous materials" (1999:201). Interrogating Russian colloquial language in my interview transcripts, I find that my interlocutors speak about good passages as peaceful, unhindered, comfortable, and, normal.

Figure 27: A Table of Russian Words for Access

Russian words for Access	
Formal translations/Official lexicon	Colloquial usage
<i>dostupnyi</i> accessible	<i>udobno</i> comfortable, convenient
<i>oborudivan</i> equipped	<i>komfortno</i> easily, comfortably
<i>bez bar'ernaia sreda</i> barrier-free environment	<i>spokoino</i> easily, peacefully, smoothly
	<i>normal'no</i> without problem, pretty good, normal

Spokoino - unlike *dostupnost'* or *nedostupnost'* - is a common Russian word, and one that is not designated as referring specifically or officially to disability. It was often used not only by people with disabilities but by other residents of Petrozavodsk to refer to experiences in Finland in which a common place experience such as taking the bus, walking on the sidewalk, or driving over the roads went unexpectedly smoothly.

Spokoino, often translated as calm or peaceful, can also mean placid or tranquil, as a calm body of water, smooth and uninterrupted. Interestingly, in Dal's dictionary, the entry for *spokoi* (*spokoinost'*) includes the synonyms *spokoinoi*, *udobnoi*, *lovkii*, calm, easy, nimble or efficient. *Spokoinoi*, the adjective, is listed as

A spokoinaia road, even, level or flat; a spokoinaia carriage [and here he uses the word koliaska, which in current usage means wheelchair or baby carriage, in Dal's definition, meaning, simply, something that rolls⁵⁷], free of jumps and jolts. A spokoinoe place, comfortable⁵⁸.

In this sense, the constellation of meanings - in which the word refers to comfortable, peaceful, and unbothersome surroundings, especially built environments and infrastructures - has existed at least since Dal's time, the second half of the 19th century. This association between access in its current incarnation and a more general sense of freedom from disturbance while moving through space, or across infrastructure, of course reminds Russian speakers of the common refrain - *Russia has two problems: idiots and roads.*⁵⁹ In the Russian imaginary stretching back to the 1800s then, roads are perceived as a problem. Whole swaths of text in Gogol's *Dead Souls* are devoted to descriptions of travelling over muddy, rutted roads in horse-drawn carriages. In this way, even reflected in a presidential comment, maligning Russia's roads is both a national pastime, and somehow linked to some amorphous concept of prototypical, essential Russianness. By which I don't mean that - as an anthropologist - I believe that there exists some definable quality of "essential Russianness," but rather that in popular imagination or everyday discourse, discussion of potholes and poorly cared for roads indexes a deeply rooted shared mythology about the governance of the Russian nation and the national territory.

⁵⁷ <http://slovardalja.net/word.php?wordid=13621>

⁵⁸ "*Spokoinaia doroga, rovnaia; spokoinaia koliaska, netriaskaia. Spokoinoe pomeshchen'e, udobnoe.*" Dal, V.I. The Explanatory Dictionary of the Living Great Russian Language. 1880. via Dal's Dictionary Online. <http://slovardalja.net/word.php?wordid=38852>

⁵⁹ This refrain is variably attributed to the writer Gogol (who indeed wrote much about driving carriages over rutted and potholed roadways), to the historian and writer Karamzin, and to others. The Russian internet is rife with circular blog posts pondering the origin of the phrase. I should also say that there is a great potential for unpacking the deployment of "idiots" here, specifically, that morons or dumb people - *duraki* - is seemingly harmless, but also related to a projection of intelligence or illogic as a "problem" that society must resolve or work to resolve, just as poor roads are. But I will save that for another paper.

Normal'no is a highly generalizable word that that can be deployed in a wide variety of conversational contexts, either wholeheartedly or sarcastically to mean, "not bad at all" or "the same as usual" (which, given the implication, could mean quite bad indeed). However, in Anya's tale of the Sots-taxi, it takes on an inflection that is related to a concept of good passage. Moreover, her narrative doubly implies that access, or normal or good passage, is out of reach for her and her friend. On the one hand, it is out of reach to them as wheelchair-users who rely on a publically funded social service for transport (and American paratransit-users would be happy to corroborate this position). As Fehervary (2013:14, 27, 40), Zavisca, and others (Yurchak 2006; Pesman 1999) have argued, this usage of '*norma'ino*' references an imaginary Europe of modernity. In Fehervary's depiction, the discourse of normal in socialist and postsocialist Hungary references a fantasy of modernity that exist abroad not abstractly, but expressed through material designs of living space and consumer objects. To call the material stuff of life was part of a "logic by which socialist material culture became emblematic of a unitary state's low regard for its citizens and failure of its economic system ... [Western] consumer-oriented design and properties were not just evidence of a better production system, but they served as icons of a more human political and economic system, a place where living a 'normal' life was possible" (2013:137). Anya's description of the absurdist bus ride posits actual normal conditions of travel or good passage as being out of reach because of the essential *Russianness* of the situation. Her description of the sots-taxi is related in the genre of the Russian Tale, as identified by Ries, punctuated by irony, humor, and absurdism.

Figure 28: Table: Theoretical and Colloquial notions of Access

ACCESS IS...

AS A THEORETICAL CONTRIBUTION OF DISABILITY STUDIES/INFRASTRUCTURE STUDIES	AS AN EMIC RUSSIAN CATEGORIES RELATED TO RITUALS OF COMPLAINT
<i>A networked assemblage of heterogeneous bodies, objects, and meanings: no item of assistive technology works in isolation</i>	<i>smooth, peaceful, normal</i>
<i>“good passage”</i>	<i>that which configures infrastructure</i>
<i>a confluence of objects, bodies, and events that is enabling for particular people, all people, or one person</i>	<i>always contingent on a relationship to power</i>

Access and Infrastructure

Geographies of urban space have long observed how particular configurations of the built environment belie spatial relations of power. The built environment both produces and reproduces social relations, and social relations in turn produce the built environment.

This dialectical relationship is not only an element of western critical theory, but also was at the core of the Soviet constructivist enterprise. By building the right physical environment, Soviet planners, architects, and designers surmised that they might in turn produce social relations and subjectivities more conducive to socialism.

Soviet infrastructure was thus built with a centrally planned logic intended to benefit the collective over the individual, to maximize the productive capacity of workers, and to facilitate communalism and interdependencies that were imagined as conducive to building a socialist consciousness (Collier 2011).

This brings me back to pothole talk, or, rather, how I think that pothole talk and inaccessible accessibility ramps are related.

One way to understand the problem of inaccessible accessibility ramps or potholes in Petrozavodsk is to consider the lack of accountability of the local authorities in terms of implementation of building code norms. Indeed, this is what Anya's litany about ramps at the town hall but not at her house - by now familiar - seems to describe: the government, ineffectual as always, has failed to implement a network of access. Ramps become de-contextualized symbols; their symbolic meaning is decoupled from their purported use. Without an infrastructure to facilitate passage to or from the ramp, the ramp itself is rendered useless to a wheelchair-user. Yet, the symbolic function of the ramp as a symbol of modernity, of progress and development, of democracy and freedom, of movement and social participation, of public space, of western values, remains intact.

When Anya delivers her litany, she speaks not only as a wheelchair user complaining about her government, but also, following Ries, as a moral person, relating her indignation through an example of absurdism: an accessibility ramp to a pharmacy when she can't get out of her house. As a discursive performance, her litany also serves to align her interest, as a wheelchair user, not with other wheelchair-users as a minority group pursuing a solution, but with the imagined *narod* maligned by *vlast'*. Even as Anya, in other moments from the same interview positions herself as a self-actualizing individual, or as an advocate for disability issues, she routinely returns to speech genres that situate disability not as a minority identity, but as secondary to a deeper identity as a member of the Russian *narod*.

Indeed, one of the functions that Ries identifies in the folk habits of Russian talk is a tendency to create an imagined essential Russianness in opposition to the West. In fact, this was an ever-present component of infrastructure talk - both about potholes and about ramps - during my fieldwork in Russia. The mythos of a Russian system in which the people are

exploited by the government and so suffer, was repeated again and again, inscribed and reinscribed. Protestations on my part that ramps are often poorly built in the US as well, or that potholes are a problem everywhere were waived away. These comments were outside of the speech genre.

Resisting the possibility of a functioning infrastructure, and instead observing infrastructure as always produced in terms of special interests or government whim was also a way of rejecting empty promises in narratives of democratization and development. By describing a state of Russian exceptionalism, in which roads are always worse on the Russian side of the Finnish border (they are), and ramps are always empty symbols (they sometimes are), Russians also align themselves with a moral universe in which development and good passage comes at the expense of other kinds of sacrifice. Talk that reproduces Russia as a territory of inaccess is talk that reproduces Russianness as outside of a Western telos of modernist development.

People with disabilities in Petrozvodsk, when speaking about experiences of inaccess, rarely propose possible solutions, or ways to “fix” the Russian infrastructure. Instead, they offered descriptions of interrupted flows and personal discomfort that, rather than describing people with disabilities as a special interest group, or a minority class deserving of special treatment, instead aligned the speaker with a collective Russian experience. Russian talk – both among people with disabilities and amongst the general population – frequently recounted experiences of inaccess and inadequate infrastructure. These litanies and ironic asides gestured to Russia as a unique territorial space defined its contrast to an imagined European modernity. And, they sketched a camaraderie and community amongst those who suffered the bumps and jolts of *takie dorogi*, of Russian territories of inaccess.

Finally, I want to suggest that not only does the academic project of applying the theoretical lens of accessible infrastructure to the Russian context offer new insights for how we understand Russian modes of complaint, it also offers a new emphasis to disability studies discussions about access. Specifically, the Russian emic concept of barriers and infrastructure always already indexes a relationship to power, or that which configures infrastructure. Because US-based conversations about disability access are so rooted in what Ries describes as the uniquely American penchant for problem-solving, citizen complaints are produced as actionable, and met as actionable. This mode of communication and complaint underlines a fundamental belief in the democratic nature of public infrastructure, and accountability of government. Yet, it also obscures the ways in which the built environment is configured by those in power as infrastructure as part of a strategy of governance and profit-making. Certainly, cultural geographers have described the politics of space, and the Foucaultian insights about biopower, so the relationship between development, infrastructure, and governance is not news to scholars.

I want to suggest that the de facto location of US discursive practice as the normative model for activism and social change may lead global advocates to miss subtle modes of allegiance building and imaginaries of other possible worlds. The Russian rituals of complaint related here, on the one hand very literal objections to substandard infrastructure, also carry performative meanings as ritual communication that help speakers to forge social ties and imagine other possible configurations of power. When disability studies asks "*for whom* does infrastructure work?" relations of power are always invoked. However, cultural training may predispose western theorists to think of the systems of oppression structuring the "for whom" as always related to minority identities; when Russians point to *vlast'*, they

emphasize the *moral* corruption of pursuing financial gain for its own sake, or power for its own sake. Infrastructure works *for* those in power, an insight which might be useful for Western disability advocates to explore further at home.

Figure 29: Photo of Nevskii Prospekt in Petrozavodsk, shortly after it was repaved, fall of 2012. My photo.



Figure 30: Photo of Petrozavodsk neighborhood roadways. Snowy dirt driveways run between apartment buildings, garages and houses under a winter afternoon sky.



Figure 31: Photo: Pothole in Central Petrozavodsk. A small sedan inches its way through a deep rut, merging into a traffic jam of buses and other vehicles on the main street of the city, as pedestrians look on. My photo, spring 2014.



Figure 32: Photo of a driveway in springtime, speckled with potholes.



Figure 33: Photo of a snow-covered ramp. A beautifully constructed ramp outside a new municipal swimming pool sits covered in snow, its intended use for wheelchair access forgotten (this photo was sent to me by the mother of a child who uses a wheelchair).



Part III
Performing *Invalidnost*'

CHAPTER VIII:
"WE HAVE ALWAYS BEEN GUINEA PIGS":
BECOMING *INVALIDI* IN POSTSOVIET PETROZAVODSK

Act One

On a Wednesday in October, 2012, I walked three fourths of a mile down the hill toward the lake, along the busy city blocks, to a repurposed kindergarten where the art therapy group met. The group gathered in the room are my age, in the late twenties and early thirties. Three of those present are the professionals – the social workers and psychologists who facilitate the program. The other eight are people with disabilities, unemployed. The brightly-colored van had made its journey through the city, picking up those who use wheelchairs. Two, Sveta and Max, who walk, came by bus. Vakas is waiting for someone to take his coat off, while one of the social workers helps Alina, seated in her wheelchair, to remove her hat, gloves, coat. "Vakas," I ask, when he shuffles over to me and gestures that I should give him a hand, "You can't do it yourself?" "Of course he can't!" tut-tuts the psychologist, upset that I would present him with such a question, "his brain injury has left him with limited mobility!" Vakas and I smile at each other. We are both at the mercy of medical facts and professional expertise - he as an *invalid*, a person with a disability, me as a foreigner and outsider.

This scene unfolded as part of an art therapy project for unemployed adults with disabilities in Petrozavodsk, Russia in 2012. The group met weekly, and had taken a photography lesson, a drawing lesson, and now was preparing for their recital. As a visiting

ethnographer, I was welcomed into the fold by the group members for the novelty factor - Our American!

The art therapy group was funded by a federal grant, disbursed to a local organization. The project's facilitators are charged with implementing the program.

But, although the social workers are the impetus for the meetings, they are really the newcomers to the group. A core contingent of the art therapy group - Alina, Vakas, and Sergei - have been the target of social programming for *invalidi* in Petrozavodsk since childhood. As children growing up in Petrozavodsk in the 1990s, they were often grouped together. Alina and Sergei were born with Cerebral Palsy; Vakas was hit by a car and suffered a traumatic brain injury when he was nine that left him with limited mobility and slow speech. Although their respective parents had little in common in terms of profession, background, and hobbies, they were all struggling with making sense of how to obtain services and support children with significant disabilities in the crisis climate of the 1990s. Over the years, the families have come to know one another and a rotating cast of NGO workers and other professionals - local or international - working in social services programming in the city.

This chapter addresses changes in postsoviet civil society through the lens of the experiences of these three interlocutors, their families, and the social service and NGO workers they have encountered over the years. I take an ethnographic approach to observe how social services play out in the lives of Russian citizens, especially citizens with disabilities. Although NGOs have frequently been categorized as part of "civil society" - the normative concept of social institutions that are neither state nor private - research in the postsoviet social service arena has shown that for many citizens who are working in or with

third sector NGOS in Russia, these organizations are not necessarily distinct from the state, but may be interchangeable with similar state-funded social service programs (Kulmala 2011:51). This chapter uses an ethnographic approach to sketch a history of how social service provision for people with disabilities has shifted continuously since the collapse of the Soviet Union in a way that ultimately brings citizens to consider NGOs as intrinsically linked to the state. This adds to a significant body of scholarship that uses a feminist ethnographic approach to document lived experiences of NGO culture in the former Soviet Union, and problematize the category of civil society (Phillips 2013; 2011; 2005; Kulmala 2011:52; Hemment 2007; Sundstrom 2006; Rivkin-Fish 2005; Caldwell 2005; 2004).

Although the concept of civil society was a core element of democratization theory that significantly impacted how foreign governments and international aid organizations invested development funds in Russia in the immediate post-Soviet period. Since that time, based on empirical research, scholars have raised important critiques about civil society as a theoretical construct, category of the social, domain of practice, or technology of governance and domination. Feminist ethnography has critiqued the presumed distinction between public and private spheres that is the foundation for the political science concept of civil society; others have observed that the notion of civil society was used as a technology of development when Western organizations rushing to democratize Russia in the 1990s insisted on programming to develop and support civil society, or *grazhdanskoe obshchestvo*; finally, following Foucault, some scholars have observed that civil society can also be deployed as a tool for governance, a mode of normalizing a political system in which citizens, rather than seek provisions from the state, ought to organize from the "ground up" to solve local problems independently ().

Building on previous scholarship, we might identify and describe three stages of postsoviet NGOs: (1) the early-late mid 1990s, characterized by a sense of chaos and local stop-gap organizing; (2) the late 1990s-2008, characterized by growing professionalization and capacity of Russian NGOs, bolstered by financial and practical support from international actors; and (3) 2008-the present, characterized by a reconsolidation of power by the state, or government crackdown characterized by the foreign agent law and what Human Rights Watch has characterized as other attacks on civil society and democratization (HRW 2013b). This "third stage" of post-Soviet NGO culture emerged in full force during 2012, the year when the fieldwork represented here was conducted; in this way, this research represents a first attempt to grapple with this new "third stage".

My core argument here is that by attending to the voices of people with disabilities themselves, a very different picture of the shifting field of NGO culture, and particularly of Putin's reconsolidation, comes into view.

Likewise, by telling these stories, this paper also addresses the ways in which disability identity is formed through performative lived interactions. Institutions, including governmental and non-governmental organizations, reproduce a social concept of *invalidnost'* as a distinct manner of contemporary Russian citizenship. Following Pierre Bourdieu, this paper suggests that the changing institutional infrastructure in Petrozavodsk acted as a "structuring structure" and had specific outcomes in the way that this group of people with disabilities has internalized certain ideas about disability identity, or what it means to be an *invalid*. That is, they simultaneously insist on refusing pity and emphasizing their own independence and sociality; yet, they also anticipate the injustice that to be an

invalid means to be marked as socially different, and, systematically excluded from mainstream systems of education and employment.

In order to describe this history, I will first briefly discuss key background topics, and then proceed to review the life history accounts of these three interlocutors, as well as narratives shared with me by parent-activists also in Petrozavodsk. I highlight these narratives because I find them to be representative of my broader sample that includes multiple in depth interviews as well as participant observation with over 70 interlocutors.

Another scholarly contribution here is the use of the lens of disability or *invalidnost'* as a category for investigating NGO culture, a tactic which has been applied in the case of Ukraine by Sarah D. Phillips (2011; 2009) (and to some extent Adriana Petryna (2002)), as well as Elena Iarskaia-Smirnova, Pavel Romanov (2006), and Michael Rasell (2013), and Meri Kulmala (2013) among others. In many ways, this paper tells the "next chapter" - the third stage status quo in the story of postsoviet civil society.

Act Two: Guinea Pigs

The view that postsoviet NGO culture has gone through three stages is reflected in interviews and participant observation with interlocutors in Petrozavodsk. To address this, I will review the process by which Sergei came to self-identify as part of a particular cohort of *invalidi* by the time he participated in the art therapy seminar at a local organization. Along with Vakas and Alina, this troika differentiated themselves from other members of the art therapy group by two criteria: age and nature of disability. But the key element of their shared association was a history of receiving services together.

This cohort was part of the first generation of children to attend a preschool program for children with disabilities. They then spent their childhoods attending a special education

school in a remote region of the city. Mainstream education would not be introduced to Petrozavodsk until 2006; in the early 1990s, though changes were already unfolding in the way that Petrozavodsk social attitudes and social services infrastructure related to people with disabilities.

Sergei recalled:

So it was, right away -- after I finished kindergarten, which was also a special program for children with disabilities, so -- um, that kindergarten, I was in the first class that we had. And I, in general, I feel like throughout my whole life, we've been doing experiments on me - I am always surviving experiments!

C: (laughs) Ahh - you're from the very first group that went to the kindergarten?!

S: Yes - yes. So this kindergarten - this kindergarten had just opened, the special education one. So. I -- I went there. And when the special kindergarten had a graduating class, it graduated the children to the specialized school. So. To the *internat*. [...] everyone from the kindergarten was designated [by the PMPK] to go to the *internat*. So. Then there was the first non-profit organization [*obschestvennaia organizatsia*] also, not long after it was started. So, it was ongoing. Everywhere everyone was doing experiments on me.

Sergei attended an *internat*, a boarding school for children with motor impairments in Petrozavodsk. Because he was from one of the "city" families, he was able to go home each afternoon, a fifteen minute bus ride from his house, while those children whose parents lived outside of the city often only saw their families at holiday recess.

C: So - were there ever moments during your childhood when you asked, why do I go to the *internat*? As in, "the neighbors go to the neighborhood school, but, I go to the *internat*." Did you ask about it? [...]

S: (immediately) No. I mean, there somehow wasn't -- there wasn't (not sure how to put it) -- it was just considered normal (laughs, a little embarrassed). Actually, it was the opposite - I thought it was good that I got to go to school. And so what if I go to the *internat*, it's still a school!

While Sergei was happy as a student at the *internat*, other interlocutors, like Tania, especially those whose families lived far from Petrozavodsk, disliked it and wondered why they were not allowed to attend their neighborhood schools. Policy toward the education of children with disabilities continually evolved throughout the 1990s, and by the early 2000s, there was a new push by parent activists to pave the way for mainstream schooling.

Nastya, a psychologist and assistant director of an early intervention center in the city

called Elements helped me to conceptualize the shifting array of services for people with disabilities in the city since the 1990s. While Elements started out as an informal parent organization, then became an official non-profit, and finally, a municipal agency, all the while providing a similar array of services for children with disabilities and their parents, with a consistent staff and leadership. Nastya described shifts in attitudes towards disability in the city between the 1990s and 2012:

Little by little the awareness of the parents and the understanding that they have to accept such a child, and not be ashamed, but usher him into life, to give him as much as possible whatever services are available, so that he would develop and could be integrated into society. The active (*aktivniye*) parents of such children got together and mounted a lawsuit so that their children should go to kindergarten, but while it was being deliberated, the children already outgrew the pre-school age, and they went to school. That is these parents appeared who decided to move forward and assert their rights. And now, today, when parents come to us, it seems to me that their mindset (*psikhologia*), and their understanding of the situation has changed a little. And having worked here for so many years, I can see that there are already a lot more children who you can catch sight of in the sandbox or out for a walk in their strollers/wheelchairs. But before that kind of thing happened very rarely, that is they [the parents] really felt ashamed and were isolated. Now parents are really actively involved with these kind of children, they understand that a child needs to live and to be integrated. The paradigm has changed.

This means that for my interlocutors with disabilities, the landscape of services and social infrastructure that they experienced has already begun to fade.

This changing institutional landscape and the resulting difference in experiences and social identity as *invalidi* means that subsequent generations (or even young people just a few years younger) have had vastly different experiences than my core cohort who were in their early 30s when I was conducting my fieldwork.

Sergei:

If before, there was a tendency, if you had *invalidnosti*, then you go to the *internat*, like everyone else with *invalidnostu*. Because before the thinking was that it would be difficult for such people to adapt to a general school environment, because they are not *like* everyone else. So that's what they thought previously. And so they sent everyone right to the *internat*, so that there wouldn't be any questions or problems. But now -- it's come around to a situation where, if you communicate well (*khorocho razgovarivaesh'*), regardless of whether or not you have difficulty getting around (*plokho peredvigaesh'sia*), the important thing is that you can hold a conversation (*obshat'sia*) and get on (*dogovorit'sia*) with people. Then, in that case, you can attend the general education school. And those kinds of kids -- now they're assigning to the regular schools.

And so the *internat*, then is left for those kids who, due to their illness/affliction (*zabolevaniye*), can't

communicate, and don't understand, for example, if you try asking them a question. These kids are the ones that have started going to the *internat*. Of course -- everything's different. Everything's totally changed. [...]

Sergei articulated the changing paradigm in this way:

There are different opinions. Because some people think that it's good when a person with special needs [*s osobennostiami*] - um - well, with *invalidnostu*, yes with *invalidnostu*, when they send him to the mainstream school. And then he more or less adapts. It might be hard for him, or, maybe - well, he has to adapt some how. And then there are those people who really take that perspective. But then some parents really are of the opinion that -- what for? Because they think that, here in Russia [*u nas*], with our government [*gosudarstvo*], um... people have hardly seen people with *invalidnostu*, right? In our time it was even embarrassing to talk about it [*stidno*]. Um, they more or less didn't talk about it. So, for that reason, well, parents have different opinions.

He felt that for himself, he felt most comfortable in these protected environments.

a person *s invalidnostu* -- so say they take him in the mainstream school, right? And at that point, maybe they're not even thinking about the fact that it might be really hard for him there. Um, because *u nas*, we, in the first place - well, we don't hate people *s invalidnostu*, they don't *hate* them, but they are somehow hidden away from society. So, because of that, it will only be with difficulty that they accept him at the ... mainstream school.

[*at the internat*] there was a sense of stability. Yeah. ... It didn't seem like -- for us it was joyful, life was interesting. We celebrated New Years together, and -- um, there were holidays - creative projects, crafts, different kinds of concerts, dancing. Everything. We really had a full and satisfying life.

Sergei recalls his childhood at the *internat* fondly. He feels conflicted about the changed landscape of educational inclusion practices in Petrozavodsk. On the one hand, he recognizes that his segregated school experience led him to identify as an invalid, separate from his broader peer group, and he can't imagine another way. On the other hand, in spite of all of the experimental programming, he has not succeeded in finding work as an adult, and he lives with his parents with no plans to leave or marry.

Following high school, both Sergei and Alina participated in the first class of students to enroll in a charter initiative to establish the first inclusive course for people with disabilities at the local teacher's college. Sergei recalled:

And now, after high school, in 2007, right, in college they also organized an experimental group - of people with disabilities who participated in the coursework at Petrozavodsk Pedagogical College. And I ended up there, again, as part of the very first group, and it turned out that once again, it was an experimental situation, What happens if people with disabilities get higher education. And then after I graduated, the whole program was free for me (*blagopoluchno poluchaetsia*), only of course, without the grant money, without the support for the project, of some kind. Because, [pause] in the college, the

classroom was renovated for us, Schnitz, right, I think, a philanthropic (*blagotvoritel'naia*) something or other, from Germany, I think. So, they renovated, and then, from that point on, it just continued, only without support. There was - the college had invited specialized workers, they invited social workers, and - individual professionals who work in that sphere, with invalidate. And... they still work there. So, we still meet up, even after finishing college. We meet up every now and then, like three times a year.

[...] So... I went three years full time to college.

Sergei, Alina and a few others in their group again took on the role of experimental subjects.

The international support of a Swiss grant-making organization that made possible the renovation of the first floor of the school and the launch of the program seemed a prestigious and progressive opportunity. But, for the ground breaking students who went to the college as the first class of *invalidi*, the experience was challenging, socially strenuous, and offered mediocre results. Sergei's description in particular emphasizes the ways in which the move to offer degrees to people with disabilities was one of mandated desegregation. Sergei recalled the timbre of social interactions with peers as stressed.

I asked Sergei on one occasion about his own thoughts regarding mainstreaming. He had talked with me previously about his conflicted feelings regarding the changes to the education system since he was in high school - today, students with disabilities like his might go to a mainstream school, or more likely, complete high school through a distance learning program. Sergei's thoughts about attending a mainstream school were colored by the expectation that he would have been socially excluded if he had done so. He presented this information as a matter of fact, rather than as supposition, or as a reason for pity or self-pity. His perception was informed in part by dominant narratives, but also largely by his own experience attending college with his nondisabled peers.

S: I haven't had that experience, of going to the mainstream school, of getting tossed into the crowd [*volivat'sia v kollektiv*]. The only example I have is that in college, we had our cohort, and -- I went to class with a group that -- besides me, there were, I think three people *s invalidnostu*, and all the rest - we had 30 people -- all the rest were *zdorovy* [normal/healthy].

So... I wouldn't say that we had a *friendly* relationship. With these people. But, you could say that we were *neutral* in our attitudes towards one another. That is, people weren't cruel, there wasn't a sense of

cruelty, there wasn't really anything, and it also wasn't friendly. It was just like a *meeting*. [...]

Maybe it's just that people when - I was already old enough to know what was going on, that you don't necessarily have to have friendship, or else some kind of really close relationship. For me, what's really important is that - we are fine with one another [*my adekuatno drug drugu*] ... like, maybe we asked one another for advice on something, or once or twice called each other on New Years. Wished each other a happy holiday. But all the same, if it's nothing more than that, it's not the end of the world [*pereraslo*]. Or -- or else maybe it was just that all we had was three years together, and so, maybe if we had gone to school together for twelve years, then maybe, of course -- wee-e-e would have gotten to know each other better. But this, just three years, it didn't work out that way. But it's not too bad [*ne strashno*]. The main thing is that -- everyone acted more or less fine towards me.

C: [sad laugh]

S: Yeah. ... And then, not everyone will be nice, you know? As much as they put up with [*ugodish'*] you, it's pretty much certain that *someone* won't like you for some reason. ... so. But going to school [at the *internat*], I have good memories of that.

After university, Sergei took part in still another experimental program with the bureau of employment. Incentives were offered to employers willing to take on an employee with a disability for a new position for a period of six months. The position was subsidized, so that the disabled worker was paid, at no expense to the hosting organization. Sergei did two such placements, and still works occasionally from home on projects for one of those organizations. He described the project:

I -- I, well, like I said already, I am a subject for experiments. They're doing experiments on me all the time. [C laughs] So, this time, I ended up in this program. That at first I was with the employment agency [*sluzhba zaniatnosti*], after I went to my studies at the college, the employment bureau ran a project [*provodila aktsiu*], "Finding work for qualified young people" [*trudoustroistvo dlia molodikh spetsialistov*]. After finishing my degree, for the period of a year, I think it was, I was supposed to find a job. During this time the employment bureau paid your wages [*zarplatu*]. So [...] the money came from the employment bureau, to that employer, and then to you. [...] they were thinking about it in the sense that the employers would, after that first half year, start to pay your salary themselves. You see? After half a year they would begin to pay the *invalidam* money themselves. But - well, as it worked out, it didn't work.

On the one hand, this project offered interesting possibilities. It allowed a governmental agency to subsidize nongovernmental and for-profit institutions if they applied to host a disabled worker. It helped Sergei and others gain valuable work experience. However, it failed to result in meaningful employment: although Sergei does still do piecemeal work from home for one employer, he is not employed full time, or in the workplace. Sergei

asserted that he is glad he participated in the program; however he is also clear that the program didn't deliver all that it promised.

Act Three: The organizational infrastructure

The continuous shifting in programs and services that Sergei and his cohort experience does not come about accidentally. Rather it was the product of concerted organizing on the part of local NGO workers, parent advocates, and international agencies. The same story can be traced through the life of several organizations and engagement of parent activists in the city throughout the same time period - from the early 1990s to the present.

One organization, which I call Elements, is particularly illustrative. It had become an *offitsiyalnoye uchrezhdeniye*, or an official facility, through which the city government directed funds to provide services to families with children with disabilities. By the time that I was conducting fieldwork in 2010, Elements had two locations in the city, where children could attend summer camp, speech pathology, and receive developmental psychology and attend art and music therapy. By 2012, they had opened a third location in another region of the city, and were also receiving domestic grants to run multiple programs, including an art therapy group for mothers of children with disabilities. Because the director of the organization remained one of the original mothers who founded the informal association in the 1990s, there was an element of continuity, not only in name, but in mission, to Elements's activities. At the same time, the organization's status as a facility of the city's department of education lent it a different legitimacy or official tone. Specialists were hired and made their careers out of the office.

The assistant director at Elements explained her own understanding of the organization's history to me in the summer of 2012. As a trained psychologist, she came to work in the organization not as a parent advocate, but as a young professional looking for a job where she could grow and see the effects of her work.

In our documents it says [that the center was established in] 1997, because that was the moment when it all came together. There already was one NGO [*obshchestvennaia organizatsiia*], where parents would get together and talk, and it was time for that to progress to the next level. So an organizational initiative first has to come into being, and then to [be registered with] the state [*idti k gosudarstvu*]. But the relationship with the state had already started to change, social services [*zashita*] in Russia had started to actively develop, starting in the 1990s. This included protections for senior citizens and disabled adults. And so as the desire mounted, people started to come together in NGOs [*obshchestvennyye organizatsii*], and carry out their initiatives. The administration of the city supported this trend [*napravlenie*] and our center [*uchezhdeniye*] was created. In 1997, they started out working with parents here. Little by little, the staff of specialists began to grow, and eventually came to be a staff of professionals with specific expertise and with corresponding work assignments. But at the beginning it was the parents themselves who did everything: they were the ones who knew or figured things out with their children, and then inserted them into the working practices of the center. But in time, as things progressed, a more formally and academically oriented approach appeared, and they started to incorporate qualified specialists, and a new form of work appeared, which, in time, they are changing all over again. So the thing is, that what was happening in 1997 has already become a thing of the past, and we have moved on to a new phase of development, because everything changes.

Another organization, known as "the Weekend School" because the members of the group - families with children with disabilities - for many years would meet on Sundays, followed a very different trajectory. While Elements affiliated itself with the state, the Weekend School had long received small and piecemeal grants from foreign funders -- money to buy computers and host an online magazine for teenagers with disabilities; money to host a two-year project promoting independence, so that children with disabilities learned household skills. The group also acted as a support network for parents, and organized outings to museums or parks. They partnered with a local outdoor adventure club for teenagers, and with funding from Finnish donors, hosted a two-week-long summer camp for kids and teenagers with disabilities at a summer camp facility outside of the city. Living in cabins and swimming in a lake left a great impression on the participants; nondisabled teenagers from the outdoor adventure club were tapped to volunteer at the camp.

Unfortunately, by 2012, the couple who had run the organization for years - a vocational activities educator and a psychologist - were aging, and no longer as able to keep up with younger families and children. With democratization projects falling off as Western governments shifted priorities, grants for social projects were less available than they had been in the early 2000s. But a network of volunteers and graduates of the program kept it going. The final blow, however, came when the city announced that the space that the organization had occupied for nearly 15 years would need to be reassigned (ironically, to store medical records). Letters were written, news reporters called in, but to no avail. The city government did not produce a reassignment, and so the organization, suddenly homeless, boxed up toys, instruments, OT devices, dishes, and books, and moved them to a temporary space for storage.

A third case of changing NGO landscapes is the conflict between two generations of NGO parents. The generation who had children in the 1990s preferred independent NGOs which carry out projects based on limited-term grants from international organizations. These women all fall into a group that social scientists have categorized as "professional NGO workers" (Hemment). Younger parents, with children now in elementary school, have a different focus: instead of relying on foreign grants, they have shifted their attention to taking on as much power as possible in government organizations.

Lena is from the older generation of parents. Throughout the 1990s and early 2000, she was the director of a small, independent non-profit serving families of children with disabilities in Petrozavodsk and around Karelia. Indeed, Lena was having difficulty finding funding following USAID's exit from the city. She feels frustrated that a younger generation of parents, rather than joining her group, has taken on other modes of advocacy. In a sense

this is related to the competition for funds. Also, Lena's own son is now grown up, and her practice of receiving funding to carry out projects or supporting international actors has dwindled since 2008. A large project on inclusive education resulted in the publication of a professionally researched policy volume in 2007, yet in 2012 her organization was without a major project. They maintained their two-room office space with desks, computers, and files, and continued to serve those families that had worked with them for years, but they had no grant funding for programming.

In contrast, younger parents, observing this have taken on a different strategy: to import models of inclusion from abroad, but to fund their implementation through Russian state agencies. Considering the trajectory of the Elements NGO - now an office of the city's department of education, this seems like a sound strategy. For instance, recall Katya, the organizer who is mother to Polya, a daughter with severe DTsP. Leaving behind her earlier strategy of working informally with other parents to organize and pursue legal court cases, Katya has shifted her strategy to obtain a position within a state institution that she might then help shape in the future. Katya has worked to insert herself into the work of the state office for labor rehabilitation, another center in the city, which long languished under a disinterested director. When that director finally left, Katya and another colleague were able to get appointed to take over the functioning of the center. While there is little money, and the building is badly in disrepair, the position of the center as a state agency affords Katya a degree of security in building programming that she feels will be safe from intervention and stable over the long term. Because Katya's daughter will likely rely on adult day services to lead a full life after high school, the stakes of what kinds of programming this languishing state office can provide are high. By investing the caliber of state services, Katya is laying

the groundwork for a program that she hopes will be in effect when her own daughter becomes an adult.

I was privy to a degree of tension between Lena and Katya, who, if I spoke of either to the other one, would respond with an air of frustration. Mutual miscommunications seemed to be the status quo; each seemed to think the other was missing something crucial in her approach to the problem of how to work toward creating the best possible services for children with disabilities in the city. Lena in particular seems distressed by what she perceives as the younger parent-advocates insouciance: Katya and her ilk seem oblivious to the level of work that Lena feels she was able to conduct with international funding. Moreover, they do not look to Lena as an elder, but instead strike out in different directions, as if starting from scratch. Katya seems aware of this dynamic, but unsure of how to smooth things over, while Lena, during our interviews in 2012 reacted to mention of Katya and her projects with timbre of someone whose feelings have been hurt by a professional rebuff. The standoff may partially be the result of a difference of opinion or framework about how to coordinate services between informal parents groups, internationally funded NGOs, and state agencies. Lena has long sustained her NGO on foreign grants supporting an array of short and long term projects, and she therefore considers the institution of the NGO and the freedom and flexibility and independence it provides to be of great value. This approach seems shaped by the conditions of the second phase of postsoviet NGO culture. Meanwhile, Katya's orientation is based on an assessment of what is possible in new the third wave NGO culture, where, under Putin's foreign agent law, it is nearly impossible to receive consistent foreign grant funding, as it had been throughout the second half of the 1990s and the early 2000s.

Conclusion

In 2013, Human Rights Watch published a report, titled *Laws of Attrition: Crackdown on Russia's Civil Society after Putin's Return to the Presidency*, researched during the same period as my dissertation work in sites across Russia. The report describes the rise and enforcement of what is commonly known as the "foreign agent law" designed to discourage Russian organizations from receiving funding from international sources. The focus of that report is the impact that these laws have on advocacy organizations and those groups that are intentionally seeking to shift public opinion (2). Also during my fieldwork in September 2012, USAID, the arm of the US government providing foreign aid, received a cease and desist order from the Russia government, closed its Russia office, and ceased activities in the country. The BBC reported:

The expulsion follows a government crackdown on pro-democracy groups. "The decision was taken mainly because the work of the agency's officials far from always responded to the stated goals of development and humanitarian cooperation. We are talking about attempts to influence political processes through its grants," the foreign ministry said in a statement.

The so-called "government crackdown" - which in popular Western discourse includes the response to the 2012 election protests, to Pussy Riot, and the adoption of anti-US legislation, including the adoption ban - is often perceived in the West as being politically oriented in terms of federal-level actions directed at the level of international relations and geopolitical power plays. The move on the part of the Russian government in some ways an exertion of political control designed to demonstrate to the international community an unwillingness to bend to human rights demands coming from foreign governments.

In another sense, it is a reconsolidation of federal power over regional and local government, and over the implementation of social services and civic agendas. The NGO culture of the 1990s and early 2000s indeed left a broad and competing arena of international

players interested in developing democratic society in Russia. This left provision of civil services and human rights uneven and uncertain across Russia. In this sense, a reemergent Russian government, no longer immediately "post-Soviet" observes a responsibility to step in and re-engage as a primary guarantor of the quality of life for its citizens. Unfortunately, the result is a diminishing of the diversity of civic voices and a demonization of "Western interests" in Russian popular discourse (HRW 2013: 1). The macro level political consequences of this crackdown or reconsolidation have been clearly elucidated in the HRW report and elsewhere.

When scholars talk about the ways in which the organization of civil society and NGO culture shifts in the postsoviet period, we often focus on macro level modeling or meso level institutional changes. These, indeed offer important theoretical suggestions for political science, policy, and development interventions. Rarely does this work focus on consumer experience of social services; interviews conducted with NGO workers help us to understand the shifting terrain, but necessarily how these shifts are understood by the people served by the organization.

Sergei's narrative tell us several things. First, that indeed the segregated approach to primary and secondary education that this group, unlike younger generations, experienced has resulted in a situation in which they are unprepared to build friendships with their nondisabled peers, or, their nondisabled peers unprepared to build friendships with them. Second, the continually shifting profile of social services and climate of NGO culture: (1) programming and practitioners are temporary, and (2) efforts to create innovative programming in a shifting cultural field have left this group feeling like guinea pigs, or like they are constantly being promised results that don't materialize. That is, the segregation of

people with disabilities in school and in the work place continues to result in discriminatory practice.

These narratives also tell us important stories about the on-the-ground consequences of this "third stage" of postsoviet NGO culture, characterized by the Russian government's crackdown on civil society or reconsolidation of authority under the auspices of the state. How have and how will the efforts of the Russian government to limit the influence of foreign funders - specifically, in democratization efforts - change the ways that people with disabilities receive services? NGOs across Russia have developed since the 1990s to support the civic needs and provision of social services to Russians with disabilities. As Meri Kulmala (2011) has observed, the boundaries between non-profit and governmental projects in these kinds of local-level organizations has always been weak. Now, however, with less international funding available, non-profits may be faced with fewer options aside from merging or joining forces with government services.

As Sergei's narrative use of the image of "guinea pig" or "subject of experiments" so vividly captures, the actual effect of the NGO culture in the 1990s and 2000s, while dynamic, in some ways resulted in instability. Sergei, Alina, and Vakas are unique as a generation that came of age on the vanguard of the democratization and civil society wave, thus often being offered the chance to be the first to utilize a given service or participate in a new program - often funded by and inspired by international organizations and models. In one sense, this put them in a privileged position - they were afforded opportunities to participate in society, to have active social lives, to move through the city and attend college, that previous generations were not. On the other hand, it put them in a position that many other Russians would recognize from this period: that is, they were constantly participating in programs

which then closed as funding dried up, or were promised results that failed to materialize as pilot project worked out the kinks. Frequently, when discussing the problems facing people with disabilities, my interlocutors, including people with disabilities themselves, as well as parents, social workers, and advocates, wished above all for a different kind of government.

As Sergei put it, when discussing a documentary he had seen about government support for jobs for adults with disabilities in the US:

The [US] government has made that possible. And I had to sort of come to terms with that, that in principle, if people like that are able to hold a job, then I realized that to an extent I could [... but,] I'd have to find my way to a different government, because there I certainly would be able to find work. According to my strengths.

It seems that in some senses, the move on the part of the Russian government towards reconsolidation can be read as a legitimate response to a call from the citizens for a more functional government. In this way I want to suggest that the view from the ground up, the perspectives of users of social services for people with disabilities, might offer an interpretation of the changes in Russian civil society under Putin's reconsolidation that is very different from the standard Russian characterizations of the intention behind, for example, the foreign agent law. On the other hand, the reconsolidation also results in a disruption of civic and democratic diversity, and new state institutions are also conducting pilot programs and testing new models of socialization therapy on adults with disabilities. Thus, in many ways, Sergei and his cohort are again guinea pigs, this time in a reimagined, more benevolent and therapeutic state social service system.

CHAPTER IX
"TOO MUCH PUSHKIN, AND NOT ENOUGH OF US":
THE AUTUMN CONCERT, OR, PERFORMING DISABLED CITIZENSHIP

As I got more and more involved with the art therapy group, I also found myself feeling torn about the ways in which the group was disciplining its members. I didn't know what to say about Alina: sometimes she seemed so sure of herself, and at other times so subordinated to others. I wasn't sure what to think of the project, or of the relationships between the social workers and the participants.

Over the course of the fall, the group worked to stage a short performance, which we called "An Autumn Concert." This episode - the conceptualization of the concert, the groups' preparations, and ultimately the performance itself - became a central happening around which my fieldwork unfolded. So, it was through telling this story, that I began to grapple with how to describe some of the most difficult questions that my research posed: how people with disabilities understood themselves as social actors and as Russian citizens.

The concert was couched as an afternoon of performances in tribute to Aleksandr Sergeevich Pushkin, the most famous poet and literary figure in Russian history. As I watched the group members grapple with the work of representing Pushkin, I realized that the social performances of self, continuously negotiated in every social interaction, were bound up in ideas about what it meant to be a moral person and a good citizen. In telling the story of the performances at the Autumn Concert, I also tell the story of everyday social performances of disabled citizenship.

The Autumn Concert

There was a moment in the course of the art therapy project that in many ways defined the experience for me, and when, perhaps, my status as a non-social worker was thrown into relief. This all unfolded in the course of preparations for the Autumn Concert, which, following the photography lesson, and two weeks worth of drawing lessons, became the sole focus of the art therapy project. In Russian, the word Concert is more akin to recital or performance, and may be not only strictly musical, but also include something of a theatrical nature.

For the work of putting together an Autumn Concert, Lidia, a local theater professional with a background in techniques of theatrical reading, joined the group most Wednesdays. Lidia works mostly as a director at an afterschool theater for high school students, where she prepares her charges to participate in theatrical reading competitions, in which they perform monologues, poetry, and other texts with high theatrical technique.

Lidia arrived one afternoon with the project of doing several rounds of enunciation exercises of the kind that are usual as warm-up exercises for actors. She began by vocalizing a quick pattern of short syllables beginning with hard consonants: bee-bai-bo-bum. We were meant, as a group, to call out in response the same pronunciation. Then the process would escalate. More syllables were added. The rate of pronunciation would grow faster. Then, warmed up, we would move on to tongue twisters, or *skorogovorki* in Russian. This was a particular genre of torture that I had experienced once at the hand of a particularly eager language lab instructor during my college Russian courses. As anyone who has ever tried to learn a tongue twister in another language can commiserate, these short poems rife with rhyme and alliteration tend to include the fantastic combination of odd word combinations,

obscure nonsense language, and generally absurdist or near-incomprehensible literal meanings. For the members of the group themselves, these sessions were at first met with uproarious amusement. How silly - what kind of adult takes the recitation of *skorogovorki* as a serious exercise? When it came time to recite tongue twisters, we shifted from the group mode to individual repetition. Lidia would introduce a *skorogovorka*, we would all practice it, she would provide some general pointers - sit up straight! project your voice! place your tongue on the roof of your mouth and move it quickly downward!

Then, as individuals, we would each in turn attempt a tongue twister, or a segment of one. This was agonizing, as the whole group's focus was on you for that moment (or, worse, you were doing so poorly that someone at the other end of the table had begun to whisper to their neighbor). The whole crew obviously had a leg up on me given that I was a non-native speaker, and I wasn't familiar with most of the *skorogovorki* (the fact that I did remember one or two from my college Russian days hardly helped me to say it correctly). My particular ineptitude was funny at first, because it was okay to laugh at me, but quickly just became boring, when the same lesson was repeated for the second and third week in a row. The activity was more grating for other members of the group like Alina and Vakas, whose speech is affected by their respective motor impairments. As witty and wordy as they both are, in large group settings, Alina often speaks very quietly, and she often has difficulty getting a word in edgewise when there are many people talking (especially if she feels that her opinion won't be taken seriously anyway). Vakas does his best to avoid talking altogether, supplanting facial expressions as his communicative device wherever possible. He also frequently used his role as group photographer as an excuse to stand back from the

action - standing at the perimeter snapping photos while others sat at a table having a conversation (a tactic that many ethnographers will recognize).

Less funny than my ineptitude was the clear implication that no one in the group was particularly *good* at this exercise. One participant has a very loud voice, which helped in some ways, but her memory isn't good, so she had trouble remembering the lines. Another had to fumble through line-by-line with gentle prompting from Lidia. Vakas, whose traumatic brain injury affects his speech quite significantly, making it much slower than the usual rate of conversation, excused himself all together, refusing to say a single *skorogovorka*. Sergei gave it a good run, and his musical talent helped, but he gets shy in moments of performance, and always ended up looking down and blushing instead of projecting his voice forward. Alina quickly got frustrated with Lidia's encouraging instructions to sit up straight and to project her voice; even when she was projecting, her voice has a raspy or strained quality that has to do with her body and can't be avoided. In short, it's hard to be asked to do repeatedly something that you know you're not very good at.

This element of Lidia's training made for an odd incursion on the group's usually non-therapeutic approach to art therapy. Overall, the therapeutic content of the project was the opportunity to get out of the house and do something new - for free - and to socialize a bit with people outside of one's immediate circle. Each week, a small minibus drove through the streets of Petrozavodsk, from one far-flung residential region to another, gathering the participants one at a time, and eventually delivering them to the location.

After our round of word games during Lidia's second visit to the group, we began making plans for an Autumn Concert. The project had run the previous fall, and Lidia had

also participated. The program had culminated in a small performance for friends and family and other members of the Center and the related community.

After a few rounds of discussion, it was decided that a good theme for this year would be to present a concert in honor of Pushkin, *velikii rossisskii poet*, the great Russian poet, the Shakespeare of the Russian language. The logic behind this seemed sound: everyone was more or less familiar with Pushkin poetry; some members of the group wanted to do something relating to autumn and to nature - others wanted something to do with love and romance, and Pushkin's vast array of poetry could satisfy all of these needs. Sergei, who wanted to sing, could choose one of the many arrangements of Pushkin poetry set to music; Svetlana, who wanted to do a wheelchair dance, could act out a poem about a waltz or love. Personally, I was surprised that the group settled on Pushkin as a theme, as it seemed awfully staid: it would be difficult to develop an original performance, given the strict reverence with which Russian culture addresses the work and history of the poet. Also, I didn't see immediately what, if anything, Pushkin might have to do with disability.

Pushkin in Russian Culture

Russia is a well-studied place. Stereotypes of Russian culture circulate in the West, summed up by platitudes about an imagined essential the Russian character - cold to strangers, warm to loved ones, a weakness for vodka, a penchant for wearing fur unapologetically compared to other industrialized nations. Another element of foreign perception of Russia is a legendary prowess in all manner of European high culture - literature, ballet, classical music, chess, and even sports. And it is into this later category of High Russianness that Pushkin and the wide array of modes of Pushkin tribute-making fall.

Most Russians study Pushkin throughout the years of their education. As small children, they memorize and recite poems about nature - autumn leaves, snow, or joy of springtime. As preteens, they study Pushkin as a historical figure, learning details about his biography. They move on to his more complex poetry. Lessons in various disciplines might be introduced with a Pushkin quotation as an epigraph. As high school students, the structure of Russian literary language, of verse and metaphor are investigated through Pushkin. His work is considered the gold standard of Russophone linguistic innovation - Russia's own bard.

Pushkin is widely referred to as "Russia's first poet," a phrase that seems to reflect both greatness and historical precedence. The details of his biography are romanticized and widely known, from his birth in 1799 to his death in 1837. Russians will note his "exotic" heritage. Pushkin was the great-grandson of Abram Petrovich Gannibal, a nobleman who - native to present-day Cameroon - had come into the Russian aristocracy when as a boy he was presented as a gift to Peter the Great, who raised him as a family member rather than as a slave. Russians know all the details of Pushkin's rarified education and boyish rebellions at one of the best schools of his time. His descriptions of romantic love are lent legitimacy by the tragic glamour of his own 19th century romances: he died in a duel over a woman he loved.

Pushkin wrote frequently in verse - short poems, prose, the novel in verse Eugene Onegin, and fairy tales. He also wrote dramas for the stage, including dramas of Russian history, which he himself described as inspired by Shakespeare's take on British history.

Credited as the creator of the modern Russian literary style, Pushkin was recognized as such and incorporated into the Soviet educational system. Knowledge of his work came to

stand as an indication of minimum levels of sophistication and civilized education. Soviets of the post-war generation are wont to quote Pushkin at all turns; his citations offer a language of commonality and shared cultural touchstone to people who might otherwise be strangers. Younger generations are less likely to spontaneously quote from Pushkin, but most Russians are still familiar with his work from their school days.

Pushkin is not only the constant point of reference for any literary endeavor, he is the namesake for numerous places, streets, concert halls, and so forth. A search of the digital archives of the Soviet journal *Kul'tura* (under various names, 1929-1991) produces 12,058 entries for the word Pushkin (in Russian).

I have often overheard Russians in conversation with strangers - neighbors in a train compartment or seated together at an event - immediately turn to Pushkin citations as a mode of interaction. In these situations, Pushkin quotes function as shared truism. Producing a Pushkin quote to describe an emotion or sentiment, a circumstance or situation - the springtime weather, a sense of the city versus the countryside, of time passing too quickly - serves to offer a performance of certain class distinction. Those who produce Pushkin quotes are seeking to build bonds of commonality; they are offering a sense of themselves as part of a collective of educated citizens; they are indicating a desire to be perceived as possessing emotional and intellectual depth. They are likewise recognizing the person as a fellow citizen. This can take multiple inflections - in some cases, it might be deployed to shame another citizen for a perceived cultural infraction - impolite drunkenness or unnecessary rowdiness on a train compartment, for instance. Or, it might be offered as a bond of shared nostalgia for one's childhood or school days.

In this group, Sergei, especially had been an avid participant in his school's theater club. In the course of his junior high school and high school career, he had therefore had even more exposure to Pushkin. In one interview he recalled:

[At the *internat*] we had theatrical performances - I did plays, from the 7th or 8th grade on. They discovered me, when I recited a poem in the 7th or 8th grade. *The Letter to Eugene Onegin*, I think, something like that. And -- they noticed and invited me to join, it was sort of like, the theater club.

And a lot of the time, it would be like this - someone who lived in the city would stay at school until 3pm, and then he would go home. A lot of the time, that was what it was like. And someone would always be rushing to finish his work, come on, hurry, hurry, time to go home. But not me, I could - skip the 3pm bus, and then let the 5pm bus go by, and then -- umm, go home somehow, like, my teacher would drive me home. So.

Because we would rehearse a lot, on a regular basis. So we would have to set aside time for that. ... A lot of teachers didn't even understand. "He may be a city kid, but why then doesn't he act like it?" We would stay and rehearse our poems there. You would stand at one end of the hallway, (as an aside) our library, it was separate and we had our rehearsals there, and it had a hallway on one side, and then another hallway on the opposed side, a really big hallway. And our teacher - he was sneaky [laughs] - we would have to talk so that you could hear us through the whole hallway. And so that's how we rehearsed - in the empty space, like that, with the echo. So we would all be laughing. So. ... Well of course, there were so many moments, and my memories of school are good ones. I think largely because I did take part in all of those activities -- the social life [*obschestvennaia zhizn'*].

Sergei's recollection of his school years experience of theater as an activity through which friendships are formed is clear in this quote. He recalls the use of a Pushkin poem both fondly and as an aside. It is so obvious that if he was reciting a poem it would be a Pushkin poem as to be hardly worthy of comment; yet, it is expected that in conversation, one would say which poem, as a way of adding color to the description - Russians would immediately know the poem by heart, much as an English speaker would know "Mercutio's death from *Romeo and Juliet*".

Vakas, whose slow speech made poetry recitation difficult, had been steered toward writing since childhood. The appearance of computer keyboards made typing his preferred form of writing, given his motor impairments. As a result, Vaka's engagement with Pushkin was more in the realm of modeling himself as a poet. In his own writing, Vakas discussed inspiration and muses- a Pushkin theme. His literary style in poetry followed ideas of verse

and romance that tied his work to Pushkin. During afternoon visits to his house, I sometimes made fun of Vakas for writing like he lived in the 19th century. He would smile and shake his head - the classics, as he and many Russians saw it, were classics because they offered a source of authenticity.

Alina too - from time to time - produced Pushkin quotations in the course of conversation. Lines from his works circulate as aphorisms. Alina's use of these aphorisms indicate the way that phrases from Pushkin get deployed across social and class settings. From Sergei's school room, to the discussions of strangers in a train compartment, to afternoon tea at Alina's apartment. Alina's class background - her mother was a janitor - situates her outside of the intelligentsia or middle class. Sergei's and Vakas' parents held professional positions and received what was considered prestigious higher education - though they lived in modest middle class neighborhoods. By contrast, Alina's mother's cultural respect was obtained through her years of hard labor as a cleaning woman in a school.

Pushkin and kulturnost'

Pushkin, then, is always available to a speaker as a way to allude to a shared sense of national culture. Invoking Pushkin, then, whether quoting him directly, or mentioning his name, also suggests an adherence to a particular set of cultural values.

One exchange I had with Alina and her mother typifies this manner in which Pushkin is invoked. In this conversation, Alina and her mother had begun to complain about the couple who lived in one of the rooms of their apartment. Alina and her mother often complained about this pair, as they shared a bathroom, washroom, and kitchen with whomever the tenants of the room were (Alina and her mother occupied three rooms). Alina

and her mother found the couple who lived in the room during the spring of 2013 particularly objectionable. They described this couple as hard-drinking, uneducated, users of *mat*, the word for the contemporary Russian rude slang dialect, rife with swearwords⁶⁰. In the exchange below, I had just expressed the sentiment that I didn't think *mat* ought to be outlawed, follow Alina and her mother's description of *mat* as an illustration of the neighbors' low moral character.

Alina: They're...

Mother: You're lucky you missed them.

A: They're...

M: It's just that we...

A: You have to understand that they're... The thing is, that you're talking about certain *levels*.

M: Yes, there are certain *levels*...

A: Like television - it's one thing on television, because they're obligated, to put the "18+" or else they can't use rough language [*rezko govorit*]. Why is this rule only for television? It only offends people...

So you started talking about levels. Actually *u nas* there are no levels in general. There is no culture.

M: There's no culture at all here, in general.

Cassandra: There is culture everywhere...

A: Because...

C: Culture is the thing that...

A: She's gone off-track.

C: [continuing] ... makes it possible for people to communicate.

M: Cultured language. ... She's with us...

A: She's lost. No one speaks in the language of Pushkin anymore. Now everyone says, "Yo, hey you, girl! Cummere!"

C: Well, thank goodness. I'm glad that we don't talk like Pushkin talked.

M: But it's really bad.

A: But why not?

M: Sometimes it's necessary...⁶¹

⁶⁰ The notion of *mat* is somewhat particular to Russian, in that it is conceptualized, as a slang genre, as a register of speech that is complete (though naturally it includes many common Russian words) and wholly deviant. Unlike English "curse words" *mat* builds on Russian grammatical structure to build vulgarity into patterned speech. Russians are generally much less accepting of vulgar language than English speakers. One way that this becomes clear is in the way that slang and vulgarity is conceptualized as an ongoing problem in contemporary art and theater. Older generations of Russians, especially, consider any use of *mat* or slang as denigrating the "level" of a piece of art. Likewise literary translation from foreign languages into Russia, faces a similar problem - translators are often stumped or readers are shocked by the commonplace use of vulgarities in foreign literature. Translation of Hollywood movies varies - in some cases the vulgarity of a curse is downgraded, while in others it is retained.

⁶¹ С. У нас...

М. Повезло тебе.

A: What's so bad about Pushkin?

C: You don't really think that everyone talked like he did, at the time when he was living? Of course not - they were kinds of ways. He just was a literary genius, an exception.

A: I understand that he was different, but you could say that people used to use three-letter-words less than they do now. I'd like to think that's true, anyway.

M: We found... It didn't used to be like this *u nas*. We didn't have the right to say rude words to a person older than ourselves.

S: It's impolite. [*nekrasivo*]

M: We didn't have the right. I grew up in a simple working family, I didn't have parents with higher education, they were simple working people. Both my mother and father.

S: But at some time in Russia we had people who were, sort of, refined [intelligent]: who dressed nicely, smelled good, and could talk...

M: Well, it wasn't like that in our family.

S: ... with good breeding.

M: But our neighbors didn't have anyone like this in their family.

S: That's how things are turning out *u nas*... did you read Gorky's "The Lower Depths?"⁶²

M: It's just - they're very poorly brought up people.⁶³

C. У нас...

M. Мы сейчас, просто...

C. У нас, понимаешь... Дело в том, что ты говоришь про какие-то уровни.

M. Да какие, там, уровни...

C. Телевизор - это одно, телевизор, почему-то обязали, вот "18+" - нельзя там ничего резко говорить. Почему обязан только телевизор это? Разве людей обижать... Вот ты говоришь про уровни. У нас уровней вообще нет. Культуры нет.

M. У нас вообще нет культуры, вообще.

K. Везде культура...

C. Потому что...

K. Культура - это то, что...

C. Она упала.

K. (продолжает)... даёт возможность, чтобы люди могли общаться.

M. Культура языка... Она у нас...

C. Она упала. Уже никто не разговаривает на языке Пушкина. Уже все говорят: "Эй, ты, тёлка! Иди сюда!"

K. Слава богу, я так рада, что мы не говорим, как Пушкин говорил.

M. А очень плохо.

C. А почему нет?

M. Иногда надо...

⁶² A well-known 1902 play by Maksim Gorky, "The Lower Depths" (or *Na Dne* in Russian) depicts a hopeless scene of harsh truths and escapist fantasy amongst a group of lower class destitutes.

⁶³ C. Что было в Пушкине плохого?

K. Вы же думаете, что все так, как он, говорили в то время, когда он жил? Нет, они все по-разному. Он как-то сам (неразборчиво) вот, вообще.

C. Я понимаю, что он сам, но, допустим, что слово из трёх букв, я надеюсь, что раньше использовалось реже, чем сейчас. Хочется, по крайней мере, верить.

M. Мы нашли... У нас такого не было. Мы не имели права человеку старше себя сказать грубого слова.

C. Это - некрасиво.

M. Мы не имели права. Я выросла в простой рабочей семье, у меня нету родителей с высшим образованием, у меня были работяги простые. И мать, и отец.

In the course of this conversation I went "off-script" - that is offered my own interpretation of language and culture, knowing full well that it would clash with Alina and her mother's. The anthropological notion of culture is markedly different from the Russian folk meaning of the concept, which is much closer to "civilized" or "sophisticated" when used as an adjective, and reserved for high culture - great art, architecture, and literature - when used as a noun.

In this exchange, Pushkin stands as a polar opposite to the lower class, morally degenerate, socially outcast speakers of *mat*. Although Pushkin was an aristocrat, the Soviet notion that a person may be poor, but also morally and socially educated, cultured, and polite is patiently explained to me, a foreigner who is resisting the script. Ethnographers have documented numerous ways in which contemporary Russians seek to assert moral standing in spite of poverty and lack of social capital (e.g. the elderly (Caldwell), the homeless (Höjdestrand), health care workers (Rivkin-Fish 2009)). The above passage underlines the way that invoking *Pushkin* acts as a beacon or pillar of example of linguistic prowess - and therefore moral character, that stands in opposition to *nekulturnaia rech'* - or uncivilized speech.

Culture here is not an anthropological notion of culture, but a modernist concept of civility and membership in a civilized nation. This meaning is emphasized and thrown into relief by my stubborn and somewhat intentional adherence to an American ethnographic

С. А иной раз у нас бывает в России так, что, вроде, с виду интеллигент: красиво одет, вкусно пахнет, а выражается...

М. Ну, у нас в семье такого не было.

С. ...похлеще кровельщика.

М. Вот эти соседи, у нас такого в семье не было.

С. У нас уже это, как бы, получается... Ты читала Горького "На дне"?

М. Это - очень невоспитанные люди.

concept of culture (in which every group "has culture"), with which the Russian colloquial noun *kultura* and adjective *kulturnoi* do not align. In the Russian case, it is fully possible for someone to be "without culture" - as Alina describes her neighbors, meaning that they are deviant and do not adhere to the aspirations of cultural citizenship. Even as I knew that an anthropological approach to culture and language was not what Alina and her mother were referencing, by challenging them, with a contradictory perspective, this conversational exchange helped to draw out and demonstrate how Pushkin comes to stand for a cultured or civilized moral orientation, a manner of expressing good standing or competent citizenship.

Later, in my fieldnotes, I write recollections from our conversations that afternoon:

Alina and I talk about the low grammatical level of common Russian speech. I tell her we also have lots of people who speak incorrectly, and don't know how to write properly in the US. But, I propose, in the US, no one is surprised that there is a large segment of the population that is poorly educated. After all, I theorized, we've always been a capitalist society, so there is no surprise that certain groups or classes are not sophisticated - they are necessary to the functioning of the economy. Whereas in Russia, in Soviet times, it was assumed that a society with full literacy for all and an educated, sophisticated workforce was possible and achievable. Alina's not impressed, and continues to recount examples of grammatical short-comings: mispronouncing the word "pozvonit'" by stressing the wrong syllable - rampant in the Moscow region, she states; not knowing how to spell even the simplest words "Ugurt" instead of Yogurt - a mistake she says a parliamentarian famously made (I try to counter with the Dan Quayle potato story, but again she's not impressed).

In both the exchange related above, and in the elaboration in my fieldnotes, one of the ways that Alina expresses her own competency as a sophisticated citizen, a *kulturnaia* speaker or person, is by comparing her own grasp of grammar and proper speech. This is a commonplace strategy and mode of expressing allegiance to civility amongst Russian speakers. But, in the case of Alina and her mother, and, I will argue, in the invocation of Pushkin in the Autumn Concert, it represents a particularly important strategy by which people with disabilities address and contest their social status, aligning themselves as sophisticated, rather than deviant or stigmatized, citizens.

Michele Rivkin-Fish has described the concept of *kulturnost'* or culturedness as one

that, emerging from Soviet modernization discourses, in postsoviet Russia "continued to be invoked as a scheme for proper behavior and etiquette in personal interactions [in which, through certain modes of social performance one demonstrated] being a cultured, moral person" (98). Modes of performing *kulturnost'* in Rivkin-Fish's description are profoundly gendered; women and men are expected to behave in ways appropriate to their gender identity. *Kulturnaia rech'* describes a mode of speaking that situates the speaker as part of a social project of ongoing civilization and modernity. By speaking properly, and shaming those who do not, one demonstrates one's own membership in the social collective, and in the national project. Of course, as a performed category, *kulturnost'* is also embodied.

Describing the way that disabled bodies are stigmatized, Rosemarie Garland-Thomson writes,

Disability [is] the attribution of corporeal deviance -- not so much a property of bodies as a product of cultural rules about what bodies should be or do. [...] The meanings attributed to extraordinary bodies reside not in inherent physical flaws, but in social relationships in which one group is legitimated by possessing valued physical characteristics and maintains its ascendancy and its self-identity by systematically imposing the role of cultural or corporeal inferiority on others. [1997:6-7]

In this way, then, social performance matters for people with disabilities, for it is through social interactions and demonstrations of cultured self-expression that their personhood and citizenship might be recognized by nondisabled interlocutors. Garland Thomson goes on to describe this process:

When one person has a visible disability[*it*] almost always dominates and skews the normate's process of sorting out perceptions and forming a reaction. The interaction is usually strained because the nondisabled person may feel fear, pity, fascination, repulsion, or merely surprise [...] Perhaps most destructive to the potential for continuing relations is the normate's frequent assumption that a disability cancels out other qualities, reducing the complex person to a single attribute [...] Even though disability threatens to snap the slender thread of sociability, most physically disabled people are skilled enough in these encounters to repair the fabric of the relation so that it can continue. To be granted fully human status by normates, disabled people must learn to manage relationships from the beginning. In other words, disabled people must use charm, intimidation, ardor, deference, humor, or entertainment to relieve nondisabled people of their discomfort.

Although it is perfectly obvious to Alina that she herself is a complex person, with years of

advanced as well as primary education, nondisabled people she may meet often initially cast her as deviant or in need of rehabilitation. In daily interactions with strangers, she is constantly put in the position of overcoming this overdetermination of the social meaning of her extraordinary body. This issue is thrown into high relief in the case of her interactions with social workers, who, tasked with conducting therapy with Alina and the other members of the art therapy group, conveniently overlook Alina's own higher education, adept cultural performance, and her sense of herself as a fully competent *kulturnaia* citizen, in order to forge ahead with the project of social rehabilitation.

Alina often, in interviews, returned to the theme of education. She frequently asserted her status as the bearer of an advanced degree in social pedagogy. She sometimes remarked, jovially, that since I was an instructor at a university back home, we might think of one another as colleagues, fellow teachers. Yet, she complained that she was unable to get a job in her field of training because no one would hire her. People frequently assumed she was uneducated.

This problem was particularly manifest in my observations of Alina's experience at the art therapy group. The facilitators, in order to perform their own professional competence, had to disregard Alina's competence, and cast her physical disability - which they are not tasked with addressing - as a social impairment, which it is their job to address. That is, stigma - a social phenomenon - renders Alina's personal embodiment deviant; yet, facilitators are expected to address the social phenomenon of stigma not by shifting broader social attitudes, but by working on Alina's social and psychological sense of self. This creates an impasse.

Disability stigma is individualized and located in a particular body, which, due to

physical realities, cannot be rehabilitated to normalcy. The art-therapy project targets the psychosocial selves of people with disabilities, but not the social and cultural framework that creates and reproduces disability stigma. In my observation, it is this mismatch between the goals and the methods of intervention that led to conflict and frustration in the course of creating The Autumn Concert. Alina and her peers did not need help learning to recite Pushkin; however, they did need help addressing the social attitudes of the broader society towards people with disabilities.

Therapy and the Good Citizen

So, how did social workers strive to conduct therapeutic interventions in the course of the project? Self-work, or the supposition that through therapeutic intervention, individuals might become more self-actualizing, has found a great cache in postsoviet Russia (Rivkin-Fish 2005; Matza 2012; Matza 2009; Lerner and Zbenovich 2013). This discourse became an important mode by which program facilitators sought to make therapeutic interventions.⁶⁴ At the same time, the adults with disabilities participating in the therapy group had been enculturated into a range of programs hosted by non-profit organizations throughout the 1990s and early 2000s, which, drawing on transnational discourses of disability justice, encouraged them to develop a sense of independence. In interviews and in meetings of the art therapy group, interlocutors negotiate these overlapping discursive logics of self -

⁶⁴ The rise of therapeutic was quite new and distinct from Soviet-era approaches, which sought to cultivate persons who were oriented towards the collective, who fit into the standards and expectations of communist ideals, and whose life project would conform to societal interests. The end of the Soviet regime opened up new forms of normative selfhood based on individual reliance and personal responsibility. As Russians came to realize they could not rely on the state to provide for their well-being or to provide standards that define what constitutes “a meaningful life,” popular psychological forms of self-help proliferated (Matza; Rivkin-Fish). Interestingly, Svetlana, in her dissertation on the socialization of young adults with disabilities in Karelia is careful to balance these perspectives: she writes that individuals must develop personalities with a “measured degree of independence” [*merennyi*] (Driakhlitsina 2009).

independence and psychological models of self-sufficiency and self-actualization.

Tomas Matza writes,

Since the end of socialism in Russia, 'the self' has become a site of concern and investment." In addition to a growth in popular interest in psychology and the consumption of self-help industries regarding concepts such as personal growth and time management, "psychologists have also found their way into public institutions, especially those that serve children." "Self-work" becomes a practice of distinction and class-making; it contributes to the formation of particular definitions of success, and to the valuation of certain "skills" [*navyki*] which are produced as valuable (2012:804).

In this way, the self becomes a "site for experimenting with different visions of Russia's political future." By training individuals to be more self-actualizing social actors, psychologists imagine their work as contributing to a more democratic future for Russia, in which people, better able to recognize their own needs and emotions, in turn treat others more reasonably, more humanely (2012: 813, 808)

In addition to normates, when people with disabilities are asked to work on themselves by social workers and psychologists employed by the state, they too become interpellated into a kind of therapeutic citizenship. In this mode, to be an object of therapy is also to be a subject or citizen of the state. The skills that therapeutic interventions build are skills that are expected of the citizen, and this mode of psychological education of citizenry is embraced by the Russian government (Matza 2009:492). So, in this sense, the project participants join with a great many contemporary Russians in voluntarily engaging in a therapeutic project.

At the same time, the therapeutic work in the case of groups for people with disabilities differs in an important way from the psychologies that apply to the general population described by other ethnographers. That is, through therapeutic interventions, people with disabilities are produced as deviant and in need of rehabilitation. With the cultural assumption that disability status alone is sufficient reason for a person to be included in these projects, being disabled automatically categorizes a person as an object of care, a recipient of social support, and someone not-yet-ready for full citizenship. Michele Rivkin-Fish calls this enterprise the work of "cultivating moral personhood" (108). In her ethnography of changes in social relations in women's healthcare in the 1990s in Saint Petersburg, she observes specific ways that medicalizing and psychologizing discourses tend

to locate social problems in individual bodies, and that Russian actors - both healthcare practitioners and consumers - often feel that their own moral personhood is at stake in interactions in a shifting cultural frame. In this sense, actors take on a variety of strategies to assert their own moral personhood. In particular, the idea of individualizing strategies is important to our discussion of the Pushkin reading at the Autumn Concert. Rivkin-Fish writes:

Individualizing strategies are primarily two approaches to creating social change. First are the numerous educational projects aiming to develop people's personality [*lichnost'*] and its related components, such as new attitudes and behaviors. These may be devised by experts in a pedagogic frame, such as for moral education [*vospitanie*] [...] the second kind of individualizing practices are devised by persons in their daily life as a self-imposed form of discipline aiming to create social change [by which by changing oneself, one hopes to relate to the world differently]. [2005:9-10]

Both Matza and Rivkin-Fish relate the rise of psychologizing discourses in postsoviet Russia to Foucault's notion of neoliberal citizenship, in which an individual is tasked with developing a particular kind of self. That is, it becomes the moral responsibility of the individual citizen to develop the skills considered necessary for citizenship. This is part of a broader trend of population-level thinking, or governance of populations through biopower. "For example," writes Rivkin-Fish, "expert discourses often took the 'self' as an object of prescriptions regarding 'normal' ways of acting, so that caring for 'the self' in appropriate ways became the responsibility of modern citizens. Exertions of biopower thereby came to be accepted as beneficial and necessary, rather than as coercion" (2005:21). In this sense, Rivkin-Fish and Matza observe the ways that biopower operates through psychologist and medical professionals and through the self-work of average citizens.

Disability, however, has a somewhat different relationship to biopower. In particular, the history of how disability was invented as a deviant category is relevant here. The invention of the category of disability is related to the rise of statistics, and the mode by

which European rulers and states came to survey and categorize their populations (Scott; Canguilhem; Davis). As technologies of the welfare state were developed over the course of the 19th and 20th centuries, modes of maximizing the productivity, or minimizing the expenditure of public resources on those bodies and minds deemed abnormal or socially undesirable became a peculiar obsession of state bureaucracies. As Foucault describes, these bodies, in the premodern era in France, were quarantined; confinement subsequently became a primary tactic of control in the 19th century (Foucault; Ben-Moshe et al). New technologies of provisioning and public health measures sought to prevent destitution in European and American cities; rationalization of the social services created new ways of minimizing socially undesirables. While scholars often associate these modes of indirect governance of a population, or biopower, with the rise of capital, and assume that state socialism relied on authoritarian or direct forms of control, this is not necessarily the case.

In the Soviet Union, rehabilitative models for children with disabilities - *defectology* - were elaborated according to socialist principles (Phillips 2011). Rehabilitative plans and technologies for those injured later in life were also considered to be the domain of the state (Bernstein 2014). Workshops for the blind were established as a mode of seeking to maximize productivity, and blind adults were trained in a trade (Phillips 2011).

In this way, the bodies of people with disabilities were considered as objects for rehabilitation, or a continuous process of therapeutic intervention with the goal of restoring a body to normalcy. In the case of people born with disabilities, this restoration implied a restoration to an imagined proper social order which had ostensibly been disrupted prior to or during birth. For instance, in the case of DTsP, or various physical differences, fetal abnormalities were explained in socialist medical texts as being the result of social ills which,

through the mother, harmed the fetus in utero. That is, the science of socialism posited that uncivilized social conditions could produce *defekty*, defects, in children. And in turn, by restoring individual children to full functioning through rehabilitation, the professionals contributed to establishing equilibrium in society. The practices of professionals aiding people with disabilities to become more like the able-bodied ideal were actually contributing not only to the life possibilities of those individuals, but to the health of the social body as a whole.

In this way, technologies of self-work in Soviet, and to a degree post-Soviet society, are already understood to be aimed at rebalancing a dialectical relationship between individuals and society. And, the necessity of self-work or moral education, *vospitanie*, is naturalized as an on-going mode of performing citizenship.

For instance, in his ethnographic account of psychological work in postsoviet Russia, Matza described the way that the notion of self-esteem, or *samoosenka*, came to be deployed as technology of biopower, encouraging the individual to engage in self-work in order to change his own circumstances. Describing the manner of a popular radio personality who provided advice based on psychology and therapeutic ideas to listeners on a call in talk show, Matza writes:

[the] concern was with the proper attitude, or relation, to one's self, which he often defined as a relation of esteem or *samoosenka*. As a technology or practice, *samoosenka* relied on a differentiation between interior and exterior domains, and careful mediation between them. Thus, *samoosenka* was a matter of proper orientation: A self-esteeming person should look to himself when faced with a problem. [...] *samoosenka* emanates outward into the world; it can have effects, for example increasing (or decreasing) the respect one receives from others.
(498-499)

For psychologists engaged in therapeutic endeavors, these were the kinds of qualities that they hoped to imbue in the group members.

In order to fully unpack how contemporary Russian psychologists understood

disability in relation to the skills of self-management, Anya provides an important counter example. Anya, who has a degenerative muscle disease, was born seemingly without a disability, and grew up becoming progressively more ill from roughly puberty onward, so that, by the time she attended college, she was a wheel-chair user requiring significant care. She earned a degree in psychology, and worked as a therapist. Anya was not a part of the art therapy group, but maintained collegial relations with the practitioners facilitating it, as she was a psychologist serving a similar population at another facility. In my conversations with Anya, she often used the language of psychology to explain the capacity of someone with a disability to take charge of their life. Anya was unique among my interlocutors in that she both *has* a disability herself, and works with populations of adults with disabilities as her clients. In one interview she said,

I think that it's really important to work with parents right now, so that they can raise their kids *s invalidnostu* adequately. But to do this, you really have to start when they're small... As soon as a child *s invalidnostu* is born, there should be some kind of psychological assistance for the parents, so that they don't take the birth of their child as a tragedy [*gore*]. [With assurance] It's not a tragedy, that this particular kid was born... For instance, kids with CP are born... Yes, they have physical impairments [*narusheniye fizicheskiye*], but they have bright minds [*golova svetlaia*]. Often enough they can move mountains [*gori svernut'*] - as long as you teach them that they can.

In this quote, Anya advances the perspective that through the right *vospitanie* or moral upbringing, if children - even disabled children - are taught the right skills, they will have the capacity to move smoothly through the world. That is, she aligns herself with the idea that self-work and an upbringing that breeds self-esteem - that is, individualizing strategies - are sufficient to carry off the project of a person with a disability becoming a moral citizen.

Anya's stake in this claim is not minor. As someone with a profound disability who operates as a socially adept, fully capable citizen, she must believe that it is possible for people with disabilities to live lives that make important contributions. Anya's own dual status as both a person with a disability and as a practitioner studying the problems of people

with disabilities put her in an unusual position. The discourses of self-realization, from where she was sitting, offered a reasonable path to social recognition and success.

In our conversations, Anya frequently talked to me as a psychologist. She shared her opinion as one professional speaking to another professional in a different, but related, discipline.⁶⁵ She often described people with disabilities in terms of clients that she worked with. Even as she sometimes included herself in the category of people with mobility impairments, and even as she frequently described the complex negotiations that she worked out in order to manage her own independence, she also narrated herself (and a few others, such as Rudak) as separate from other people with disabilities whom she did not consider to be self-actualizing. In this view, disability, as a mindset, was not something that belonged to a body, so much as to an individual's failure to balance inner and outer worlds to achieve a self-actualizing perspective on the world.

This assessment of self-actualization was inevitably bound up with class and family background. When facilitators considered Alina, for example, to be a disabled person who was not self-actualizing, they did not consider how Alina's situation was significantly shaped by her family circumstances. Alina was the daughter of a more-or-less single mother who, retired from a working class job, survived on a pension that barely covered food and rent. By contrast, Anya's own family was quite well-off financially, and had certain official social ties so as to hold the kind of cultural capital that required that Anya be met with respect. They were able to support her in ways that allowed her to work as a professional psychologist, her

⁶⁵ Also, as a peer or friend, she was interested in my psychological state; perhaps because we shared similar levels of education and high emphasis on career achievement, I felt more able to talk candidly about myself with Anya than with other interlocutors.

mother transporting her personally to and from work in the family car. If Alina had had the kinds of familial resources - in terms of both financial and social capital - available to Anya, her situation might have been quite different.

In this sense, Anya's role as a psychologist - a purveyor of therapy, rather than a recipient of therapy - hinged on her status as an employed person. The definition by which participants were categorically invited to participate in the art therapy program was *unemployed* adult young people with disabilities. In this way, it was the attribute of employment/unemployment which separated Anya from the other members of the group. It is notable that employment, in this context, stood for much more than merely having a job: having the status of being employed represented the existence of the social capital required to get the job in the first place. It indicated that she possessed, and was recognized as possessing, an imagined set of social skills and competencies that made her an eligible candidate and a capable worker. Finally, the perceived social contribution of Anya's work-- its contribution to a collective national project—distinguished her from others with disabilities were not able to contribute in such meaningful ways. Anya's employment, in her own estimation and in the estimation of her peers in psychology, stands as a testament to her particular *vospitanie* or moral upbringing. She has mastered skills of self-management. She is more adept at the presentation of self in public life than her age-mates with severe physical disabilities. Indeed, Anya is, in fact, unusually intelligent and socially capable. At the same time, whereas many Russians may attribute Anya's success to her "moral upbringing," I suggest that it is important to note the impact that her inherited cultural capital and class status have had on her unusually high social status relative to others with disabilities.

Seen through this lens, we can observe a mismatch in the respective objectives of the

members of the art therapy group. Participants in the group imagined themselves as participating in and collaboratively creating an artistic project; the psychologists, on the other hand, tasked themselves with encouraging their clients' development of appropriate technologies of self. Whereas the participants attempted to enact what they perceived as their own already-existing moral personhood by performing *kulturnost'*, or engaging in social interaction in a shared space, psychologists found themselves in the awkward position of continually disavowing the moral personhood of the participants in order to enact their own roles as purveyors of *vospitanie*, coaching disabled selves in the development of new skills of self-regulation. That is, the framework of rehabilitation, a special mode of therapeutic citizenship reserved for bodyminds deemed permanently deviant, overdetermined disability. It cast Alina, Sergei, Vakas, and the other participants as wholly disabled and therefore as less than fully human/ less than full persons/complete selves, rather than as moral citizens with extraordinary bodies.

The Capable Independence/Minority-in-Democracy Model

This discourse of postsoviet therapeutic citizenship contrasted with another discursive concept of the disabled self, that, although related, operated quite differently. At the same time that this concert preparation was going on, the group was also used to negotiating a similar but different manner of self-work that has been delivered to Petrozavodsk via Western democratization efforts. That is, the notion of the independent, capable disabled citizen.

This is a conceptual framework in which the person with a disability is considered to be part of a minority group that has been unjustly prevented from participating fully in society. As the result of social attitudes, people with disabilities run the risk of not being

given the platform to realize their full potential. By encouraging people with disabilities to act confidently and independently, disdaining shame and pity, people with disabilities are constituted as political actors, entrusted to speak out against injustice on behalf of themselves and other members of their minority group. The realization of personal goals, and the achievement of a democratic society, are possible when members of the minority group achieve a liberatory consciousness, and speak up politically to make claims on a state to address injustice.

Although the psychotherapeutic and democratic approaches to selfhood and disability seem very similar - and indeed, they are made up of different constellations of similar ideas - the genealogies by which they arrived in Russia differ, and the meanings that they hold in terms of who is empowered to speak and in what way are quite different. In a psychotherapeutic view, there is inherently something wrong with the bodyminds of people with disabilities. In the minority model, there is nothing wrong with a disabled body, but the bearer of an unusual body is socially handicapped by cultural attitudes and the resulting configuration of a system that privileges the normate. In the therapeutic view, it is up to professional practitioners to assist PWD in becoming ever more self-actualizing by building *samoosenka* and skills for achieving success. In the democratic framework, it is up to people with disabilities to speak up for themselves and advocate for a social system that ought to change to accommodate them.

In certain instances, these threads became mixed. In Anya's telling, for instance, encouraging *samorealiziatsia* was a step on the way to civic advocacy. In other settings, people with disabilities were prompted to enact one script or another. Meanwhile, Alina, in interviews with me, an American versed in a minority model/social oppression concept of

disability, frequently voiced stories of the ways in which she had been wronged or prevented from full participation by a social system that always favored the normate or nondisabled; she often asserted a sense of frustration and helplessness in the face of a broken system; and she sometimes made off-color or ironically-pitched comments. In meetings of the art therapy group, however, she almost never raised such issues; instead, she worked to present herself as *kulturnaia*, *grammotnaia*, and to perform cultural citizenship by speaking when it was her turn, by volunteering for challenging or leadership roles, and behaving cooperatively and speaking in an educated cadence.

My interlocutors in the art therapy project had had multiple encounters with Western perspectives on disability as a minority political identity throughout their lifetimes. Examples of exposure to Western modes of understanding disability include: Sergei's father's trip to Duluth, Minnesota on a cultural exchange; the on-going non-profit projects that the troika participated in from childhood onward; Finnish intervention at the Martial Springs retreat, where they had all visited, until it was repossessed by the Russian government not long before my fieldwork; several inclusive summer camp programs sponsored by Northern European funds. Through all of these activities, the group was exposed to the core concepts and ideas of independent living, and moral citizenship through lobbying for social change. These approaches tend to value independence and individual accomplishment. Some were targeted toward practical life skills, or social participation. But an underlying goal became self-esteem and self-actualization. When I asked Natalya, an administrator at the center for children with disabilities, to describe the trajectory of that center over the years, she narrated the organization's move from self-help organization for mothers of children with disabilities, to a recipient of foreign-funded projects, to state-run state-funded social work agencies that

employ young professionals with degrees in psychology and social work. In this way, disability discourse and rehabilitation in Petrozavodsk was bound up in a complex amalgamation of discursive fields representing Soviet, liberal-political citizenship, and neoliberal therapeutic citizenship.

I find this complexity, and variation in discursive referent in many of my interview transcripts. For instance, in one case, I asked Sergei, not long after meeting him, how he had become involved in the art therapy project.

C: So how did you find out about the project?

S: They invited me. I always try to take part in these kinds of events. And they know that, the people, and in general, they invited me, they called me up. They said that there's this project, and that it will be interesting.

C: (laughs)

S: I came and then, so, it worked out, that I got invested in it, *vlilsia v nevo*, and it was even sort of my kind of thing.

C: You mean, that it turned out to be interesting?

S: It turned out to be interesting. Yes. And then, um... Now I am thinking that if there will be another project in the future, that I'll join in now and then. [unintelligible].

[...]

I feel like I have a very active life position [*aktivnaia zhinennaia pozitsia*]. I try to take part in all of the things, like the events, that the rehabilitation and social services organize. And here, after all, I'm doing this project, like we were saying. [...] And now there is this project, for the second time, at [the same organization]. ... I did pretty much whatever the non-profit organizations for young people had to offer.⁶⁶

⁶⁶ С. Насчет инвалидности...? Так, сейчас... То есть, ты хочешь спросить, в сфере инвалидности? Нет, я интересуюсь, вот, как раз в сфере инвалидности-то я интересуюсь вот этими различными законами. И я знаю, что я даже пользуюсь ими. Вот я получаю, допустим, путевки от государства, практически каждый год получаю, грех жаловаться. Туда или куда-то еще по стране езжу, в реабилитационный центр "Марциальные воды" езжу в Карелии здесь. Очень хороший тоже центр. Там очень много новых знакомых появляется, и общение - общаешься по телефону, по интернету, - и встречи. Вот, сколько я уже там был? Получается, 5 раз, всего. Так что, я считаю, что все-таки то, что для инвалидов положено, я получаю.

Я считаю... Может быть, какие-то, там, законодательные нормы не очень хорошо работают, но, опять же, я сильно на этом не закиваюсь как-то. Поэтому, наоборот, я считаю, что у меня активная жизненная позиция. Я стараюсь принимать участие во всех вот таких, вот, мероприятиях, когда реабилитация и досуг организуются. И здесь, после того, как я уже бывал, получается, этот проект...

That is, in Sergei's own narration, he is at once an acquiescent therapeutic citizen ("they invited me"), and an active, self-actualizing moral citizen as well as an independent political actor ("I feel like I have a very active life position").

Rehearsal: Cultivating Moral Personhood

One Wednesday afternoon in the fall of 2012 I happened to bring my digital camera and tripod to group. Everyone agreed that it would be all right with them if I videoed our meeting. Our meeting unfolded that day was a comedic spectacle of frustrations and collaborative politics. The social workers, seeking to encourage the development of group identity, self-esteem, and self-actualization, met with a profound sense that no one was interested in either these abstract goals or in the concrete goal of working on the final performance. The group members, meanwhile, seemed amused by the unfolding spectacle of the group dynamic. Some, like Denis, pursued only their own entertainment. Others, like Alina, worked concertedly to present a performance of selfhood, of *kulturnost'*, that demonstrated a moral personhood that was not in need of therapeutic intervention.

The previous week, some discussion had been devoted to the idea of creating a group "logo" or a sort of seal or symbol to represent the project. This was a sort of collaborative task that had been proposed by one of the psychologists who worked with the group. The

Значит, один раз я был, когда без проекта, просто, тут вот дневной стационар был. Я сюда ходил, вот эти получать. Сколько, там, она сказала? Три недели, да.
И вот два раза на проект, то есть, я, вот, и в «Истоке»... В общественных организациях молодежных я, наверное, состоял везде. Когда это было возможно, старался и там, и там - везде быть полезным и что-то сделать для общего блага. Может, это, конечно, и не очень хорошо, что я не интересуюсь этой общественно-политической жизнью, но мне кажется, что проще живется в таком случае, если не обращать на это все внимания.
К. Ну, и не надо.
С. Да.

group already had a name, and so, she proposed, we ought to also have a logo. It seemed like an exercise that she may have take from a group work textbook: generating a collaborative group dynamic. Asking the members of the group what they valued, they had come up with a list of things the group was interested in that included: literature, drama and theater, art, learning, and community. Under the direction of the psychologist, I was tapped for my representational drawing skills to sketch in colored pencil a sort of seal that incorporated icons representing each of these values. Somehow, we had generated a sketch of a book, that was also a stage (designated by curtains), and surrounded by a bright yellow sun. There had also been some talk of a drama mask, the kind that are somehow represent comedy and tragedy in a single image, which I had gone home and googled, not knowing how to draw it. There was also a suggestion that perhaps the rays of the sun could be tracings of the hands of the group members.

As my video of the group meeting opens, the group is seated around a table. The walls of the room are painted pale green, in two shades, switching from light to dark about 5' up the wall. The tabletop is a brown laminate wood, long and narrow; fluorescent light fixtures are visible on the ceiling. A clock and a few boring art prints hang on the walls, and two balloons inexplicably float in one corner. The seven members of the group who were present were seated around the table, except for Vakas, who stood at the end of the table, camera on a lanyard around his neck and clasped in one hand, using his role as group photographer to exempt him from conversation. Three facilitators were also seated around the table, interspersed with the group. One group member, a wheelchair-user named Svetlana, who was a bit older than the others - a spinal injury survivor in her late forties, is not present. Lidia, too, had another commitment that week, so isn't present there.

The previous week, Lidia had presented us with a script for the performance based on the poems that each group member had selected to read or perform over the previous two weeks. She had woven the individual poems into general commentary about the great Pushkin, his poetry, and the autumn season. A minor disagreement had ensued when Lidia announced that according to the script, the group would need to select someone to act as an MC along with Lidia, providing the introductions and transitions between the various poems. Alina volunteered, but Lidia and one of the facilitators were concerned that her voice wouldn't carry, and that she wasn't up for the task of being constantly in the spotlight. I think they expected Sergei to volunteer, since to outsiders he would seem the most MC-worthy: he presents as the most physically capable, theatrically trained, and conventionally handsome of the group. However, Sergei tends to get shy in performance situations, and he didn't offer to take on the role. Alina, meanwhile, as I had discovered on the day when I first met the group and she volunteered to be the photographer's model, quite likes being in the spotlight (a different social worker had been facilitating on that day). These social workers had been surprised to realize that not only did Alina want to MC, she was assertive in proposing that she would do it. Realizing that they would be insulting Alina - and going against the principle of the project - if they told her that she was not an appropriate MC because of her embodiment and vocal presence - the facilitators backtracked. They couched their concerns in terms of her ability to speak loudly and clearly to an audience. Alina assured them that she could speak loudly. "I just don't usually need to," she asserted. Lidia agreed to work with Alina on her oral presentation style, and Alina promised to be a charismatic presenter.

In an interview with another theater professional, I learned a little more about how it is that this kind of thing might happen. In the theater, he explained to me, the most important

thing is the actor or presenter's ability to manipulate his or her voice and body. This notion of *plastika* is a talent that very few people have, and it is the job of the theater director to select the most talented actors to perform. In many ways, Alina's musculature, which, due to her DTsP, is tight and limits her motion⁶⁷, made her the least able to exhibit the quality of *plastika* (for more on *plastika*, see: Kayiatos 2012; Weygant 2011). Talent, a near supernatural capacity that flows through a person, is not necessarily related to an individual's personal merit. Unlike the American notion of meritocracy, artistic talent in Russia is perceived as extraneous to a person's individual character, a gift. In this sense, the untalented need not feel shame for their lack of talent, only to step aside and allow those who have a gift to perform. The facilitators' implicit feeling seemed to be that if Alina was MC, the level of the performance would suffer. They felt awkwardly stuck between the model of encouraging Alina's self-esteem - an explicit goal of the project -- and protecting her from possible embarrassment by selecting an MC with a greater talent and capacity for *plastika*. Because *plastika* refers to an actor's flexibility and capacity to seamlessly interact with his environment, in this context, Alina's body represents to the normative Russian theater professional the definitional opposite of *plastika*.

Meanwhile, Alina's offer to act as MC was one of good will. Had she not been the bearer of an extraordinary body, her willingness to volunteer for a leadership role, and one that surely required more work, would have been perceived as a gesture of good citizenship. By offering to take on the MC role, in Alina's own perception, she was enacting the habits of a moral member of the collective. Moreover, because she perceives herself as intelligent,

⁶⁷ A major symptom of Cerebral Palsy is muscular contracture, a permanent shortening and tightening of muscles.

capable, and willing, it would have been inappropriate for her not to volunteer, in the moral universe of collaboration and collective projects that draws on a Soviet model of citizenship. In this way, the response of the theater professional and the facilitator served to underline the stigma carried by her disability: why should she *not* be the one to speak on behalf of the group? Yet, Alina appeared unperturbed by the discussion; it would have been perceived as capriciousness or egotistical self-centeredness for her to take the selection of an MC personally.

On the day of the video recording, the scene gets going as the psychologist reviews the image of the group's "logo" we had prepared the previous week and that I had touched up at home. It was horrendously ugly. The draft sketch wasn't particularly well rendered, and moreover, the elements of the logo were banal: dull, overused symbols amassed together. The composition felt forced. Perhaps the failure of the composition was the result of my own inability to understand the intention behind the suggestions, or, perhaps it was a reflection of a basic ambivalence that the group members had expressed about the endeavor. In short, it was an uninspired rendering. When the project of creating the logo had come up the previous week, none of the group members felt strongly enough about any given idea to defend it. Opinions and ideas about what should be included in the group logo were produced by group members only with prompting and prodding from the psychologists, acting as facilitators. While their goal in suggesting a logo was most likely to encourage people to listen to one another articulating goals for collaboration, this was not what happened on the day we revisited the sketch. Instead, everyone talked over everyone else, constantly interrupting and speaking off-topic. No one liked the logo, nor was anyone invested in the basic idea of creating one. This was not a group with a PR agenda.

As the recording begins, everyone is talking amongst themselves. One of the programming professionals takes on the role of facilitator. She asks everyone to take a look at the script, while she asks me about the sketches we had prepared the previous week. Two of the facilitators begin to talk about the utility of the logo, and describe to me how the stage could be decorated using various drawings and photos. Everyone talks amongst themselves; two girls, Sveta and Sasha, do as directed, and practice reading their poems to one another. Sergei talks about something with the third social worker at the other end of the table. Vakas shuffles back and forth at the end of the table, shifting angles, snapping photos, listening to the various conversations. Alina looked bored; she had no one to talk to from her seat. Then the facilitator calls everyone's attention to the sketch.

She asks, "What will the logo be for our group, our team? We made this logo - does it work? What do you recommend? Quiet - I can't hear - Alina, what did you say?"

At this point, everyone begins talking over each other at once. No one at the other end of the table can see the small sketch on a notebook sized piece of drawing paper, and they can't remember what the various elements of the logo - the icons that make it up - are, nor can they tell from a distance. Even though the facilitator attempts to ask for opinions from members of the group in turn, it takes a full two minutes before she can actually hear Alina's question in full, because she keeps getting interrupted. Denis, an older man with MS at the opposite end of the table, keeps interrupting with non sequiturs. Sveta, sensing that the facilitator feels that no one is respecting her authority, attempts to come to her rescue by interrupting to explain the obvious to Alina. Sasha sits bewildered by the scene, overwhelmed by the frenzy. Sergei goes back to his separate conversation with the other social worker.

Denis: Exactly that? I would do it differently. What is it? [trying to see from the other end of the table]

Facilitator: It's a theater curtain and a book. It's a curtain because we are putting on a small play. Right? And this is a drama mask - because sometimes we are one way in life, but then, when we read poems, we become something different altogether. And we are collaborating on a theatrical project.

Denis: [slowly, slightly mocking the sing-song] Well that explains it. [turns to Sergei, across the table] Well, whatdya think? *VAM NORMAL'NO?!* [Sergei smiles, giggles, embarrassed].

Facilitator: Well, now you're already - [general uproar] decide without me!

Alina: /It's fine with me!⁶⁸

Sveta: /Fine with me!

Alina: I don't know what else we would put.

In spite of the group's attempt to dismiss the conversation, the facilitator pushes on. Vakas makes his way to the near end of the table, out of the frame of the video, where he can see the drawing. Someone asks how the final rendering will include the drama mask, which was set to one side of the other elements in the sketch. When Alina finally produces an actual opinion, she suggests that maybe it would be better without the sun, or as Denis puts it "that yellow part." This leads to a long discussion of the "sun" and the symbolic intention of its *iarkost'* or brightness.

Sergei:[into a sudden pause in the fracas] It seems to me that that works pretty well.

Facilitator: If you say that it will work, then we'll redo it on a really big paper. And then we'll hang it on a huge piece of paper.

Sergei: So it's supposed to be like... a logo - it's //generally our, it describes our project.//

Alina:// [to Sergei, talking over him] What do you want it to be?//

Facilitator: Our project. Yes. //Our collaborative work [*sovmestnaia deiatel'nost'*].

Denis: //Ah - can I just say/-- that thing, what's the yellow part?

Everyone together: It's the sun//Sun//it's a sun. [the facilitator's voice is loudest]

[Denis smiles that it was so obvious to everyone else, and then Sveta laughs]

⁶⁸ In this transcription, a single slash indicates two people speaking at once; a double slash indicates an interruption or overlapping speech.

Denis: Reeceally?

Alina: Yep.

Sveta: Sun, sun, sun.// It brings everything together [*Vse eto soediniaet*].

Denis: //The sun? Allllright then. //

Cassandra: Well, Sergei is our expert on-- [gestures, asking Sergei what he thinks]

Alina: [taking the opportunity of the momentary pause to be heard] Well, it would be okay, if it was --

Facilitator: Right now you don't need to pay attention [Sveta is talking, fretting over details, and the facilitator hears her but continues talking, drowning her out] to the details of the shape. It will all be drawn properly.

[...]

Alina: // Why did we put that sun?//

C: What?

Facilitator: What?

Alina: Without the sun.

C: [verifying] Without the sun?

Denis: *DA!* Yes! Without the sun -- just the book.

Alina: [matter of factly] And the mask.

Facilitator: [dejectedly] But should there be something in the place of the sun?

Sveta: [trying to please the facilitator] Yeah, it might be a little boring without the sun.

Facilitator: It seems to me that it would a little boring for one, and then secondly, it would also be -- everything is really sunny, as I see it //

Denis: Hey guys -

Facilitator: - as I see it, the sun, it brings everything together, and it brings a brightness to the book. The brightness of our project, I think you'll agree. The first time that we worked together we also did a theater project, right? //And now we are doing another one. //

Denis: //[monotone, talking at the same time as SW] The first time was a *delight*, and the second time *tozhe prelest'* //

Facilitator: *Iarkost'*. Brightness. The brightness of our collaborative work.

In the course of the conversation, Alina, the only one who is actually thinking about the question that was posed, manages to offer three different possible opinions - that the logo is fine, that it should be redone without a sun, and that she agrees with whatever everyone else

thinks. Meanwhile, the dogged facilitator attempts to defend her idea of the sun as a symbol of collaboration, which everyone besides Sveta - who is acting the role of the teacher's pet - seems to be mocking or maligning. Denis's main goal seems to be to cause distractions and draw attention to himself; he interrupts with sarcastic remarks and even songs. Sergei's goal seems to be to get this conversation over with as soon as possible; he keeps quiet or voices agreement at moments when the conversation seems able to swing toward to resolution (he is waiting for rehearsal to start). Vakas stays out of the fray, grinning, and watching the events unfold.

Later, the following spring, Sergei would say of the project that he was disappointed with the level of theatrical work. Always polite, he couched this assessment in endless paragraphs of carefully weighed observations. "I wish we would have rehearsed more," he told me.

In the moment, the dysfunction in the attempted collaboration seems driven by the group's general sense that the idea of a logo is pointless - especially one that relies on mundane symbols - and by a general glee for the raucous chaos of large group conversation. In later interviews, Alina, Vakas, and Sergei would all tell me that they enjoy going to the group for the social interaction.

As the conversation about the logo continues, Alina gets bored and begins flipping through her script. The facilitator had also gotten overwhelmed, saying shortly to anyone who interrupts, "Shush! We are speaking one at a time!" as if to kindergarteners. She gets fed up even further when Denis begins rambling about nothing; he refuses to answer questions but just extends the exchange. "Do you understand what a symbol does? What a logo is?!" she cries, exasperated.

After more than 15 minutes of conversation in this mode, I interject, seeking some resolution, and reread the written list of possible symbols that we had come up with the previous week. The majority votes to accept the symbol as it is. The facilitator asks me to go on with drawing it.

At this juncture, Alina announces that it looks like something advertising a daycare center. Indeed, she has a point: sunshine, *solnitsa*, is frequently used as a name or logo for kindergarten and daycare centers in Russia. In making this comment, she speaks up suddenly, as if against her better judgment. She seems frustrated; in a sense, her accusation that the logo is childish is also a way of pointing to the pedantic nature of the conversation as a whole. Even though everyone would rather move on, she can't keep from voicing this frustration. Everyone responds that the issue has already been decided. Implausibly, the conversation continues for another four minutes.

Then, the facilitator says, "Okay - we've moved on - let's do it. Let's read the script." Sergei looks relieved.

As everyone turns their attention to their stapled paper packets, Alina asks how long the performance will be. "Twenty minutes," respond the facilitators. With this opening, although the intention is to read through the script, what ensues is a series of questions about the script. As everyone begins to raise questions and problems with the script, the facilitator moves to supports this line of thought.

"What would you add? It's your project," she points out. "Alina, what's good and bad in it?"

Alina looks at the script; she appears dissatisfied, but doesn't know where to start.

Finally Denis says, "Excuse me, but who is Pushkin to us? *Izvinite, no Pushkin - on*

nam kto?" There is an incredulous silence, then everyone laughs. After all, we all know who Pushkin is.

"He's Pushkin." says the facilitator, then laughs, as if that's explanation enough - Pushkin is Pushkin.

"A poet," says Alina.

"Aleksandr Sergeevich!" someone adds.

Of course, Denis knows who Pushkin is - his question is rhetorical. Why the focus on Pushkin? He goes on. "We don't read any of the long poems, he complains, only short ones."

Alina points out that there is an excerpt from *The Bronze Horseman*, an epic poem of considerable length. At this point my video cuts off, but I well recall the ensuing conversation. Having finally stumbled upon a topic that everyone can chime in with an opinion on, the facilitator proceeds to go around the table. She has been attempting to spur a conversation about the group's collaboration for over half an hour by this point, and has stumbled into a topic that the group members are actually invested in. Various group members weigh in: some like the poem they have selected, others aren't sure that they see how it all fits together. Someone wants to know who will play the music for the sections with singing. Sergei, in his measured, round-about way first praises the script, then admits that he wishes it were more like a real play, and less like a series of readings. Finally, everyone has spoken but Vakas, who is still haunting the outskirts of the group, camera in hand.

"Vakas, what about you?!" asks the facilitator.

Vakas rocks from foot to foot for a moment, considering the shortest possible sentence to express his sentiment. His facial expression shows that he is about to speak, creating an air of anticipation as the group waits for his pronouncement. "There's too much

Pushkin, and not enough of us!" he drawls.

The group bursts out laughing. "Valery," the facilitator chirps, "you have summed it up perfectly!"

Having arrived at a seeming momentary consensus, having coaxed opinions out of the participants, and having come to the end of the session, the facilitator wraps up for the day, declaring that everyone should think about changes they'd like to make to the script at home. The usual bustle of returning coats, and finding hats, conducted to the sound of Denis's raucous singing and Sveta's busy socializing ensues. All of the participants are relieved to be done with the conversation, and several are eager to get on to the real socializing, the unstructured bus ride home.

The next week, Lidia is back. And, in spite of the social workers' imploring that participants consider changes to the script, when it's time to consider changes, no one has anything to suggest. The opinions that everyone had produced the week before may have been real at the time, but they were not compelling enough for the group members to take on the daunting task of trying to rework a script. Rather than spur the group members to self-actualizing action, the previous week's conversation rendered all too apparent the reality of how difficult collaboration can be. Instead, the group goes back to reciting tongue twisters and rehearsing the script, as written. The facilitator's effort to encourage the group members to claim a shared identity and to build skills of self-actualization by revising the proposed script come up short.

Later, when I get home, I'm still thinking about the unfolding events, about Pushkin, and puzzled by the group's disinterest in altering the script. While checking my email, I get an online chat with a friend, a Petrozavodsk native, online in his parents' apartment in

another part of the city. I ask him how well he knows Pushkin's poems and biography. "In school we read Pushkin like the bible," he types. The knowledge of Pushkin, the recitation of his work, is at the core of Russianness. I have never heard a Russian say anything against Pushkin (while one can find plenty of English-speakers who will dismiss Shakespeare).

In this way, the comment, "too much Pushkin" carries a subtle blasphemy. Even as the participants answered the social workers' questions, admitting to not really liking the Pushkin script, competing logics and objectives kept them from proposing revisions. On the one hand, they may have perceived the conversation about making changes as nothing more than a hypothetical exercise: what WOULD you write, if you were to rewrite it? In this sense, the facilitator's solicitation of their opinions was less about changing the script, per se, than about encouraging each group member, as an object of therapeutic intervention, to build self-confidence by voicing an opinion. On the other hand, perhaps, the group members felt that to make or suggest changes to the script would insult Lidia as a theater professional; they may have abstained from suggesting changes out of respect for her, and a sense that a *kulturnyi chelovek* - cultured person - would not undermine the expertise of a trained professional. A cultured person, after all, loves Pushkin. Or, perhaps in addition, the participants were more interested in the social bonds that they built with other group members than in the details of final production. In this sense, there was little incentive to make or sustain suggestions to change the script, when the object of getting together and socializing was already achieved just by attending the group meetings.

Performing Disabled Citizenship

On the day of the concert, we gathered at the new municipal facility for disabled adults. The courtyard had not been paved, but all the entrances had functioning ramps, and

the shipping plastic had been removed from the new furniture. The paint on the walls had dried, and the new doorman - himself a local person with a disability - had taken up his post by the main entrance. There was no sign on the building, or out on Nevskii Prospekt to let anyone know where the facility might be. The half of a building that the facility occupied was set down a driveway behind two separate apartment buildings and courtyards, and very close to my own rented apartment, like others in the neighborhood, in a mixed-use building with residences upstairs, and shops or offices on the first floor facing the street or driveway. The main entrance was on the far side of the building from the main road, and faced a further driveway area, bounded by a small metal barrier, on the other side of which was a public park type of area through which ran a small river, making its way from the forested regions to the west of the city, under the railroad tracks and through the center of the city into the lake. This was neither particularly ceremonial land nor wholly unimportant. Residents walked and skied along the river banks, and at points, nearest to the center of the city, the paths were well kept and even somewhat landscaped. Elsewhere, the small river was traced by rough, muddy and eroding pathways, or small trails would run along one bank for a time between a pair of bridges, or an apartment complex and a road, and then disappear.

Inside the new studio, the walls were a peachy-pink. One wall was lined fully with mirrors, and the previous week a long discussion had ensued about where and how to seat the audience. Some felt that it was best to have the performers sit with their backs to the mirror wall, in order that they not be distracted by their own reflection. Others felt that the audience members would inevitably be distracted by *their* own reflections, and so it was best for the performers to sit facing the mirror wall. One of the psychologists asserted that in her professional opinion as a psychologist, the burden was much greater for a performer to have

to see his or her own image. And so, in the video of our performance, shot, again on my small digital camera and portable tripod, we are seated with our backs to the mirror, facing an audience that is out of range of the camera.

To our surprise, the week before during our dress rehearsal, we learned that we would be sitting at a table. There was protest: what is the point of the table? How is it a play if we are sitting at a table? Wouldn't it make more sense if we just entered and exited?

Not sitting at the table were Lidia and the facilitators. Somehow-- I don't think anyone really thought it through-- I was deemed a member of the collective and seated at the table with the rest of the group. Perhaps this was because I had no responsibility except to recite my Pushkin excerpt.

We had run through our script several times the week before in a dress rehearsal and knew the order of presentations. My friend Masha had helped us find a volunteer from the music college to play keyboard in accompaniment of Sergei's song, which he performs as duet with Denis who was not about to let an opportunity to sing in public pass him by, and although Sergei had rehearsed with her, the rest of us hadn't seen her before or seen them play together.

Unlike in our maligned group logo, there was no curtain, so there was no secrecy or magic to our assemblage in the room. We sat, backs to the mirror, hands on our laps behind a long table, facing parents and other guests seated in folding chairs. The logo concept had been abandoned, and the rendering of the image sat abandoned on an 11x17 sheet of paper in one of the social worker's offices. But photos and drawings by members of the group had been hung along one of the side walls.

The social workers opened the event by offering an oral report of the achievements

and work of the project. An extremely dull – and obviously last minute - 15 minute PowerPoint presentation about the art therapy program was presented on a large screen TV. The two project facilitators making the presentation were suddenly sheepish themselves after weeks of cajoling group members to speak up and be assertive and self-actualizing.

Meanwhile the group members sat still, already seated at the table before the audience. We tried not to fidget, since the eyes of the assembled parents and friends and social workers were directed toward us, even as the focus was on the PowerPoint presentation. There was a palpable sense of being reduced to a bureaucratic tally, a project realized, and a strange silencing, in that the group members were not invited to speak their own assessment of the program. Instead, everyone - even Denis - waited patiently for the planned program to begin. Disability Studies observes that people with disabilities are frequently denied the opportunity to speak for themselves, both in advocacy settings, and in representations in literature or other media. Rosemarie Garland Thomson writes, "representation tends to objectify disabled characters by denying them any opportunity for subjectivity or agency. The plot or the work's rhetorical potential usually benefits from the disabled figure remaining other to the reader -- identifiably human but resolutely different" (1997:11).

In the case of the Autumn Concert, the narrative presented to the audience was one of competent and benevolent work to rehabilitate and provide meaningful social interactions for a group of disabled figures. The social workers spoke directly to the audience, with no invitation for the performers to chime in. The voices of the performers were heard only in the expression mediated by the scripted text, largely composed of Pushkin poetry, with connecting passages presented by Alina and Lidia. If one were to watch the performance, one

would get the distinct impression that the disabled performers themselves were removed from the construction of the narrative. Yet, as the events at the group meeting several weeks before demonstrates, the facilitators made concerted efforts to provide a forum for the discussion of the script with the group; their efforts to foster collaboration made headway, but ultimately, the script contained almost no words written by the performers themselves. In fact, the only exception was a poem by Vakas; but, at the last moment, Vakas refused to read the poem himself, leaving Lidia to present it on his behalf, although he was still seated at the table along with the other performers.

Given the cultural context, the insertion of an "official" presentation of the project at the start of the concert came without forewarning, but it was also not unexpected. In Russia, it is customary at the start of events for those who take responsibility for the proceedings to offer a formal introduction. The participants never mentioned the insertion of the PowerPoint presentation to me in later discussions.

The event itself went off smoothly. It opened with a choreographed wheelchair dance between Sveta (the forty-something wheelchair user) and one of the social workers, that used the pretext of acting out a scene from Pushkin's era, and reading a love letter from one of his works, to tie it to the theme. Lidia stood to one side and presented with panache; Alina fulfilled her role as MC, her cheeks sparkling with blush that we had applied hurriedly in a nearby room just before the performance (she usually doesn't wear make-up). Sometimes her voice was a bit quiet, and she often gave the impression of reading her lines from her script, but she offered a sense of good will to the audience and her fellow performers. Everyone recited his or her poem well (except for Vakas, who grinned as Lidia read his). Sergei's song was a particular hit.

As the concert came to a close, the audience applauded, and soon there was a great general milling about and mixing of audience and performers. They were busy chatting with one another and family members, taking group photos, and reclaiming their artwork from the wall, spirits high. After a time, we were shepherded by the project facilitators to a kitchen room, where a table had been set with food and a cake. A proper celebration ensued, including an early celebration of a birthday, some toasts, and much socializing amongst the facilitators, Lidia, members of the group, and a few parents who had stayed.

When I asked Vakas several months later if he remembered the conversation about the script and Pushkin, he told me that he didn't. Later, in his 2014 book, *My World of Inspiration*, in a section titled *A Diary of Golden Days*, Vakas included the following reflection:

The concert was amazing! I got out of reading somehow: it was an intimidating event I put Lidia A-- (the actress) up to the task: she read *Rubin* for me. But even so the really really most amazing number - it was Sergei and Denis's duet! They sang [the folksong] "*V Kuznitse*"! I am on my way, out there, now I'm blustered away! ... Afterwards, when we were already drinking tea, our Lenka the Eternal Optimist came by (in the sense that she wasn't online, and I begged O--- to invite her). I got her in a hug right away, and so did Deni-Melon as well. Then I stole her back and we hugged again, and I ran around with her in the corridors a little: in my glee I forgot everything and I had to look to find where we were holding our celebration: Lena asked. Well, and Cassandra, of course! We were walking arm in arm -- until Lena came... And really I am not exactly indifferent to O---! At one point I liked one of them, and then having gone down the staircase, I liked another one! So suddenly! Oh, I was grumbling to her after falling down, I wished she would hug... then that she wouldn't hug; then I started to hug her - and often!⁶⁹

Vakas' recollection of the concert focuses squarely on his own experience of sociality. As he often says, talking to people, seeing people, "gives him positive emotions." So often isolated from everyone besides his immediate family, Vakas finds the social enterprise of being

⁶⁹ In Vakas' publication, he retains all of the idiosyncrasies of diary writing - typos, strange word use, inside jokes with himself. I have tried to maintain this style in my translation, though avoiding typos. I have however, altered the names of some individuals, replacing them with just an initial in a style that occurs to Russian literature (e.g. A--- in place of Aaron, for example), in order to preserve the privacy of certain identities.

around so many people weighty with possibility and emotionally charged. His journal entry conveys his deep fondness - and sometimes romantic sentiments - toward familiar people whom he otherwise rarely sees. Vakas, in his literary mode, squarely resists therapeutic citizenship; he also resists any suggestion that he ought to assert a sense of individuality. At the same time, Vakas stakes out a different role for himself - that of the artist. He uses his speech impairment as an excuse to speak infrequently - a characteristic that works to his advantage, as it is customary for culturally adept masculine artists in Russia to withhold comment until they might have the last word. Meanwhile, he situates himself as a man of culture - even as his romanticism might cause some women to roll their eyes, his literary and artistic interests locate him as such. His move to reveal himself in writing, rather than in impaired speech, bolsters this identity. His silence is then perceived by others - social workers, psychologists, peers - as pregnant with unsaid thoughts, which might be retrieved, later, in literary form. Vakas may have wanted there to be "more of us" in the script, but he also has no trouble finding Pushkin in himself.

Conclusion

Denis's irreverent question about what Pushkin had to offer the group, and Vakas' proclamation that the script contained "too much Pushkin, and not enough of us," suggested a further critique. Pushkin is not only Pushkin the poet, whose words had edged out any of the group members' own. Pushkin also stands for the myriad ways in which adults with disabilities are asked to constantly work on themselves. Their adulthood and citizenship is constantly implied to be less-developed than that of other adults around them. The work of becoming citizens is never done; they are always the subjects of ongoing therapeutic interventions.

In therapeutic settings, my interlocutors engaged a variety of modes of coping with the implication that as bearers of disabled bodies, they were not bearers of moral personhood. One mode of challenging this and presenting oneself as a moral citizen was to assert a sense of independence, a willingness to participate, and a degree of cultured sophistication in sanctioned/recognized performances of selfhood, indicating that one is already a moral person. Another mode is to profess cultured sophistication. Yet another would be to engage in the tasks of self-work, demonstrating the development of skills of self-work and therapeutic citizenship. Each of these strategies attempts to delocalize the social stigma of disability from the individual body, through the enactment and performance of a range of competencies, each of which demonstrates a mode of self-realization.

At the same time, a topic for further consideration might be to address the ways in which the forms of therapeutic citizenship that circulate in Russian neoliberal popular culture, as a mode of encouraging the able-bodied citizen to engage in ongoing self-work, *differs* from the therapeutic intervention, perhaps *rehabilitative* citizenship, that occurs in the case of this art therapy group. That is, in this case, as bearers of non-normative bodies, the participants are cast as not fully capable of performing competent self-work, or behaving as self-actualizing citizens without the intervention of professionals, who are tasked with urging them to develop these skills. At the same time, by virtue of their status as *invalidi*, my interlocutors will never be fully "restored" to full citizenship, in that their journey to "successful" socialization cannot be completed in the existing social milieu, which will always perceive their difference as deviant.

Despite this, the members of the art therapy group exhibited great virtuosity in their negotiation of competing discourses of virtuous or cultured behavior. Even as the social

workers presented tasks and posed questions to the group in sometimes frustrating and pedantic tones, no one - aside from Denis, who does so intentionally - spoke offensively or in the wrong timbre for the setting. The group members manage to remain polite, to express themselves without offending, to tease and play and have fun, to show indifference to facilitators' irrelevant ideas (the logo!), at the same time that they ultimately do assert themselves, negotiating complex relationships of hierarchy, discursive forms, and social positions. Everyone got what they wanted: Vakas' poem was read aloud, but he didn't have to read it; Alina was co-MC; Sergei performed a song. The cathartic moment prompted by the idea of "too much Pushkin" gave way to a culmination of the project in which the social workers were able to perform professional competence, the participants falling back into the appropriate role for the *invalidi* receiving therapeutic socialization during the unannounced formal presentation. And, in the end, the true impetus of the participants was indeed to socialize with one another and with other visiting acquaintances, to present their creative work in a setting that was safe and supportive. Self-actualization was negotiated through culturally appropriate performances of identity. Once I began to see past all of that Pushkin, the Autumn Concert turned out to be by and about the group members after all.

CHAPTER X

SERGEICHBURG: IDENTITY AND MEDIA REPRESENTATIONS OF DISABILITY

An online video clip.⁷⁰ A comedian standing on stage tells a joke: "People watch me all the time... someone watching this video online probably thinks that their internet is slow!" (Comedy Battle. Season 3, Episode 13). Sergeich, the comedian, has *DTsP* or *detskii tserbralnyi paralych* (a Russian medical diagnosis similar to Cerebral Palsy). He walks confidently and wears a graphic t-shirt and suit jacket with jeans. His tone is ebullient, though his speech is unusually labored. His joke pokes fun at his difference, in this case, the slowness of his speech, and, the politics of staring (Garland-Thomson 2002; Phillips 2001: 139-150). At the same time, the joke references the online mode by which his image, ideas, and jokes travel.

Sergeich was a contestant on the 2012 season of a Russian television show *Comedy Battle*. The show aired on TNT, a channel featuring mostly comedy and entertainment programming. Additionally, clips of the show can be viewed and shared online. Sergeich, following his Comedy Club appearance, gained an online fan base, and even his earlier videos became popular. One, a rap parody video titled "Welcome to Sergeichburg!" (Kutergin 2011) is particularly compelling. There is no such city as Sergeichburg; rather, it is a made up place that exists only in the video, in which Sergeich himself is a hip-hop superstar. In creating the imaginary city of Sergeichburg, Sergeich opens a new metaphorical

⁷⁰ A version of this chapter was published in Russian and English in the Russian academic journal JSPS, (Hartblay 2014). An early version of this chapter was presented at the Crippling Development Conference in Prague, Fall 2013.

space. Sergeichburg, morphologically, is clearly *Russian* (Sergeich +*-burg*), but it is Russia redrawn, a Russia in which people with disabilities are recognized, embraced, and can be celebrated by their fellow citizens.

Sergeichburg is significant because it offers a counterpoint to the normative marginalization of people with disabilities in Russian public life and in media representations. People with disabilities are excluded both *materially*, as pedestrians and fellow citizens on the streets of Russian cities, where physical barriers block participation, and *symbolically*, when real voices of people with disabilities are left out of public discourse and mass media (Iarskaia-Smirnova, Romanov 2011), and many Russians would refuse to employ a person with a disability or send them to school with their child (FOM 2012). People with disabilities were systematically segregated, isolated, and institutionalized throughout the Soviet twentieth century, culminating in a state official declaring to an international audience that there *were no* people with disabilities in the USSR (Phillips 2009; 2011).

As discussed in an earlier chapter, Soviet-built apartment complexes are still the most common type of housing in contemporary Russia, and are notoriously inaccessible (Kikkas 2001; Mazzarino 2013). In the Post-Soviet era, media coverage of people with disabilities has grown, often as journalists seek to cover "social problems"; frequently portrayed in this idiom, people with disabilities come to be seen as social problems themselves (for example, see: Verbilovich 2013:263-264). Even as real people with disabilities are mostly left out of public discourse, metaphorical invocations of disabledness are frequent (Phillips 2011; Iarskaia-Smirnova, Romanov 2011). All of this renders Sergeich's appearance as a contestant, and as an actual person with DTsP on Comedy Battle, remarkable. In these

circumstances, televised events and online interactions become an important mode of social interaction and cultural engagement for people with DTsP. While people with disabilities in Russia are often physically isolated from their peers (Driakhlitsyna 2009; Kulmala 2013), Sergeich's online video clips - as a medium - have particular potency in that they can be shared across architectural barriers and passed via online networks of people with disabilities⁷¹.

I first heard about Sergeich from Alina, who also has DTsP, on a visit to her apartment in the fall of 2012. Alina spends much of her time in her computer room, online, or in the living room of the apartment, watching TV. She is a fan of TNT, a channel that features programming that she categorizes as aimed at younger audiences (as opposed to cultural programming on other channels). TNT, she points out, doesn't have a news show - just talk shows and reality shows and comedy⁷² - and when you're bored and stuck at home, she says, it's depressing to watch the news.

Alina talked about Sergeich regularly over the course of that fall, often sending me online video clips of his latest appearance on the show via the social media site *V Kontakte*. Sometimes, at her apartment, between recording an interview and drinking tea, we would take a break to watch Sergeich videos. Alina always was several steps ahead of me in figuring out who Sergeich was, where he came from, and what he was up to in real life as well as in the reality programming that we streamed. Over the course of that fall, Sergeich went from a largely unknown comedian to a nationally known media presence. The first or

⁷¹ Internet penetration in Russia is over fifty percent throughout the country (even in small cities) with higher user-ship in urban areas and amongst younger users. See: TNS Global Usage Report 2013 (<http://www.tns-global.ru/services/media/media-audience/internet/description/>)

⁷² According to Wikipedia, TNT was founded in 1997. The acronym stands for «Твоё новое телевидение»

second time that Alina showed me one of his videos, she then showed me his personal page on V Kontakte. At that point, his page was like that of any other Russian in their twenties - full of personal remarks, offhanded posts of music and photos to friends, and clearly maintained by Sergeich himself. By the time I prepared to write about him, the following spring of 2013, his VK page had become a PR interface, revised and reworked into a sleek professional presence. Alina's experience of watch Sergeich grow famous was particularly satisfying - she had immediately upon seeing him on Comedy Battle searched for him and added him as a friend on VK - and so she felt a sense of authenticity about her attachment to him, having watched his career develop.

Sergeich's remarkable departure from Russian cultural norms of disability representation call to mind crip theory. The term *crip* is a linguistic innovation of disabled self-advocates. A self-described *crip* is a person who is tough and self-actualizing, the opposite of traditional understandings of crippled, as in, *in need of charity and help*. As a theoretical intervention, *crip theory* is often located at the intersection between disability studies and queer studies (McRuer 2006a; 2006b). These two spheres of critical theory - queer and crip - are each concerned with traditionally stigmatized populations, and work to understand how these subcultures form and develop pride in identities that are maligned by majority culture.

Orthographically *crip* is short for *cripple*. It came about as a rejection of politically correct language in favor of short, descriptive word. Like *queer*, *crip* reclaims a term that was once derogatory as empowering. A similar move is unfolding amongst some disability activists in Russia who refuse descriptors such as "people with special needs" in favor of the stigmatized but direct "*invalidi*" (Perspektiva 2012). In contemporary anglophone scholarly

works, the word *crip* immediately references the goals of expanding rights and justice for people with disabilities. It also calls for public recognition of people with disabilities as imbued with personal characteristics that are opposed to traditional concepts of disability: strength, self-confidence, independence (or, considering feminist critiques, interdependence), sexuality, a sense of humor, and a sense of self that seeks liberation from stigma.

Crip theory holds that a non-normative embodiment does not preclude participation as a citizen. Rather, able-bodiedness is a temporary condition of all human bodies. All humans experience physical and intellectual impairments, temporary or permanent, throughout our lives, and a great deal of cultural work goes into reproducing the myth of normalcy and the idea of the normative body (Davis 2006). This work of perpetuating a myth of a normal body is called *ableism*. *Ableism*, can be defined as the systematic discrimination and exclusion of people with disabilities, which functions to privilege able-bodied members of the population through institutional and cultural norms (Castenada et al 2000; Linton 1998: 9, 34–36). A crip outlook requires actively working to undo ableism, that system, which like other "-isms" (racism, sexism, heterosexism) works to discriminate and exclude, and, is intimately entwined with other systems of domination (McRuer, 2006b).

This chapter considers how crip theory, as a specific strain of disability theory, carries over into the Russian context. Here, I offer a close reading and possible interpretations of two of Sergeich's comedic performances. Centering crip theory also offers a further inquiry into the discursive norms of disability and the related formation of *invalidnost'* as a minority group identity in the contemporary Russian cultural context, especially in relation to media representation of disability and its affects on media consumers with and without disabilities (Markina 2013; Verbilovich 2013:258; Iarskaia-Smirnova and Romanov 2011). In this

chapter, I theorize the Russian public sphere as an imagined community of strangers, continually re/produced, in which minority groups may or may not be interpellated as fellow citizens through performative action. The question of interpellation is elaborated through a close reading of how it is that Sergeich, in his performances on Comedy Battle, uses parody and comedy to rupture the normative discourse, recasting the role of people with disabilities. I am interested in the moment of recognition⁷³ when Sergeich's audience members must encounter their own ableism, or complicity in the marginalization of the disabled minority. Additionally, I am interested in the ways that Sergeich's appearance in the reality television genre offers a case study in the relative deployments of therapeutic self-work that reality TV participants are routinely asked to engage in: how does Sergeich's transformation over the course of the Comedy Battle season differ from that of other contestants on Comedy Battle, or participants in other contemporaneous Russian reality TV shows? Finally, situating this investigation vis-à-vis crip theory, in what ways do heterosexism and ableism collude in implicit messages about what constitutes normal, and what constitutes a socially rehabilitated or dramatically redefined self in the Russian reality TV genre?

Publics, Strangers, and the Comedy of Recognition

Comedy is an arena in which critical scholars recognize a potential for the subversion of dominant discourse even as that very discourse is performed (Yurchak 2006). Televised stand-up comedy can incite social transformation; it is a performative address that calls on dispersed audiences to assimilate shared truths (Yurchak and Boyer 2010). Broadcast

⁷³ I use the word *recognition* here as a sort of inversion of Bourdieu's concept of *misrecognition*, wherein an actor fails to locate herself accurately in a network or hierarchy of power relations (e.g. complicity) (Bourdieu.1984:176,336. For an application of *misrecognition* to the postsoviet context, see: Rivkin-Fish. 2005. P. 29).

technology, in its reception by an audience that actively interprets and integrates its messaging, "mediates between reality and representation" (Askew and Wilk 2002:16). At stake, then, in Sergeich's televised comedy, is the dialectical relationship between the representation of people with disabilities and the actual behavior of Russians toward disabled fellow citizens. A shift in the social status of people with disabilities as a minority group (in Russia) becomes possible in the public arena, where stereotypes or cultural norms are both enacted and challenged (Verbilovich 2013:261).

Comedic performance offers an important opportunity to disrupt ableism. McRuer argues that both compulsory heterosexuality and compulsory able-bodiedness are inscribed through performative utterance and repetitive action. "Able-bodiedness itself not only [is] a compulsory law," he writes, "[but an] inevitable comedy. Indeed, I would offer able-bodied identity as both a compulsory system and an intrinsic comedy, a constant parody of itself, as an alternative disabled perspective" (McRuer 2006:304)⁷⁴. A crip sensibility *reveals the able-bodied norm as a comic farce*. Through performative parody or camp, the queer or crip performer points to the precarious contingency of normalcy. Queer/crip comedic performance makes light of and reveals the extraordinary cultural work that goes into reinforcing normalcy, and, by transgressing expected rules of behavior applied to certain embodiments, exposes our habitual complicity in the reproduction of the norm (McRuer 2006).

Sergeich's comedy is part of a broader idiom of disabled performance that forces an (often able-bodied) audience to relate to the experiences of disabled persons. For instance,

⁷⁴ McRuer is proposing a concept of compulsory able-bodiedness that builds on the concept of compulsive heterosexuality by paraphrasing Butler's description in *Gender Trouble: Feminism and the Subversion of Identity* (1999), thus extending queer theory into crip theory.

Josh Blue, an American comedian with Cerebral Palsy was the winner of a TV-show called "Last Comic Standing" [2006], similar in format to Comedy Battle. Even some of Josh's jokes share elements with Sergeich's. For example, they each tell a joke about how they got in to comedy. Sergeich's version reads:

People ask me how I got in to comedy. And I look at them and say, "What else was I gonna do - become an airline pilot?!" I mean, imagine - it'd be like - you sit down on a plane, and I start talking, with my voice - you'd be stunned. [emphasizing the waver and slowness of his voice] "Ladies and gentlemen, were now at a cruising altitude of 10,000 kilometers -- and everything is FINE!" (Comedy Battle, Season 3, episode 13)

In this joke, the popular associations of slow/labored speech with intoxication and incompetence, or, of rapid and steady speech with competence, allow Sergeich to poke fun at the kinds of occupations that would not be open to someone "like him". At the same time, by referencing drunken speech, the joke functions to draw attention to the ways that all bodies are only temporarily able-bodied: drunkenness is an impairment that his able-bodied audience can relate to.

The joke plays on what I want to call the *comedy of recognition*: the audience recognizes the horror they would experience as a reaction to hearing such a seemingly intoxicated voice from someone piloting an aircraft, and they laugh, agreeing that they would be shocked. They are also implicated in recognizing their own assumptions about what someone with DTsP can and cannot do. And, in doing so, they recognize Kutergin as both a fellow citizen and as a member of a particular minority group (the disabled) characterized by a set of experiences of discrimination.

The concept of *recognition* has multiple theoretical resonances. Nancy Fraser's essay on the politics of redistribution and recognition (Fraser 1997; Shakespeare 2006) theorizes the manner in which identity comes to stand for a class of people within society. This is useful in considering the path to justice for minority groups in a complex social field in the

Russian context as well as in the West (for example, Verbilovich 2013). The notion of *recognition* deployed here is also a sort of theoretical inverse to its linguistic cousin, Bourdieu's concept of *misrecognition*. *Recognition* as a theoretical concept is bound to Althusser's concept of interpellation, of recognizing oneself as a citizen, as the intended audience of a public utterance (Yurchak 2006:116; Althusser 1971). Warner's discussion of publics, particularly the moment in which a person recognizes an address as referring to him or herself and thus becomes a member of an audience or agentive public, considers and revises Althusserian interpellation (Warner 2005:77-78). By juxtaposing this complex of *recognition* with the crip notion of *comedy* described by McRuer (2006:304), that is, a performative unveiling of the absurdity of ableism, to form the phrase *comedy of recognition* I mean specifically, a moment in which a transgressive performance does two things: (1) it implicates the audience in the reproduction of ableism, *and*, (2) retains a comedic effect via the everyday notion of recognition - that is, the audience member laughs because he recognizes something of himself in the joke.

Sergeich both makes the audience laugh, and draws their attention to the lived reality of inhabiting a disabled body. His performance creates space for the audience to encounter the difference of his body with humor, rather than with pity or disdain. Again, the very fact that he has created an audience for a disabled body is, in itself, significant.

But what is an audience? This meta-event of creating an audience, in the digital sphere or in the televised ether, for a disabled Russian body, deserves some unpacking.

Social theorist Michael Warner points out that there are many different ways in which we deploy the term "public" in common speech. The "public sphere" as used in politics refers to a very particular idea going back to Habermas. In this usage "the public" is almost always

related to a state or citizenship. "Public" often simply means "audience" - a group of readers (like the readers of this essay), or viewers and listeners (as in a theater or listening to a radio broadcast). The two meanings overlap at times, for example, moments when an amassed public listens to a speech on a patriotic topic. Warner observes that we often use the idea of a public as a shorthand, in order to avoid having to comprehend the vast, unknowable, and heterogeneous nature of any of these collectivities. So, an address that creates a public is "an address to indefinite strangers" without a "sutured space of circulation" (Warner 2005:120). Television audiences become part of the "public" simply by watching; yet they remain strangers to one another and to the performers. As an individual audience member both contributes to the formation of a public, she is also recreated as a subject; her sense of identity is altered by an awareness of the public being formed, of strangers perceiving her as a stranger (Matza 2009).

In the modern world, strangers are everywhere (Warner 2005; Simmel 1950:402-408). Strangers - on the metro, in the market place, voting at the polling place - are critical to our modern social imaginary and sense of self. Warner writes:

In modern society, a stranger is not as marvelously exotic as the wandering outsider would have been in an ancient, medieval, or early modern town. In that earlier social order, or in contemporary analogues, a stranger is mysterious, a disturbing presence requiring resolution. In the context of a public, however, strangers can be treated as already belonging to our world. More: they *must* be. We are routinely oriented to them in common life. They are a normal feature of the social.
[2005:74-76]

The stranger is akin to the citizen, a fellow subject in the imagined community of the modern state (Anderson 1997). Appearing as a contestant - or talented stranger - on television or web video, then, Sergeich is hailed by viewers as a stranger worthy of attention. This is significant because strangers in the Soviet public imaginary - with the possible brief exception of heroes of the Great Patriotic War - were always able-bodied (Phillips 2009; Kikkas 2001). Since the

collapse of the Soviet Union, disability activists in Russia have been working to change the public perception of disability (Iarskaia-Smirnova 2001; 2011; Phillips 2011).

Given this theoretical explication of the audience or public, we can see that the media presentation of Sergeich's performances produce him as a Russian stranger-citizen. Sergeich postulates a public in which strangers may be *differently* bodied, and the disabled are seen and heard along with other citizens. Sergeich, simply by appearing on the show, or in the online videos, calls into being a public that recognizes people with disabilities as fellow citizens.

Moving our attention to the Sergeichburg video, Sergeich seems to voice this shift in the perception of disabled citizens, rapping,

*So many friends, so many around - seems like you're in Sergeichburg!
A city of friends, a city of girls!
In Moscow or Anapa - it feels like Sergeichburg!*

Sergeichburg is an imaginary place full of imaginary strangers, but these imaginary strangers recognize Sergeich, who is the most popular *chuvak* in town. In the video, Sergeich cruises around in a gold convertible, consorting with famous comedians and hot babes. The video although there are no specific "jokes", presents a carnivalesque atmosphere in a genre that is legibly a parodic gangsta rap video. Whether in Anapa or Moscow, the video suggests, there is a certain state of mind that *is* Sergeichburg. In the Sergeichburg state of mind, disability does not preclude participation and success.

Parodic comedy, along with its Russian cousin *stiob*, may function to shift the dominant paradigm by embodying it with subtle changes (Yurchak, Boyer 2010). Parody can reveal to hegemonies of style, hypernormalization that otherwise goes unnoticed. Yurchak and Boyer argue that such performance allows the "invisible and unthinkable" to be "suddenly recognized and apprehended (2010:212)," and can dramatically alter public

perception. In this case, Sergeich's performance reveals two elements of hypernormalization in Russian mass culture: the uniformity of bodies, and the tropes of masculine success. By encouraging the audience to recognize that strangers with DTsP are normally excluded from a Russian masculinity, it also lays bare the components of this masculinity, which Sergeich pokes fun at in the video: leisure, money, cars, disposable sexualized women, and powerful friends. The parody invites the viewer to question the status quo through a dissonance of form (what's that disabled guy doing with those hot women?), a potential subversion of the dominant paradigm, but the execution is playful. Sergeich relishes the role of kingpin, and the expression of masculinity. This is where the element of *stiob* enters: it is unclear whether he is mocking or identifying with these images; it seems to be some of both.

Yurchak describes *stiob* as an ironic aesthetic that thrived in late-Soviet socialism. *Stiob* “differed from sarcasm, cynicism, derision or any of the more familiar genres of absurd humor” in that it “required such a degree of *overidentification* with the object, person, or idea at which [it] was directed that it was often impossible to tell whether it was a form of sincere support, subtle ridicule, or a peculiar mixture of the two” (Yurchak 2006:250; see also 1999:84). I hesitate to call Sergeich's parody *stiob*, in that Yurchak has developed the term specifically to refer to mockery of "official" discourse, while Sergeich aligns himself with the figure of the rapper. The hip-hop kingpin plays with a paradigm of illicit masculine success; at the same time that the rapper holds cultural clout, he bucks "decency" and domesticity, everything "official" (McRuer 2006:66-70; Bailey 2011).

Kutergin - visibly an *invalid* - does not live the life depicted by his character, kingpin of Sergeichburg. This is a masculine role reproduced in the gender order of contemporary Russian digital publics - from MTV to advertisements (Yurchak 2000). Disabled people in

Russia are considered to be in need of protection and care. They are excluded from the world of work, and therefore of labor and masculinity as the breadwinner for the family- a discursive identity, related to what Yurchak has elsewhere called *muzhskaia ekonomika* or, *an economics of masculinity* (2001). In Sergeichburg, Kutergin makes visible this exclusion by rupturing the reproduction of masculine success as always able-bodied. In this way, Sergeich enacts a Russian crip performativity by calling attention to and subverting normative Russian logics about disability.

Crip Masculinity: From Social Problem to Therapeutic Citizen

Sergeich's appearance on the final episode of the Comedy Battle season helps to unpack the relationship between disability, masculinity and normativity. In this episode (*"Comedi Battl" Season 3, Episode 19*). Sergeich has made it to the final round of Comedy Battle; a winner for the season will be selected and prizes distributed. A teaser raises the drama: how will Sergeich fare in this high-pressure moment?! Something, it's hinted, goes awry. Indeed, when Sergeich's turn arrives, the show departs from its usual format - a contestant's stand-up routine, followed by judging. Sergeich steps out onto the stage more or less as usual. Then, in a sequence that is constructed with such a contrived series of repetitive cuts that the experienced reality-TV-viewer quickly observes the emotional intensity to be partially manufactured, Sergeich appears to become suddenly nervous, stammering over his words and losing confidence. He asks the judges to allow him to leave the stage to get a drink of water. They urge him to do so, with exaggerated empathy.

When he returns, instead of continuing with his stand up routine, he expresses his deep gratitude for the opportunity to be on the show. His performative tone shifts from stand-up comedy to personal confessional. Appearing on Comedy Battle, he says, has changed his

life. Not only because of the professional advance, he goes on, but because it enabled him to meet the woman of his dreams. He then describes meeting and falling for a woman from a neighboring building in his own hometown. It was only after his appearance on Comedy Battle, Sergeich explains, that she noticed him. In a confessional tone he explains to the judging panel and audience that he is now engaged to be married. The camera cuts to a pretty girl with a shy smile and shining brown hair - the fiancée.

"Is this for real?" asks one of the judges. "It's totally true," replies Sergeich. Sergeich has obtained a normative measure of masculine success: he got the girl (and she's hot!). The normative impossibility of this outcome makes visible the degree to which disabled bodies do not appear in the Russian mass media as neighbors and strangers and citizens. Sergeich has become desirable. His appearance on Comedy Battle redefined him as a man, as per Yurchak's estimation: this occurred simultaneously both symbolically - as his image was pixelated and delivered to living rooms across Russia - and literally - as his earning potential as a comedian skyrocketed with his new widespread reach.

In this segment, the Comedy Battle producers intentionally break from the format of the show in order to create a space to talk about Sergeich's experience of difference. Playing on the sympathy of the audience, Sergeich first "disables" himself: he is nervous, fallible, and in need of indulgence or special treatment (leaving the stage to get water in the middle of a set). But, after he tells the story of how he met his fiancée, and the camera cuts to show her seated in the audience, the segment reveals Sergeich in a different light: as a desirable husband and partner.

On the one hand this break in the usual sequence of the show to allow for Sergeich's personal disclosure might be seen as "special" treatment that prolongs a reification of

disabled identity as different and requiring some manner of extra help. Contestants on Comedy Battle rarely offer such a long segment of candidly rather than comedic performed personal narrative. On the other hand, by deploying the idiom of self-realization and therapeutic self-reinvention, Sergeich is further interpellated as a fellow citizen, in that he is included in the spectacle of public self-making, the bourgeois project of therapeutic self-improvement. The concept of contemporary Russian therapeutic citizenship and the (re)production of this idiom through broadcast media has already received in recent sociological work (Lerner and Zbenovich 2013; Kayiatos 2012; Matza 2009). "Reality" genres like Comedy Battle are particularly ripe for this type of cultural work.

For example, Lerner and Zbenovich (2013) describe the manner in which therapeutic discourse is manifest in Russian public culture, by reviewing the rhetorics of self-making on a popular Russian fashion makeover show. They observe that a standard component of this idiom is the discovery by a judges' panel of a relationship between internal and external characteristics (or flaws) of the person under consideration. Internal psychic issues are revealed to be the root of external disorder or pathology of the citizen in question (Lerner and Zbenovich 2013:840, 844). Through the public intervention on the show, a person's psychic pathology is revealed, and she is afforded the self-awareness to take control of both her outward appearance and thus her inner self. Similarly, Tomas Matza describes the process by which Russian citizens participating in various "reality" or "talk show" programs, deploy discourses of popular psychotherapy (2009:491-492), and in doing so, produce themselves as rational subjects, who, by working on themselves by interrogating and relieving themselves of psychiatric "complexes," are contributing to a project of Russian national improvement (493-494).

Thus, this process of shedding one's hang-ups or complexes by engaging in popular psychotherapeutic discourses can be considered a legible manner by which contemporary Russians assert themselves as citizens. Given this configuration, Sergeich's final performance on Comedy Club could be interpreted in yet another way. His sudden stuttering and departure from the comedic script can be seen not as producing him as disabled or weak, but as a mode of integration into Russian citizenship via the discourse of therapeutic citizenship. Rather than the Soviet public denial of the very existence of bodies like Sergeich's (Phillips 2009), Comedy Club's producers, by casting Sergeich as a participant in this project of rational self-realization, produces him, and his body, as identifiably Russian first, and disabled second.

On the other hand, the mode in which Sergeich's comedic talent is cast aside by producers in order to present an emotional narrative stands out from other contestants' trajectories on the show. Furthermore, where viewers are not imagined by the show's editors or producers to be concerned with the details of personal love lives and emotional and social landscapes, the show's creators clearly envisioned this moment of breakthrough, in which Sergeich shares his path from hardship to true love as dramatically and emotionally heightened by his disabled body. This is good TV.

Conclusion

At her house one Sunday afternoon, Alina has me pull a chair up to her computer desk where she is seated in her wheelchair. We scroll through her V Kontakte video collection, rewatching favorite Comedy Battle videos. "Which one is it where Sergeich tells the pilot joke?" I ask, thinking of one particular joke that I remembered and wanted to memorize exactly. "Can we search by episode number?"

"Wait, I can find it," she says. "I've watched it so many times that I can recognize the

video by which clothes the comedians are wearing in the thumbnail."

Sergeich's Comedy Battle appearance was important to Alina in part because it had ramifications for her perception of her own social identity. To see DTsP on television (or the internet) offers a forum Alina to imagine scenarios in which she, too, is recognized by the Russian public as talented and loveable. Given the overall lack of people with DTsP represented in mass media, Sergeich's appearance was a significant event. Another Russian reality show, in the American Idol vein, also featured a physically disabled contestant that same season. Alina had researched her, too. She's rich, Alina explained to me, that's why she was able to get on this show. Her parents have a lot of money so she always has things like people to do her make and her hair for her. Meanwhile, in Alina's take on the situation, Sergeich was from an average family from a provincial city, and his success was based not on wealth, but on talent.

Sergeich's persona offer Alina access to several modes of reworking disabled identity. Watching his heterosexual epiphany on national television (and again and again in streaming videos) offered a glimpse of romantic possibility that Alina enjoyed. Through the proposition that Sergeich as loveable and rehabilitated to masculine sexuality both in comedic farce and reality TV spectacle offers Alina a representation of a person DTsP that is absent from her daily life. Watching Sergeich perform as a talented fellow citizen and his reception by the shows hosts (although cheesy, sentimental, and overwrought) also offers an escape from scripted interactions that Alina has in her daily life. Where at the art therapy group, Alina conducted herself as a cultured citizen, hiding her snarky and sarcastic side, Sergeich was both disabled and publically sarcastic; yet, his performance was recognized as talent rather than degeneracy. Moreover, Sergeich's capacity to talk openly, through comedy, about the

conundrums of enacting a social persona with DTsP resonated with Alina's own experience. His jokes were funny, and in them, she recognized her own experience.

This chapter has considered the ways in which the Russian comedian Sergeich disrupts the reproduction of ableist paradigms, and described his performative idiom as a comedy of recognition. It has also considered Sergeich's performance through the lens of crip theory as developed by Western scholars. It is tempting to argue that Sergeich's work is *crip* and transgressive. But even as Sergeich's non-normative body is "included" in the media, the manner in which his narrative is folded into a normalizing, disciplining discourse means that even as he is "recognized" as a fellow citizen, his trajectory is ultimately assimilationist, and this implicit critique of the marginalization of disabled Russians is also complicit in reproducing a heterosexist masculinity. This complexity is linked to the difficulty of translating disability studies across cultural contexts. Crip theory relates to cultural logics of inclusion and exclusion along lines of bodily deviance, and these logics are culturally contingent. More work is needed to delineate and theorize the contours of disability inclusion and exclusion in contemporary Russia.

Finally, a disability studies perspective reminds us that when we talk about public, we must not rely so heavily on normative metaphors of embodiment and sensory perception. For instance, how frequently in this essay has language convention led me to write "seen" or "heard" when I really mean "recognized"? The digital public sphere increases some of the mobility and communicative and participatory possibilities for Russians like Alina (e.g., she can watch and rewatch Sergeich videos, and comment on forums), but it also restricts (it allows politicians to justify "distance learning" for students and children with mobility impairments, meaning that another generation of Russians with disabilities will be segregated

from their peers). When we talk about the public sphere as a spatial metaphor, it may be useful to consider the ways that actually embodied barriers and mobility impairments prevent some Russians from participating in some publics. And, moreover, how digital movement may open new pathways for circumventing marginalization and barriers in the physical civil sphere.

CHAPTER XI
"I TURN ON MY COMPUTER AND THE DAY BEGINS":
CRIP TIME, VIRTUAL SOCIALITY, AND PIXELIZATION ON RUNET

"The best way to appreciate the merits and consequences of being digital is to reflect on the difference between bits and atoms. [...] A bit has no color, size, or weight, and it can travel at the speed of light. It is the smallest atomic element in the DNA of information. It is a state of being: on or off, true or false, up or down, in or out, black or white. For practical purposes we consider a bit to be a 1 or a 0."

"Unlike face-to-face settings in which people took their bodies for granted, people who went online had to consciously create their digital presence. Media studies scholar Jenny Sunden describes this process as people typing themselves into being. Although [theorist Sherry] Turkle [1995] recognized that a person's identity was always tethered to his or her psyche, she left room for arguments that suggested that the internet could - and would - free people of the burdens of their 'material' - or physically embodied -- identities, enabling them to become a better version of themselves." (boyd 37).

In this chapter, I will argue that while *marginalization* has been the major spatial metaphor by which disability exclusion has been conceptualized, isolation and sociality take on new spatial forms and new modes of exclusion and inclusion in digital worlds. I combine ethnographic material from my interlocutors with disabilities in Petrozavodsk with theory from digital anthropology and disability studies. As an alternative to marginalization, I suggest the idea of *pixelization*, or isolation in physical space at the same time that connection occurs via digital networks: like pixels on a screen, people are isolated in the physical cells of their apartments, yet at the same time connected and enlivened through networks that together produce meaning making interactions. This attention to the digital complicates notions of public space, mobility and access described in earlier chapters. It also encounters the notion of *crip time*, an element of disability theory which I argue is important

for understanding the experience of technology in relation to disability or non-normative embodiments. This focus on the enacted modes of digital communication also offers important overlaps with communication studies, anthropology of design, and performance ethnography.

"I turn on the computer and the day begins"

As I began to reconceptualize my fieldwork around the life experiences of my key research participants, I noticed something that I had not expected: the role of the digital in their lives. While the idea of accessibility as inherently tied to culturally and historically produced barriers in the material world was easy to reconcile with the literature in disability studies, I had read little about digital forms of sociality in relation to people with disabilities. How did digital access facilitate and shift social experiences? What barriers existed in the digital sphere? How were digital and material barriers related?

It was Vakas who first led me to consider the digital as an object of study rather than a mode of communication while I was in the field. Because he speaks slowly, and with a degree of difficulty, he sometimes prefers to share information online. When I hadn't know him for very long, one afternoon when I asked him a question in a group environment, he suggested that he would send me an explanation online, rather than try to give an answer verbally. The digital option - messaging on VKontakte - offered a shortcut in what disability studies scholars call "crip time," the elongated temporal frame in the performance of disability (Kuppers). When walking, talking, moving from one space to another, getting together with friends, or negotiating accessible networks all take on a particular temporality that contrasts with the cultural norms in a way related to doing disability, disabled folks need

a quick way to winkingly let one another know what is at play, and the anglophone disability studies community has come to call this "crip time."

For instance, in disability theorist Louise Hickman's video about performance/experience of crip time, she documents the process of waiting for a university shuttle to arrive in order to transport her across the UCSD campus. When a shuttle finally arrives, other passengers waiting at the bus stop file on. Hickman waits for the driver to lower the chair lift; the driver shouts out the bus door that she thinks that the lift is broken. Then, the driver, realizing that she will make Louise late, makes a good faith effort to make the lift work, but, having demonstrated that it is broken, apologizes and says that Louise will have to wait for the next shuttle. Crip time, in this recording, is about always having to plan ahead, about always leaving earlier than everyone else to arrive on time, about efforts that don't pan out, and a very particular feeling of slow and mundane accumulation of dysfunctions. In the video, the viewer's perspective is placed in and with Louise's powerchair, and the low and unframed camera angle emphasizes the missed moments and failed connections. For the more than two minutes of tape, the viewer is captive to the unfolding reality of a non-working chairlift in an excruciating string of moments of uncertainty and indeterminacy, which ends only when the bus drives away, leaving the Hickman, her chair, the camera, and the viewer stuck at the bus stop, stuck in crip time.

Later on, during a one-on-one interview in Vakas's room, I asked him to describe a typical day. The text of this interview is transcribed in a manner related to Vakas's performance of these words, and my transcription of them. Because he speaks so slowly, Vakas asked that I not record his interviews on tape; over the years, he has been made to feel ashamed of his voice, and he didn't want his perspective captured in this way. So, instead, as

he talked, I would jot down his words in a notebook (in Russian, which I later typed and translated to English). Because I was writing longhand, and fairly quickly, his words would shortly fill a line on my notebook page. I used the natural breaks in his speech as a way to break up lines. This had a useful effect of also capturing something of the performance of his speech: his breathe comes at irregular intervals that don't necessarily correspond with punctuation in a sentence. Where most people will breathe at a comma or between phrases or sentences, Vakas often pauses to breathe or swallow mid sentence. Listening to his narration of his own life has the effect of requiring the listener to enter into a copformance of crip time. The transcription of his interviews reflects this.

Vakas: i don't set an alarm, it's easy
because i really - it's
no problem for me - to get up early
i just say to myself - get up
early

C: when do you usually get up?

V: when my brother is getting ready for school

C: you hear him and get up?

V: yes
i get up, i go out to the kitchen
i have some tea - i can't
eat cereal - my stomach
just needs to drink tea. around
seven mama gets ready
and when she leaves, i
take myself back
to my room - and turn on the computer -
VK - and the day begins

For Vakas, the moments in his day when he feels as if he is his true self, happen when his family leaves and he can go online, uninterrupted. Online, he is someone engaged in a social world through voluntary communication; he is part of a network of human connection. Online, he shares his writing, he makes new friends, he participates in public contests and events. Offline, in family apartment, he feels forced to interact with family members, and

because he isn't allowed outside without someone to help him walk without falling, without his computer, he has no means of escape, and little chance to encounter surprises or build new relationships.

Digital Performance

If the experience of crip time is a unique temporal configuration, and the performance of disability in space is a unique configuration of material and social, as disability studies scholars have argued, then a crip experience of digital worlds is also unique. After all, digital worlds are distinct from the analog or material precisely in elements of temporality and spatial-material relations. In this sense, I realized that I could not talk about disability and access in Petrozavodsk without considering the digital.

Anthropologists consider *the digital* to be those realms of human social interaction that are in some way undergirded by binary code (Miller and Horst 2012:4). This definition or digital anthropology was preceded by STS or cultural studies descriptions of the digital. In 1995, Nicholas Negroponte's book *being digital* observed the enacted ways in which digital possibilities shift cultural exchange, and Sherry Turkle's book *Life on Screen* described the many ways in which identity and concept of self was shifting in relation to digital communication. Miller and Horst also gesture to the ways in which exchange is relevant to the study of the digital: they point out that *money* offers a historical precedent of a modality of human social worlds that shifted with a commodification of value into a material object that altered practices of exchange (and indeed continues to change with the digitization of money today) (2012:5-7).

Negroponte argues that *bits* - the smallest unit of digital information - might be considered in contrast to atoms as a means of understanding the ways that material and

digital interactions are at once interrelated and at odds. At the start of the first chapter of his book, Negroponte illustrated this with the following anecdotes:

I recently visited the headquarters of one of America's top five integrated circuit manufacturers. I was asked to sign in and, in the process, was asked whether I had a laptop computer with me. Of course I did. The receptionist asked for the model and serial number and for its value. "Roughly, between one and two million dollars," I said. "Oh, that cannot be sir," she replied. "What do you mean? Let me see it." I showed her my old PowerBook and she estimated its value at \$2000. She wrote down that amount and I was allowed to enter the premises. The point is that while the atoms were not worth that much, the bits were almost priceless.

In this example, Negroponte illustrates the ways in which the value of digital information was overlooked in favor of quantifying the value of the atoms, or material elements. This gestures to two elements of North American cultural practice in 1990s North America: first, that the commodity fetish around material manufactured goods was so great that it overshadowed and obfuscated other forms of value; second, that digital value may be invisible even while the hardware or matter that carries the digital information in bits and pixels fully visible. I will argue that both of these elements have important consequences for how scholars understand disability performance in⁷⁵ digital and material worlds.

The second anecdote that Negroponte provides is this:

Not long ago I attended a management retreat for senior executives of PolyGram in Vancouver, British Columbia. The purpose was to enhance communications among senior management and to give everybody an overview of the year to come, including many samples of soon-to-be-released music, movies, games, and rock videos. These samples were to be shipped by FedEx to meeting in the form of CDs, videocassettes, and CD-ROMS, physical material in real packages that have weight and size. By misfortune, some of the material was held up in customs. That same day, I had been in my hotel room shipping bits back and forth over the Internet, to and from MIT and elsewhere in the world. My bits, unlike PolyGram's atoms, were not caught in customs.

In this example, Negroponte highlights the ways in which digital data can traverse boundaries and borders which material objects might not, or at a rate and temporal pace that

⁷⁵ I am dissatisfied with the preposition "in" in the phrase "in digital and material worlds"; I think that perhaps a better preposition would be "through" or "across" digital and material worlds, as I worry that "in" might imply some kind of discrete and mutually exclusive formation as which I do not think either digital or material qualifies. Rather, experience and sociality occurs across and between digital and material spaces; that is, they are mediated by digital and material interfaces.

is impossible for material objects. Even though the data or music on the CDs was in fact digital recordings, that data didn't reach its intended recipients on time, because the material vessels were held up at the border. The fact that the anecdote includes an international border serves to illustrate the ways in which material space remains inaccessible or bound to geopolitical boundaries which do not exist in digital space.

Of course, this is true for digital anthropology as well: as an ethnographer of Russia based in North Carolina in 2014, I can follow-up on questions or conversations with my interlocutors in Russia and stay in touch via online forms of communication. In relation to the current project, Negroponte's anecdote gestures to the question about how Russians with disabilities might traverse barriers in material space using digital channels. An important literature of digital anthropology and the work of doing ethnography through digitally mediated communication has also emerged in recent years (e.g. Horst and Miller 2012; Coleman 2010). Faye Ginsberg asserts that the questions that attention to disability raises have important implications for theorizing digital sociality generally (2012).

Unlike the internet of the 1990s, which was thought of as an escapist space for misfits (boyd 4), with mobile technology available to consumers by 2006, digital interaction became a part of mainstream socializing. By the time cellphone and smartphone mobile technologies emerged, the telephone function of the device faded. Ethnographer Danah Boyd's study of American teenagers using online social networking sites observed that these digital platforms became a way for teens to extend the space and time of their real-world social interactions into time when they were expected to be at home (boyd 3). While adults who adopted mobile technologies tend to use their devices independently, teens use the technology socially: even when hanging out with friends in real life, they are looking at their devices together, as a way

to share and extend the social space. "When teens did look at their phones, they were often sharing the screen with the person sitting next to them, reading or viewing something together" (boyd 3). For these teens, the phones were "a glorified camera plus coordination device" (boyd 3). The teens' goal of social interaction with friends was fulfilled through these uses of the technology (boyd 4).

This mode of extending social space and time by engaging in digital sociality in moments of material isolation holds true for my interlocutors, who also seek interaction and feelings of togetherness. But for Russians with disabilities, the question of landscape and access differs. And, the idioms and timing of digital trends were specific to time and place.

Digitally Mediated Communication and Disability

Sherry Turkle's quote at the beginning of this chapter seems to speak to the unique modes by which embodiment comes to matter in created identities online. Yet her discussion, and much of the scholarly writing on enacted digital technology use has little to say about non-normative embodiments. The only reference to disability in Turkle's book, *Life on Screen*, which is over 300 pages, relates the story of a woman who gradually became comfortable with a traumatic injury in part through her creation of an amputee self in a virtual world (262-263). Such an investigation reinscribes disability as always an anomaly, always a rupture, and always being overcome. In contrast, in the lives of real people living with disabilities, non-normative bodies are neither new nor anomalous - they simple *are*.

Turkle's few sentences have been followed by a longer investigation of disability in the online virtual reality game Second Life (Bollerstroff). Both of these studies dealt with the social and technological conditions of web 1.0, and do not account for the development of mobile technology and social networks that offer intertextual experience with social

experience in the real world. Additionally, in rehabilitative therapy and occupational therapy fields, mediated communication for people with disabilities has long been an important field of investigation. A more generative and general approach to the subject was needed (krueger et al 2009; Gordon and McClimens 2008). Only the most recently publications move disability and networked publics out of the rehabilitative or virtual world subcultures. Meryl Alper's book *Digital Youth with Disabilities* was released in November 2014; several volumes since 2010 have also addressed this intersection (Ellis and Kent 2011; Jaeger 2011).

In this sense, ethnographic research regarding digital identity and non-normative embodiment are sorely needed. The fruitfulness of this intersection has been well-documented, if not in academic research, in journalism and documentary work. A stirring episode of the documentary film season of *This American Life* (usually a radio show) dramatizes the extensive writing of a man who is mostly paralyzed, but who can type using facial muscles and an adaptive technology, and whose life in the blogosphere is dynamic. Online neurodiversity activist Amanda Baggs, an autistic adult in New Hampshire, has used YouTube to share her message that non-verbal autistic adults may not appear to be "present" to neurotypical people, but are in fact listening and aware (Baggs 2007; Gajilan 2007; Ginsburg 2014).

RuNet

The Russian language internet, affectionately called *RuNet* by users and bilingual net researchers, comprises an important subdomain in the global network of digital systems, and space of sociality for the enormous worldwide Russophone diaspora. From Moscow to Brighton Beach, Bishkek to Tel Aviv, Russian speakers around the globe perform digital sociality according to trends and methods that circulate on RuNet (and through the

dissemination of handheld devices through culturally and locally specific ways). For instance, RuNet has its own search engine, *Yandex*, which emerged simultaneously to Google, and which operates according to its own algorithms, with a clear focus on RuNet. If one searches for the same term on Google.com, Google.ru, and Yandex, each search will retrieve different, or differently ordered results (of course, the same search performed on any of those search engines from different locations, computers, or over time may also return different results (Hillis 2013)). When I conducted predissertation research in Petrozavodsk in 2010, Google Maps and Bing Maps had not yet added accurate maps of smaller Russian cities like Petrozavodsk; the Russian satellite navigation company had an online site with a searchable map. By 2012, Yandex had a maps app, which, downloaded to my iPhone allowed me to fairly accurately find any location in the city. Hardware trends in Russia, and in particular regions of Russia, also unfolded in unique ways. For instance, in the spring of 2013, the Taiwanese company Asus released the PadFone, which was hardly heard of in the US, save for a few mocking reviews on tech blogs, but was very popular and coveted in Petrozavodsk at the time.

Which is to say, the digital landscape of RuNet and its relationship to the material world of Petrozavodsk was actively changing and unfolding in new ways throughout the duration of my fieldwork. Russophone digital socialities, like digital socialities around the world, were rapidly changing and continuously being negotiated as technology and practice shifted, one in relation to the other.

Trends on RuNet follow their own surges and directional flows. Until about 2009, when LiveJournal had already become an archaic blogging site on English-language internet, as Facebook and other social networking sites took over, LiveJournal, *Zhivoi Zhurnal*, or

Zhe-Zhe for short, became the most popular online space for RuNet users. The media industry in Moscow accumulated a class of young digital media professionals and tech start-ups akin to a New York-LA juggernaut in the US. Before Facebook went global, *Odnoklassniki*, a social media site intended to allow Russian-speakers to reconnect with their high school classmates became the default social networking site for a time. Then, *VKontakte* - a veritable Facebook knock-off - emerged. While the global media elites in Moscow use mostly Facebook and Twitter, in more provincial regions like Petrozavodsk, or with older generations or populations less tied into global culture and the English-speaking world, *VKontakte* remains more popular⁷⁶. As the touch screen phone market emerged, Russians quickly adapted to using the free messaging

Networked Publics

Boyd defines *networked publics* as:

publics that are restructured by networked technologies. As such, they are simultaneously (1) the space constructed through networked technologies and (2) the imagined community that emerged as a result of the intersection of people, technology, and practice. (8)

In the previous chapter I argue that media representations lead Russian digital publics to imagine certain roles for people with disabilities. People with disabilities were always seemingly "just emerging": each depiction of people with disabilities was portrayed as a rupture or breakthrough. Barriers had been overcome to allow such a person to appear on television or in digital spin-offs from television networks.

In this chapter, I extend boyd's notion of networked publics to apply to disability in digital publics to talk about *pixelated sociality* as a crip experience. I am interested in the

⁷⁶ Unlike Americans, Russians who use VKontakte were, long before Edward Snowden, readily aware of the governance and surveillance potentials of such networking sites.

ways that digital technologies offer reconfigurations of Russian publics in ways that are specifically illuminated by disability experience, and in how barriers in the material world are interrelated in complex and undocumented ways with barriers in the digital world.

The desire to "find a place in society" that boyd described in American teenagers is not unique to that subculture; it is a concern to groups that tend to be marginalized, or excluded from the mainstream. Teenagers are considered irrational, untrustworthy, and are expected to socialize only with other teenagers. Likewise, people with disabilities in Petrozavodsk in 2012-013 were similarly corralled. The digital as a plane of sociality is intricately entwined with material social worlds, imagined communities, and the politics of space. Boyd has theorized the spatial aspects of digital publics and described the kinds of communities they might gather. She writes:

Publics provide a space and a community for people to gather, connect, and help construct society as we understand it. Networked publics are publics both in the spatial sense and in the sense of an imagined community. They are built on and through social media and other emergent technologies. As spaces, the networked publics that exist because of social media allow people to gather and connect, hang out, and joke around. Networked publics formed through technology serve much the same functions as publics like the mall or the park did for previous generations [...] social media creates networked publics that allow people to see themselves as a part of a broader community. (boyd 9)

Key here is the insight that even as material and digital networks foster human connection and undergird sociality in ways that are mutually reinforcing, the infrastructures of connection act differently in digital networks than in physical space (boyd 10). That is, the enacted social roles and modes of meaning making on and offline are inextricably linked, but they are not the same.

Digital access: mobility as an object of desire

Access to networked public space requires access to the hardware. There were three important ways that hardware impacted my interlocutors in ways specific to disability: financial access, physical capacity to use a device, and familial approval or consent. For

instance, when Sergei told me that he often streams movies online, he immediately followed this comment with an assertion that ever since he got an unlimited data plan (in which an internet service subscriber pays a flat monthly rate, rather than paying up front for a set amount of data which then has to be rationed, which was how most internet service providers operated in Petrozavodsk until about 2010), he can watch whatever he wants. These technologically enabled forms of access and inaccess in some way align with the broader themes in this dissertation. Between digital worlds and material worlds is a common desire for mobility, and for the ability to cross borders and occupy different kinds of spaces. This freedom of access is characteristic of what many contemporary Russians conceptualize as a "normal life" (*zhit' normal'no*) (Zavisca) or, in what Americans tend to call *freedom* to do what one pleases. One attribute or even defining characteristic of *privilege* is comfort moving between different spaces and contexts (Khan 2011:135).

The capacity to access social ties and maintain relationships that one is unable to continue to build in physical space is an aspect of social media that American teens and contemporary professionals alike appreciate and utilize (boyd 20). In the case of the American teenagers that boyd describes, they are "stuck at home," not allowed to move freely through public space⁷⁷ - much like my participants experiences "life in four walls".

Like the teens in boyd's study, my interlocutors were online, but not necessarily tech-savvy (22). This was frequently a problem in my communication with Alina. Once I had left

⁷⁷ "Many American teens have limited geographic freedom, less free time, and more rules. In many communities across the United States, the era of being able to run around after school so long as you are home by dark is long over. Many teens are stuck at home until they are old enough to drive themselves. ... socializing is also more homebound. Often, teens meet in each others homes rather than in public spaces [due to public regulations and parental fears]. ... Teens simply have far fewer places to be together in public than they once did [...]Facebook, Twitter, and MySpace are not only new public spaces: they are in many cases the only "public" spaces in which teens can easily congregate with large groups of their peers. More significantly, teens can gather in them while still physically stuck at home" (21).

the field, we sometimes wouldn't communicate for months at a time, because she would forget the password to one of her social media accounts. I spent three months of 2014 worried that something had happened to her, only to visit in April and learn that she had gotten locked out of her account and needed help resetting her password. In a moment of digital network disaster familiar to many of us, she had forgotten the password to both the email that would allow her to reset her VK password, and the VK password itself.

"Tach skrin" - the Russification of touchscreen - devices also present problems. Not only are they prohibitively expensive for many Russians, they are also difficult to use for people with limited dexterity. Alina, Sergei, and Vakas all used flip phones in 2012-2014. "Touch screens aren't that great," Vakas wrote to me on VK, when I asked him.

Talking Through Walls: Digital Space

The digital space of RuNet provides an alternative mode of engagement, even for those trapped in four walls. This pixelated mode of socializing is not specific only to people with disabilities, but reflects broader social trends in relation to the adoption of digital technologies. But, the ways in which disability or life in four walls limits interactions in the material world has consequences for digital social lives as well. That is, how we socialize online is profoundly tied up in how we socialize in public space.

Because digital platforms allow us to talk through walls, or communicate across space in ways that previous media did not, they have led to new configurations (boyd). Digital communication, especially online social networks, played an important role in the narratives of selfhood for Vakas, Sergei, and Alina, the most homebound of my interlocutors. In this way, digital platforms allowed these three to access public spaces in ways that they

were not able to do in the physical world. In this sense, digital sociality is an enabling technology that has particular benefits for the social lives of my coauthors.

Figure 34 - Alina at the computer Alina talks with her neighbors at her computer desk, the log in screen for a social network site glows white on the screen, and one of the neighbors, a young boy of about twelve leans over the keyboard while his younger sister looks on. Winter 2013. My photo.



However, the social experiences that Vakas, Sergei, and Alina have online are related to the kinds of social lives they lead in public space. This is because media or communication cannot easily be separated from other experiences; material and digital sociality are deeply interrelated. For instance, Boyd writes:

Although some teens still congregate at malls and football games, the introduction of social media does alter the landscape. It enables youth to create a cool space without physically transporting themselves anywhere. And because of a variety of social and cultural factors, social media has become an important public space where teens can gather and socialize broadly with peers in an informal way. Teens are looking for a place of their own to make sense of the world beyond their bedrooms. Social media⁷⁸ has enabled them to participate in and help create what I call *networked publics*. (5)

⁷⁸ Regarding the definition of *social media*, Boyd writes, "I use the term *social media* to refer to the sites and services that emerged during the early 2000s, including social network sites, video sharing sites, blogging and microblogging platforms, and related tools that allow participants to create and share their won content. In addition to referring to various communication tools and platforms, social media also hints at a cultural mindset that emerged in the mid-2000s as part of the technical and business phenomenon referred to as 'Web 2.0.'" (2014:6) Social media contrasts with first generation internet technologies enabling sociality such as chatrooms, webchats, message boards, and emails. Social media is arranged around individuals, while previous technologies were organized by interest (boyd 2104:6-7). Additionally, with web 2.0, online sociality moved

This manner of making plans and gathering informally is still largely inaccessible to my interlocutors with disabilities. With the exception, perhaps, of Vera, who can move through the city when her husband drives her places, for others in my circle, outings had to be planned carefully, well in advance. Anya would have to make sure her mother was available to drive, and make room in her busy schedule. Rudak would have to arrange a ride and make sure that a couple of guys strong enough to lift him and his chair would be able to carry him out of his apartment and into a venue (and the reverse on the way home). For Alina, Sergei, and Vakas, it was even more complicated, because their social perception and sense of self meant that they were largely uncomfortable with informal meetings, especially in mixed company. If they were to attend an event not explicitly for invalidi, they would prefer that it were "official" e.g. publically advertised, and that they had been invited by someone. Crip time requires a different approach to planning.

Although mobile technologies can make communication on the fly easier for everyone with access to the devices, there is an additional layer of complexity. Digital sociality as part of networked publics frequently involves having been there in the physical sense. Boyd writes:

The day after [I attended a] football game in Nashville, I interviewed a girl who had attended the Homecoming game. We sat down and went through her Facebook page, where she showed me various

out of the world of nerds and computer savvy, and became a normal part of daily life for mainstream cultures and subcultures (ibid 7).

Boyd also writes that the normalcy of a given social media platform is related to the fashions of the moment, in a given time and place. "teens who used Facebook or Instagram or Tumblr in 2013 weren't seen as peculiar. Nor were those who used Xanga, LiveJournal, or MySpace in the early 2000s" (8). Of course, she means, *American, nondisabled* teens. Not only do trends and technologies change and fade, they do so in cultural contexts, so that the interest in Facebook versus another platform is geographically specific as well as it is temporally specific. This was clear especially during the period in 2008-2010 when Facebook and Twitter pushed to "go global" and present their platforms to various language groups and the corresponding internets and users. By the time I did my fieldwork in 2012, I could set my Twitter "trending" hashtags sidebar to "Russia" or any other country.

photos from the night before. Facebook hadn't been on her mind during the game, but as soon as she got home, she uploaded her photos, tagged her friends, and started commenting on others' photos. The status updates I saw on her page were filled with references to conversations that took place at the game. She used her Facebook to extend the pleasure she had in connecting with her classmates during the game. Although she couldn't physically hang out with her friends after the game ended, she used Facebook to stay connected after the stands had cleared. (4)

This insight, that the digital space of Facebook (or online social networks, even when not fully mobile) are engaged by users to extend the temporal and spatial scene of a social interaction in the material world, has important implications for my interlocutors.

boyd's insight becomes relevant if we recall Sergei's description of losing touch with the social network of able-bodied peers that he developed during his time in a college program, was punctuated by his description of these people one by one unfriending him on VKontakte. "Being there in a physical sense" as a prerequisite for online interaction helps explain why Sergei was "dropped" from the list of friends by people that he went to college with. His peers may have considered it appropriate to include him in their list of friends when they saw one another daily at the college building. But, once they had graduated, Sergei dropped out of the social circle in the physical world. The sense of shared social space and/or obligation to include Sergei dropped off; there were no consequences to the able-bodied graduates who chose to remove Sergei from their list of friends on VK.

In one exchange that I recorded during an interview, Alina shared a frustration with always having to be the one to receive guests because it is so difficult for her to get around outside of the apartment. It creates an imbalance, she implies, between friends, and online talk is not a full substitute for face-to-face communication.

A: All my life I've loved information about actors and singers. And not in the sense of who married who, but who was in what movie, and what kind of roles. It used to be that it was hard to find this kind of information. But now -- "Baskov bought three homes" -- there's all this kind of gossip. When I'm sitting at home alone, then I like to find brainteaser games and answer the questions. Like right now I'm on V Kontakte, and I've got a few games going. My brain may as well get a workout now and then. But in general I really like to talk to people (*obshat'sia*).

C: Yes, it's better than sitting in front of the computer.

A: Well unfortunately, out of all of my friends - it's only you who is better to talk to in person.

C: Everyone else only wants to talk online?

A: No, not so much online [*po komputeru*], it can be hard to pull off, it's like pulling teeth. So it gets to the point that I'm fed up with always sending invitations, so that people would come visit me.

Alina finds that the transitions between online and face-to-face sociality can create problems in her social relationships, because while online she might communicate at a similar pace to other users, in the physical world, she lives in crisp time. The time, money, planning, and energy that it takes her to visit a friend in their home on another side of the city make it a practical impossibility. Her body and its temporal engagements traversing physical space may not limit her in online communications, but because social ties are cumulative between physical and digital interactions, she falls out of line with acquaintances who are used to peers appearing both digitally and in person.

Online All of the Time

It is hard to underestimate the role of digital technology in the lives of especially the most home-bound of my interlocutors. For instance, in describing his typical day, Vakas continued:

[every day, I'm on VK
or someother website]
or i ride my bike [gestures to stationary bike in bedroom]
i might get on it at any time
after 20 minutes - i strength drains more quickly and it's harder for me
[he means than for others, but doesn't say] i use up more energy on motion
two times as much - a bunch of times
i fell because i was
at it for too long
i get tired and rest for
awhile
like 10 minutes or so i don't do anything

-do you lie down?

-yeah, and eyes closed - really
it's to get a break from the computer --
i forget about time and sometimes
i forget about food - and

only at night - when my stomach starts to rumble - then i go to the kitchen

This mode of communication is not unique, of course, to those with mobility impairments. Many young people, especially those who are unemployed spend hours of time each day online, playing games, talking to friends, or watching videos. What distinguishes Vakas's crip digital social experience from gamer or computer junky culture is that he *does* enjoy going out and meeting people in the real world, but practically, he rarely has the chance to do so - his desire to go out alone always causes fights with his parents, who want him to stay inside unless he is accompanied. Sometimes he does goes out alone anyway, and, he tells me, braces himself for the results when he gets home!

In his recent memoir, he recalled one such stolen excursion:

One day I went in a taxi by myself to [a local organization]. Mama was against it, as always, but remembering what happens if she tries to keep me at home, let me go anyway. I wanted to give my chapbook to L--a - she wasn't at her desk, but it was still worth it that I went!

I talked with an acquaintance who was working there as a psychologist (and I left two copies of the chapbook there), then I went as far as the intersection with Komsomolskii, and on the way saw so many people. But the real culmination of the walk ended up being asking someone that I met to call the operator for the taxi service. I asked her to call me a taxi from the 777-777 number. She asked if I didn't want a different one, 56-06-06, I think it was. She said that she works there and would get me a discount (she said she would do it). She took me across the street and set me up there to wait for the taxi (and told the driver to help me), then she wished me well (In general, I have good luck). This is what I need in life: to talk to someone, to walk through the city, and not just to sit and sit in front of my computer screen.

Vakas's description of what might for anyone else be a very mundane outing for him becomes a fantastical adventure. His enactments of crip time - his slow and labored speech - mean that engaging anyone, especially strangers, in person can seem like an insurmountable task. There is always a risk that someone will mistake him for drunk, or otherwise misunderstand his shuffling, uneven walk and slow, slurred speech. This reality turns each twist of fate, each tiny kindness into a small miracle. His memoir writing, and his descriptions in interviews, often have a breathless quality of someone shocked at his own

luck. These moments of chance connection with strangers given him a sense of satisfaction and unexpected delight that online interactions can simulate but never fully recreate.

However, because his experiences of digital sociality are far more frequent than his experiences of face-to-face interaction, he often seeks the same sense of wonder in his online social interactions. For instance, in one case he told me, in person:

like, remember? about the girl?
i found her on a site

i'm all set, i'm chatting - recently especially -
messages are coming in - and i listen
to music, and play games - you don't
know the game "heaven"? -
i've played it lots of times - they have this
contest. i entered -
there in the game - they made a contest-
"miss heaven" - the sweetest girl.
it was even on the radio station
TorrentFM - during the program broadcast
i entered a question [for the contestants] on the site and the announcer read it
it was my question about poems.
and she answered - while i was listening.
"there's something of love in poems"
and i found her page
on VK, and I showed her my poems

and she
wrote back
she said, that
she liked the poem about love

In this interaction online, Vakas recreates the sense of wonder at a chance connection with a stranger that he feels when he is out on the street. Although Vakas has friends and acquaintances that he adores (as the passage from his memoir in an earlier chapter illustrates), his most prized moments of social interaction are with strangers. Well, mostly with attractive young female strangers. As the above narration about the radio station contest wound down, I asked as much. "So," I said, "let me get this straight. Every day - you're online looking for ways to meet pretty girls?" His answer was quick and straight forward: "Yep," he replied. The example of sending the radio station girl a poem of his online

represents a classic Vakas wooing strategy (it's unclear, perhaps even to him, if he's looking for love or friendship in these interactions).

Because Vakas's spoken voice operates in crip time, it can be frustrating for him to engage with people in the real world - short of the miraculous happenings that he records in his journal. But because digitally formed words are both persistent - in that they stay the same and are able to be read long after they are created - and mobile - in that they can be copied and pasted between frameworks - in boyd's framework, he can easily use the same poetry text or description of himself over and over again. Because the tempos of conversation and communication in digital media occur at a different pace from spoken conversation and don't require voiced speech, online, he can participate in social life in a way that his speech impairment impedes in face to face communication.

As this episode in Vakas's self-narration demonstrates, digital sociality and social engagement in the physical world are not equivalent, but both are important, because, in his words, communicating with people "gives him positive emotions." In interviews and participant observation with adults with disabilities in Petrozavodsk, I observed that narratives of daily activities in virtual worlds came to stand in for other forms of sociality more frequently experienced by non-disabled in narratives of daily activities. There is a manner in which narratives of virtual sociality might be understood as crip technologies of self, performances of autonomy, competence, and mobility.

For Alina, this extends not just to talking with her actual friends and acquaintances online, or, like Vakas, making friends with strangers online, but also to her cultural consumption online. As with her affinity for Comedy Battle, Alina is always quick to produce tastes and opinions about television shows, news items, or celebrity personalities; in

this way, she makes her media consumption a practice of self-fashioning. Like Vakas, Alina turns to TV or the internet when she feels that she has no other opportunities for social engagement.

C: So, tell me - paint the picture. What room are you sitting in when you're watching Comedy Battle? Who are you with?

A: Well, in the living room. Sometimes I sit in my room and watch online (*chez internet*). There's a link for all the different channels. So then if - like - when there's someone else in the room I'll sit and watch it on the computer.

C: Mmm

A: And so during the week when it's boring... when there's time. And when I'm really looking for a good mood, I'll turn it on. It's different every time.

C: So, what moments do you like?

A: Which episodes were my favorites?

C: Mhmm

A: Well, all of them. The thing is that when a person can hold my interest -- umm -- with that kind of person it's always interesting. ... I think that that's true in any profession, not just on TV, but on TV it's especially so. Because you get tired of the same sounds and TNT (the channel) it fills the time. There are some hosts where you don't really want to keep watching. But this channel - on TNT, I mean - there's no news, at all. It's for young people, you could say. So. We call it - in our country, a channel that lifts your mood.⁷⁹

⁷⁹ ну расскажи - опиши картинку. в какой комнате сидишь, когда смотришь Комеди Баттл? с кем

ну в гостиную. бывает, что я сижу в своей - через интернет

там есть ссылка на каналах различных. так бы - и - когда другой там в комнате сижу и смотрю по компьютер

я просто скину ссылку на канал ТНТ, и смотрю. я так некоторые выпуски скину, повторю смотрю

mmm

и так как на неделе скучно бывает... когда есть время. и когда очень проверзу хорошее настроение, включу. что то другой каждый раз бывает.

ну... какие нравится моменты?

какие выпуски больше всего?

mxmm

In this way, Alina creates a social identity for herself through her interpretation and opinions about mass media, which she can share with others, and which she knows others are also watching or accessing online. While physically she is set apart from people, in her apartment, she can participate in communal experiences of media consumption, and later make this meaningful in conversations.

Meanwhile, Anya highlighted a different process of identity development through online networks. For her, because she has a condition that is both degenerative and fairly rare, turning to the internet provided a practical method for her to find support and information. On several occasions, she told me about friends that she has whom she's only met online, living in Moscow or St Petersburg, with whom she became acquainted through an online portal for people looking for information about her diagnosis. She recalled,

People were figuring out these diagnoses on their own and I gave some kind of instructions, but a lot of people were asking around online, because there aren't a lot of the people that I needed in Petrozavodsk -- I'm literally the only one. ... and the ones that were here, they already died, because it turns out that people with my disease don't live long. ... All of the questionnaires say that the disease is fatal within three years of onset. But I am somehow alive... A lot of the kids with disease died because the disease had been progressing [*zavolevaniye progressivruish'ee*]: it's faster with some, and goes on longer with others, and sometimes there are pauses. There aren't a lot of people like me in Petrozavodsk, because I did a survey online.

да, все. дело в том что, когда человек умеет заинтересовать - ааа - с таким человеком всегда интересно. ... я думаю что, это в любой профессии, и не только по-телевидене, но, потелевиденно особенно. потому, что оченоь встал нас такой ушные - ТНТ телеканал занимается времени. правовудующие бывают, но особенно как остаться у него нет. а этот канал - в ТНТ имею виду... там нет новоста, совершенно. молодежного можно говори. поэтому. у нас называется - в стране телеканал, который увышеет настроение.

Всю жизнь люблю информацию про артистов или певцов. И не в смысле того, кто на ком женился, а Кто где снимался? Какие роли? Раньше такой информации мало было. Это теперь – «Басков купил себе 3 дома» такие вот сплетни. Когда я дома сижу одна, то люблю смотреть интилектуальные игры и отвечать на вопросы. Сейчас, например, ВКонтакте сижу, сама в некоторые игры играю. Хоть мозг мой постоянно тренируется. Вообще очень люблю общаться.

Of course, the same holds true for other disabilities - the formation of online groups has allowed people to share information, build relationships, and create united advocacy strategies - both in Russia and elsewhere⁸⁰.

Disability, Digital Mobility and Isolation

In *VITA: Life in a Zone of Social Abandonment*, Joao Biehl suggests that one of the most painful aspects of finding oneself in a place of abandonment (in the case of his unorthodox ethnography, in a slum/rehabilitation camp on the outskirts of a Brazilian city) is the loss of social meaning or mattering. For the people he meets who populate this place, called *Vita*, the ongoing struggle is not only one of physical survival in the most destitute of conditions, but a struggle to make oneself meaningful to other people. Biehl refers to the residents as "ex-persons" in that their personhood, their sense of value to other people, has been ravaged and slipped away. Not only is Vita a place where physical death happens, it is a place of social death (Mauss 1979) (38). In his book, "the struggles of the person to find her place in a changing reality vis-a-vis people who no longer care to make her words and actions meaningful" (18). This "struggle over belonging" (91) is both about displacement and about social personhood.

Unlike the population in Vita, as documented by Biehl (in words) and Torben Eskerod (in photos), the people at the center of this ethnography have not *lost* personhood. Rather, as *invalidi detstva*, people who been disabled since childhood, they have always occupied struggled to assert their social personhood.

Our lives have meaning because of other people.

⁸⁰ Liz Lewis also recently talked about the role of online social networks as crucial in the identity formation, information sharing, and meaning-making practices of families in the US raising children with rare and undiagnosed conditions. (American Ethnological Society Spring Meeting, 2015)

This fundamental insight - that humans are social beings - is at the center of biological, socio-cultural, and psychological anthropology. Yet, very rarely do ethnographers pay attention to the margins: what happens when the capacity to be recognized as a valued social actor, someone whose life bears meaning, is contested? The role of crip theory is to allow the marginal to expose the center to itself.

Pixelization/Conclusion

The configuration of crip embodiment and digitally enabled social selves that my interlocutors describe is a unique configuration of technology architectural infrastructure, and cultural and personal expectations of self-making. They exist in a state of pixelization, that is although their bodies are physically isolated, their social selves extend in digital time and space. Social worlds, selves, and meaning are enacted, negotiated, and sustained. Performances of interest and taste online involve making distinctions about who they are, who they are not, and what they desire. But pixelization is also limited by access to technology, and the uneven development of social relationships that begin on social media, where the normative expectation is of mobile, intertextual experiences that are both face-to-face and online for nondisabled users, with distinctive temporal characteristics marking each kind of utterance (the comments you receive for a photo posted on a friend's wall, versus a conversation over tea). The diversity of temporal forms in digital sociality make more space for crip time to assimilate into normative communication. Pixelization doesn't resolve problems, but it creates patterns. My interlocutors come to know themselves as social beings through mediated communication in digital space.

CHAPTER XII
CRIP ENGAGEMENTS?:
INTERDEPENDENCE, KINSHIP AND SEXUALITY

Anya: There are no invalidov. [...] In Russia, for many years, we had no sex, and no disabled people.

Cassandra: (laughing) exactly...

A: And then I laughed when I thought: "Yes, we don't have sex, and we don't have disabled people, but sex between disabled people - that's really the end."⁸¹

In 1980, a Soviet official remarked publically to a western reporter inquiring about a Soviet team for the upcoming Paralympic Games, "We have no invalids in the USSR!" [*U nas invalidov net v SSSR!*] (Phillips 2009). Seven years later during one of the first joint television events between the USSR and the United States, in which citizens could ask their counterparts questions, a Soviet woman famously responded to a question from an American with the phrase "We don't have sex!" [*U nas seksa net!*]. Immediately drowned out by laughter, the rest of her answer lost, the phrase became a cultural catch phrase in the escalating Russian sexual revolution, repeated by journalists, media, scholars, and in casual conversation (Borenstein 2008: 24, 28).

During an interview in 2013, Anya, describing, with characteristic wry wit, the popular attitude toward the sexuality of people with disabilities in Russia, drew on both of

⁸¹ С. Инвалидов нет... У нас в России много лет не было секса и инвалидов... К.(смеётся) Точно.

С. Я ещё тогда смеялась: «Да, у нас нет секса и нет инвалидов, а секс среди инвалидов – это вообще капец.»

these cultural touchstones to observe the utter impossibility in popular imagination of "sex between disabled people." The "problem" of disabled sexuality in Russia, like in many regions of the world, occupies a space of taboo and assumed incongruence. While Western disability studies has examined the ways in which disabled sexuality is stigmatized, ignored, or pathologized, given the particular Russian configurations of disability, kinship, gender, reproduction, and sexuality the specific ways in which sex between disabled people is rendered impossible may have valences that are unique to the Russian context. In this chapter, I explore the ways in which both the abstract category of Russian futurity, or imagined futures, as well as actual conditions of daily life, discursively and practically exclude certain disabled bodies from reproductive activities. At the same time, using narratives and stories from my interlocutors in Petrozavodsk, I offer some examples of the ways in which disabled people do express their sexuality, construct families, and have children.

The cohort of *invalidi* with whom I conducted research were unique, as we have seen, in their life trajectories. On the one hand, they were protected from institutionalization by their parents. They were encouraged to pursue education. And although they were raised with the idea that they occupied a social status apart from their non-disabled peers, they were encouraged to develop a sense of self that was "fully-realized," self-actualizing, and capable. Yet, in many ways, they learned to speak as capable independent agents, yet continued to live lives of codependency with their parents. In one sense, this pattern was an indication of family relationships typical in families with children with severe disabilities: the adult children continued to live with their parents. On the other hand, this pattern was not so simple: the implication of adult children living with their parents as *invalidi* had particular

kinds of implications for their own reproductive opportunities, and curtailed expectations of the creation of families of choice for this cohort. Others did assert their right to romantic relationships and reproduction; for instance, Vera's motherhood was often held up by local activists as an example of how people with disabilities are "normal" and have a right to public recognition.

The implicit or perceived reproductive capacity of a given person seemed to have important consequences for "how disabled" that person was perceived to be by others. This has important implications and intersections with feminist assessments of Russian national policies that are intended to maximize fertility of the (female, able-bodied, heterosexual, ethnically Russian) population. The complexity of kinship relations and various intergenerational interdependencies are difficult to parse. Kinship relations remained central to both my interlocutors' sense of self, and to their lived experiences of their daily lives and social worlds. What does it mean to be a person with a disability in a family? What kinds of family futures are open to those who have had disabilities since childhood in Petrozavodsk?

To fully understand the kinship relations in this scenario, it is important to conceptualize the ways in which lifecourse patterns of residence and the resulting kinship relations in postsoviet Russia are culturally specific. As we have already seen, the illiquidity of the Russian housing market and the comparatively low income of middle class Russians means that the majority of Russian adults continue to live with older generations in a shared apartment after graduating high school, and frequently even for the first years following marriage and the birth of a child. Two-and-three generation households are a normative configuration of residence. In this sense, the occurrence of adult children living with their

parents is not what makes the experience of this cohort unique. That is, an intergenerational household is not an indicator of deviance or social failure for a young adult in Petrozavodsk.

Coming of age as a person with a disability presents moments of tension particular to disability and its effect on kinship ties across cultural settings. Especially in cases in which a child with a disability coming of age has had a mother as a primary caretaker, that parent may have difficulty accepting a new degree of independence for a child (Landsman; *This American Life*). There is a fairly developed Euroamerican disability studies literature on the role and complexities of parenting a child with a disability (e.g. Berube; Iarskaia-Smirnova). Additionally, studies of disability over the lifecourse, that is how people with disabilities move through different life stages of childhood, adolescence, adulthood, middle age, and old age, can also speak importantly to the ways in which people with disabilities coming of age must work harder than their nondisabled peers to assert their sexuality and right to establish a family of choice (e.g. Priestly 2001; Frank 2000). And other scholars take up the question of sex and sexuality explicitly (Kafer 2014).

An important thread in recent scholarly conversations about kinship and disability is the theme of care work and In(ter)dependence. Several anthropologists have called for a further attention to the intersections of these modes of thinking (Phillips 2011; Ginsburg and Rapp). In the conclusion of her monograph on disability in the Ukraine Phillips writes,

families – and parents in particular – have been a major force in the Ukrainian disability rights movement. Parents of disabled children have spearheaded early intervention programs, calls for the deinstitutionalization of disabled children, and projects for inclusive education. ... The parent's movement provides a strong, well-developed base from which to expand narratives of family, kinship, responsibility, and citizenship.[...] As in the United States and many other places, in the Ukraine the burden of care for disabled family members is overwhelmingly assigned to women as the traditional caregivers. Rewriting kinship and expanding notions of responsibility of care beyond the nuclear, heteronormative family this becomes a critique of gender inequality and discrimination in and beyond the family. (2011:243-244)

Phillips, joining anthropologists Rayna Rapp and Faye Ginsberg, closes her monograph with a call for further investigation of this intersection.

Crip Futurity: Kinship, Disability, Feminist and Sexuality Studies

Disability is queer, argues crip theory, because it creates nonnormative sexualities. That is, when people with disabilities are cast in "deviant" roles or are excluded from participation in typical kinship patterns.

Kinship has long been an area of interest for cultural anthropologists. Classically speaking, kinship refers to the system of identification by which members of a culture organize their relationships to kin, and, especially to members of the same household or lineage, depending on the local customs of association that we might call family. [citation] In the postcolonial era, or since at least the 1970s, many anthropologists have expressed skepticism that the classical manner of examining, documenting and observing kinship deployed by anthropologists as far back as Lewis Henry Morgan's 1871 treatise on Systems of consanguinity and affinity of the human family (Trautmann 1987) have any relevance to local systems of perceiving self and other. In short, the very notion of kinship is rooted in assumptions about human society that remain Eurocentric, and perversely universalizing (Borneman 1996).

The historical notion of kinship as a historical anthropological construct is intimately tied to European understandings of social relationships, which, contemporary scholars have argued, are tied to biological notions of rank, status, and genealogy (Schneider 1984:54-56; Rubin). Early ethnographers and ethnologists own understandings of a social relationships and social standing created a bias toward a kinship as an interest in paternity and patriarchy, systems of reproduction as a manner of carrying on a lineage, and deviations from this

implicit norm (Schneider 1984). In this way, kinship presupposes a belief in coitus as the basis for and model for social relationships -- and fathers are always tenuous in this regard. But, because coitus and the biological father /mother /brother /sister /son/ daughter are always 'real' and then divided based on a "kinship system" the division between biological reality and social organization remains unchallenged.

In this sense, the notion of kinship is also profoundly biological. It is a primary system by which bodies are organized and ordered within social, cultural, and national systems. The ways in which disability affect the anthropological notion of kinship have been deeply undertheorized. Feminist and queer scholarship has done important work in the investigation of how biological determinism functions to enforce particular kinship norms both in scholarly bias and in social worlds.

However, feminist and queer anthropologists have “reclaimed” the terrain of kinship studies, redefining the study of familial associations as critical to studies of power relations that take into account gender, sexuality, and reproduction. Kinship, argue many contemporary feminist anthropologists, is an essential lens through which to investigate the role of women as political subjects (Lewin 2006; Gal 2000; Gal and Kligman 2000; Anne Phillips 2002:2; Strathern 1988; Collier 1987). Scholars have observed that kinship studies are particularly salient to understanding the kinds of reciprocity that unfold in the lives of people with disabilities (Sarah Phillips 2011; Kafer 2005; Kittay 2002; Kittay 1999; Rapp and Ginsburg 2001). Ethnographers of the postsoviet arena have found the subject of women’s political subjectivity to be of particular importance to understanding unfolding changes in contemporary postsoviet society (Ashwin 2000; Kay 1999).

Feminist anthropology always understands the politics of reproduction and hence kinship as related to an ethnofuturism, or sense of shared national and ethnic future, as imagined by a popular vision in a living population. For instance, Marilyn Strathern writes:

By kinship I understand not just the ways in which relatives interact with another, but how relationships as such are held to be constituted. Having sex, transmitting genes, giving birth: these facts of life were once taken as the basis for those relations between spouses, siblings, parents and children which were, in turn, taken as the basis of kin relations. Incorporated into such a reproductive model were suppositions about the connection between natural facts and social constructions [e.g. how conception happens]. These ideas about kinship offered a theory, if you like, about the relationship of human society to the natural world. They also incorporated certain ideas about the passage of time, relations between generations and, above all, about the future" (Strathern 1992:5).

That is, at the core, especially of feminist questions about kinship, but also anthropological engagement with kinship more generally, is a question about the nature of the social, and how it is imagined, how groups are conceptualized, in and out groups defined and bounded. Strathern argues that kinship acts as a central manner of classifying humans in a way that allows an imagined collective made up of individuals (1988:12-13). In this sense, in relation to kinship systems, futurity implicitly or explicitly values certain bodies as reproductive vessels, and devalues others. Feminists have long observed the ways in which women's bodies are socially valued in relation to reproduction and gene lines. Queer theory, disability theory, or their synthesis in crip theory are interested in how particular bodies are socially valued vis-à-vis imagined reproduction.

Russian Kinship Patterns: Obfuscated matrilocality

Russian family structure is profoundly matrilocal, but these patterns are somewhat obscured by discursive practice. Ethnographers have long found that matrilocal patterns of residence and kinship may coexist with patriarchal naming practices, political systems, and disenfranchisement of women. Moreover, emic and etic kinship systems are often at odds, and kinship and patterns of residence are frequently changing, contested, or in flux, so that stated patterns of kinship may or may not match up. Societies may exist in which emic and

etic systems match would be those in which, for example, people say that divorce is legal, and it is in fact both legal and practiced.

In many ways, contemporary Russian society exists in the collective imagination as a patriarchal system. Russian naming practices trace patriarchal heritage: the patronymic middle name or *otchestvo* is a name drawn from a father's first name and combined with the gendered ending -ovich or -ovna (many Americans recall Anna *Arkadyevna* Karenina or Alexei *Fyodorovich* Karamazov from their college courses on Russian literature).

The core ethos of the etic Russian kinship system is the mother-father-child as core family unit. This unit of nuclear family is widely considered by Russians to be the ideal image of "family." Yet, emic patterns observed by both critical practitioners of the culture and by scholars demonstrate that in fact kinship and residence patterns are quite different. As Jane Zavisca demonstrates in her ethnography of contemporary Russian residence patterns, the idea of "living normally" (*zhit' normal'no*) revolves around the idea of an apartment for a couple and their children. However, in practice, Zavisca demonstrates, most Russians throughout the Soviet era and today, live in three-generation households. Moreover, families often follow patterns of women living with their mothers, with children's fathers only sometimes present. Many Russian men accept this arrangement as a normative status quo (although some are devoted fathers, either living in a nuclear family setting or visiting with children). Jennifer Utrata has shown that rather than an instable structure, the single mother living with her mother pattern is an important poverty survival adaptation (2008; 2011). This situation, in which the stated kinship system is one of a heterosexual male-female couple living with offspring, is contrasted by a widespread practice of matrilocal residence in which grandmothers raise children is also present as an adaptive strategy in impoverished American

populations (Stack 1974). In both cases, these families without fathers in the residence are stereotyped as instable, "deviant, matriarchal, and broken" (Stack 1974:22).

At the same time, the expectation of dating, marriage, reproduction, and cohabitation (not necessarily in that order) remains an important narrative of the expected lifecourse for Russians as they come of age. Family-building is bound to both national pronatalist concerns and policy-making at the macrolevel (E.I. Pakhomova 2010; Shpakovskaya and Chernova 2010; Rivkin-Fish 2003; Rivkin-Fish 2006; Rivkin-Fish 2010; Zakharov 2010); to bureaucracies and classes social expectations on the meso level (Hartblay 2011); and to personal, affective imaginaries about love and romance on the microlevel (Lemon 2008).

Feminist scholars observe the Russian kinship system as deeply rooted in patriarchal configurations of political exercise of power, and the subordination of women to sexualized roles and low prestige work. Nanette Funk claims that it is the perpetuation of historically rooted notions of collective good (i.e. the nation) over the individual's rights that "prevent the implementation, institutionalization, and legitimation of women's rights in postsocialism" (Funk 2004:702-703) Michele Rivkin-Fish's writing on the demographic crisis and pronatalism documents the complex manner in which women both embrace and resist their role as reproductive vessels.

Kinship and In(ter)dependence

In April 2005, a special issue of *The Journal of Contemporary Ethnography* appeared with a focus on *Ethnography and Disability*. In the preface to the special issue, Casper and Talley observe that

A pervasive and somewhat surprising theme addressed in all of the articles is that of social relationships. How is disability conceptualized, produced, and experienced in the context of relationships of various kinds—especially family relationships? That is, the disabled people in these articles are conceptualized, introduced, and understood in relation to other people within family and community networks. Indeed, families and communities become key sites in the struggle to make

social and cultural sense of disability. [117]

That is, given that disability studies had worked thus far with an eye to recentering the voices of people with disabilities themselves, and exposing the structural effects of a medical model of disability in the domination of people with disabilities, an emerging and fruitful territory for the development of a stronger social model of disability was turning out to be the family as a realm of relationality in which kin, as well as people with disabilities themselves, had to make sense of, work in spite of, de-pathologize and re-normalize difference. Non-normative embodiments require different structures of care, patterns of habitation, and perceptions of self (Wu 2012).

Considering disability and kinship speaks to anthropological perspectives on the necessity of human diversity, both as an essential characteristic of humanness and social worlds, and as evolutionary strategy (to consider the perspective of ecological and biological anthropologists), and centers diverse patterns of exchange, care, reciprocity as a primary component of the human experience (O'Donovan 2013). That is, kinship relations across boundaries of bodily and cognitive difference are and already have been fundamental to human society; by attending to the unspoken ways that these diverse care relationships continue to work or don't in our contemporary societies will both enrich the anthropological literature on kinship and return embodied alterity to a place of relevance in scholarly literature to mirror its import in lived reality.

The notion of kinship or family also summons an idea of the domestic. McRuer argues that the creation of 20th century hetero-ableist domesticity is linked to capitalism (2006:ch 2)In his discussion, rehabilitation is cast as seeking to restore a body to the unmarked categories of heterosexual and nondisabled. Like Sergeich's reality TV therapeutic revelation, a completion of 'successful socialization' of People with disabilities (in

Driakhlitsina's formulation) includes romantic and sexual relations, which are always assumed to be heterosexual.

Tracing Disability & Kinship Relations: Family, Residence, and Future in Petrozavodsk

Family relationships comprised an important part of the social lives and personal identities of my interlocutors with disabilities living in Petrozavodsk. In both our casual interactions and formal interviews, relationships with immediate cohabitating family members were central to how people with disabilities experienced their daily lives, and their sense of possibilities for themselves in the future.

Growing up with a disability, children were profoundly influenced by the kinds of possibilities that their parents imagined for them. Some of my interlocutors were self-reflexive about this, while others talked about their kin relations matter-of-factly. The levels of dependency and interdependency that interlocutors experienced and described in narrating their stories to me were diverse and related to complex factors of intersectional identities including their parents' level of education, social class and familial financial assets, relative independence of the person with a disability in negotiating society and being self-supporting, gender, and more.

Anya interpreted the role of parents in raising children with disabilities through the lens of her work as a psychologist. In her view, the sense of self that a parent conveys to a child has important impacts on how that child comes to view him or herself as an adult. In this sense, she felt that the tendency of some parents to view a child with a disability as a burden, sacrifice, or special mission can be very damaging.

Or sometimes, a mother says, [using a distinguished voice] "I bear my cross." And you just want to ask, "And what kind of cross do you bear?" There's no need to *bear a cross*. You raise your kid *s invalidnostu* in such a way that he's not whipped, so that he can carry himself in society, and you get yourself some help...

In Anya's view, when parents perceive disability as a hardship which they must face, they - often unwittingly - pass on to their children the feeling not only that disability is a burden, but that a disabled person is a burden.

So it's these kinds of moments - because of *this* that I think that it's really important to work with parents right now, so that they can raise their kids *s invalidnostu* adequately. But to do this, you really have to start when they're small... As soon as a child *s invalidnostu* is born, there should be some kind of psychological assistance for the parents, so that they don't take the birth of their child as a tragedy (*gore*). [With assurance] It's not a tragedy, that this particular kid was born... For instance, kids with CP are born... Yes, they have physical impairments (*narusheniye fizicheskiye*), but they have bright minds (*golova svetlaia*). Often enough they can move mountains (*gori svernut'*) - as long as you teach them that they can.

In Anya's telling, the sense of self and concept of disability that a nondisabled parent conveys to a disabled child can be. In her own relationship with her mother, she turns this into a joke, as she rankles her mother by joking about how her own disability is a positive thing in her life. For instance, talking about her studies at the university level, Anya related that she depended on her mom to drive her to the university, and carry her up and down stairs.

So it was hard for my mom of course. She should get a monument! (laughter) Now I say to my mom, "Mom, look, you're 63 years old, and you are touch and strong physically, and thanks to what? That's right - thanks to me! And if you hadn't been carrying me, by now you'd be a decrepit old lady, but look at what great shape you're in. So, go ahead, mom, say thanks that I exist.

This raises important questions about care and interdependencies. For instance: Who cares for bodies that relationally require care? Who decides when care is necessary? How are notions of "independence" couched even within interdependencies?

One important series of events in my fieldwork captured this tension well. When I first met and interviewed Anya, she lived in her parents's apartment, where she had her own bedroom. But, she was in the process of looking for and attempting to build for herself a space away from her family of origin. In March 2013, she told me about how she wanted to move out, and the conversations that she had begun to have with her parents about her plans.

On the eighth, my friend got into town. She moved to Pitr in December. She decided to get a change of scenery... it gets claustrophobic living in Petrozavodsk... and I said to her "Try it now, because if you

don't try it now, then you'll feel bad later that you didn't do it. But if living in Petersburg doesn't work out for you, you'll come back because it's never too late to come home." And so it worked out that in November I started to work out a plan to live independently, to move out of my parents' place. I want to live separately from them. My papa, of course, really had a hard time with this, and he and I had a really hard conversation... Papa doesn't understand - how would I live on my own with out them? He thinks this is a totally crazy idea. My Mama said, "Give it a try." I'm saying to my papa, that if it doesn't work out for me, if it ends up being hard for me, if my helper won't cope with me, if it's hard for me to pay rent and and pay for her [the helper's] work, you will help me at first, while I figure it out with work. I want to live there and to work at the same time, so that my mom can chill out a little. My mom drives me to and from work and she's already 63 it's starting to get hard for her to lift me and everything else... and I want to arrange m professional life so that I can work from home. You understand, right?⁸²

C: Yes.

A: So I'm saying to my dad, "Help me. For now I don't need much - 5,000 rubles a month as help from you... that's enough "for eyes and ears" to play a person to care for me: I will pay half myself, and half you can pay. But as far as food I can take care of myself in that regard..." It was hard for papa, but I suggested doing a renovation in their apartment. And then my friend said to me, "Well, I decided to move to Pitr." And I supported her. "Do it! You will start your new life and I will also be starting a new life..." If I don't try and separate myself from my parents then later I'll feel bad about it, because I'm 35 years old and I want to live my own life [*khochetsia kak-to zhit' dlia sebia*]... I want to have a personal life. And, at the end of the day, that's not possible to do at my parents' place. Or else, it's really difficult, no matter what... And my parents also want to live a little. So that my mother isn't having to get up every two hours all through the night to turn me over [Anya can't roll over on her own, and so she needs help changing position every two hours to avoid pressure sores]. So that she could have a good night's sleep... I mean I did go to Anapa for a month without my parents and spent the whole month there and everything was good... If it doesn't work with this attendant, I can find another one -- we are all people... Maybe we will be able to agreed.⁸³

⁸² Восьмого числа – подруга приезжала, она в декабре месяце уехала в Питер жить... Решила обстановку сменить... Ну тесно человек в Петрозаводске... Я ей сказала: «Попробуй сейчас, потому что, если сейчас не попробуешь – потом будешь жалеть, что ты этого не сделала. А если у тебя не получится жить в Питере – приедешь, потому что вернуться, никогда не поздно.» А так получилось, что в ноябре месяце я затеяла мероприятие по отделению меня от родителей. Я хочу жить отдельно от них. Папа, конечно, по этому поводу очень сильно переживал и у нас с ним были тяжёлые разговоры... Папа не понимает, как я в своём состоянии буду жить без них?... Для него это дико. Мама сказала: «Попробуй.» Я папе говорю, что если у меня не получится, если мне будет трудно, если сиделка не будет со мной справляться, если мне будет тяжело оплачивать своё проживание и её услуги, то вы мне помогите на первом этапе, пока я не определюсь с работой. Я хочу там жить и работать одновременно, чтобы маму немножко разгрузить. Мама же меня возит на работу, а ей уже 63 года и становится тяжело поднимать меня и всё другое... И я хочу организовать свою трудовую деятельность на своей территории. Понимаешь, да?
К. Да.

⁸³ С. Я говорю папе: «Помогите. Мне пока надо не много – достаточно 5.000 рублей в месяц помощи от вас... Хватит (образное выражение) «за глаза и за уши», чтобы оплатить человеку услуги: я половину ей сама оплачу, половину вы мне поможете оплатить. А пропитаться я сама могу у меня хватает дохода...» Папе было тяжело, но я предложила делать ремонт в своей квартире. И тут подруга говорит мне: «Вот, я решила в Питер переехать» Я её поддержала: «Давай! Ты начнёшь новую жизнь и я тоже начну новую жизнь...» Если я сейчас не попробую отделиться от родителей, то потом буду жалеть, потому что мне всего 35 и хочется как-то жить для себя... Хочется устроить свою личную жизнь. В конце концов, а на территории с родителями – это невозможно... Или это очень трудно, на самом деле... И родителям

So, that was that, my friend will try to live on her own... and so we took her to Pitr and she lived there for two months and then came back to Petrozavodsk to visit... She and I were sitting there talking. And I understood that the adaptation period is difficult to get through... but I said to her: "Don't get it into your head to move back... it hasn't even been six months... You have to stay and live half a year in Pitr, so that then you can say whether or not it really didn't work out for you, or, completely the opposite, that you're going to keep living there. And in the mean time, don't wiggle back here." So she said she would stay there for a while.⁸⁴

And I will try to set it up -- the place that I'm going to live. It's not far from here. I'll have one room where the girl [who takes care of me] will live, I'll give her her own room. She'll help, or at least not refuse to help... And well, I'm the kind of person, it's not hard for me to share space with another person [*myie nie trudno s kem-to uzhit'sia na odnoi territorii*]. I don't get into conflicts, take sides, I can just say something with weight and certainty... I won't shout and argue with someone.

Subsequently, Anya did move to a new apartment of her own, not very far at all from her parents's apartment. Her new apartment was located on the ground floor of the walk up building (well, the Russian version of a ground floor, so from the front stoop she still had to go up half a flight of steps to reach the landing where the doorway to her apartment was; this was much better than the fourth floor apartment she previously shared with her parents. This was the apartment in which she engaged in the long battle with the property manager to build a ramp to the front stoop. In May of 2013, I visited Anya in her new apartment and we recorded an interview. There, she had already established a new routine, and had furnished her bedroom and begun to furnish the common area. She had done a renovation to make the toilet and washroom accessible (many bathrooms in the style of apartment from that era have a three inch step up from the hall into the small toilet or washroom), and to cover the floors

хочется тоже свободно пожить. Чтобы мама не вскакивала ночью ко мне каждые 2 часа, чтобы меня переворачивать. Чтобы она спала ночью спокойно... Ведь я же ездила на месяц в Анапу и без родителей... Нормально жила там целый месяц и всё было хорошо... Не получится с этой сиделкой, найму другую сиделку – все мы люди... Можно будет договориться...

⁸⁴ Так вот, подруга моя пусть попробует жить отдельно... И вот мы её отправили в Питер, она 2 месяца там прожила и приехала в Петрозаводск в гости... Сидели мы с ней разговаривали. Как я поняла – тяжело проходит адаптационный период, но я ей сказала: «Не вздумай переезжать обратно... Ещё полгода не прошло... Ты должна полгода прожить в Питере, чтобы потом говорить о том, что у тебя не получилось или наоборот, что остаёшься жить там. А пока, даже не рыпайся сюда.» Она говорит, что пока останется там.

and walls with new light resin panels. In her new kitchen drinking tea while her attendant, who helped her care for herself in exchange for room and board, worked at cleaning one of the bedrooms. Anya told me that she was very happy with the change, and explained her plans to no longer work at one of the part time social work jobs she currently held (it was quite far away, and she had to get her retired mother to drive her there), and to start an entrepreneurial business conducting trainings and seminars on life skills in the common space of her apartment.

When I returned to Petrozavodsk to conduct follow-up interviews the following spring, in April 2014, I visited Anya twice in her apartment. On one of the visits, she received a series of short phone calls in quick succession, and then a friend stopped by to visit. A man several years older than her with a quick sense of humor and a energetic manner, he stayed and visited for half an hour. When he left, Anya whispered to me, he thinks that he isn't interested in me because I have a disability, but at the same time, it's obvious from his behavior that he is.

What will you do? I asked.

Nothing. She replied. As it is, he entertains me.

That same trip, Vakas told me that he had been attending Anya's new seminars, and that he really enjoyed them. In this way, over the course of a few visits, I watch Anya, as a single woman in her mid-thirties, achieve a major victory, not just for a woman with a disability, but for any one of her peers. To have one's own apartment (even sharing with another person who has their own room, as long as they are your age) and not live with parents represented a major accomplishment. In Anya's description of her life, and in my observation, her degree of professional and social independence had grown since leaving her

parents' home. She told me in 2014, that she had actually been over to visit them recently, for a holiday, and it was lovely to be there for a day, but that her parents were just the same, and completely unbearable to be around.

Anya's independence was highly unusual amongst my interlocutors with disabilities. Everyone else that I was close to lived with members of their natal family, or did occasionally depending on circumstances.

Anya's experience related to Vera's, in that they are both wheelchair users who are very accomplished, and do not belong to the population considered to be unemployed or unemployable. Vera's description of married life as a young mother (at the time her son was just barely 8 and her daughter was still a toddler) was very funny in its own way; she has a sly way of commiserating, or saying something in just such a way that you recognize yourself in what she has described. In our interview she appealed to me as a peer and fellow woman; that I must know what it's like to have to clean up after a man, and to have never ending chores. But, although Vera talked to me at length about her children - flawlessly projecting the persona of a caring but not overindulgent mother, she never talked to me about sex directly. In fact, nor did any of my interlocutors.

For instance, Tanya was another interlocutor who exhibited a great deal of independence. In her early-to-mid thirties, when I first met Tanya, she was living with a boyfriend. They had been together for several years. Tanya, who has dwarfism, had happened to meet an old high school friend from the *internat* at the bus stop one day when she returned to Petrozavodsk from her family's small town some years after high school to pursue a higher education. They hit it off, and dated all through Tanya's college years, and eventually moved in together when she was already in her late twenties. I met Tanya several

times before I interviewed her, and she knew of my project, so when I did sit down with her to record an interview, she had already thought through the stories she wanted to tell me. These included the story of the chance meeting at the bus stop. One thing that came up that I don't think she had intended to share was that she was trying to get pregnant. She explained that she had been pregnant once not long after she first started dating her partner, but that she hadn't been ready to be a mother yet. Now, she told me, she had been trying but hadn't conceived. She suspected, darkly, that if she were to attempt to a child, she would never be "given" one, because excuses would be made to keep a child from being raised by *invalidi*. This story was literally the closest that any of my interlocutors came to talking about sex with me - in an interview or otherwise.

Meanwhile, Vakas and Sergei both harbored fantasies of meeting the perfect woman. Vakas's habit of meeting young women online, telling them he liked their photos, and then sending them his poetry has already been discussed.

Sergei, meanwhile, was characteristically slow and somewhat resistant to thinking and talking about romance or what he would like in a woman. Because we are quite good friends, I urged him to think about this and give me an answer; his long thoughtfulness in response to this question it almost seemed as though he had never thought about it before, but I wondered if maybe he was just considering what the right response to such an *American* - straightforward and personal - question would be. Eventually he told me that he would like to meet a girl, maybe a bit younger, who was able bodied, so that when they got married, she would be able to take care of him. At first I thought that this answer represented some strange internalized ableism, that Sergei would never consider himself with a woman with a disability. But as I asked him to explain further, I realized that he had produced this answer

because he felt that it was the most pragmatic and fair. His mother currently does all the grocery shopping and cleaning in his family household, so he couldn't imagine falling for a woman who wouldn't offer a similar level of services; the incentive to disturb his content existence in his parents' apartment would be lost.

At first I was somewhat shocked by this unabashed lack of independence. Sergei is smart and capable, and at first it seemed self-defeating for him to be so reliant on his parents. But later, as I came to think about how Russian men are brought up and what they are and are not trained to do, I realized that in saying that he would want to marry a woman who would shop and cook for him, Sergei was actually expressing not dependency of someone who is incapable, but the privilege and swagger of Russian masculinity. Unlike American men, who frequently move out of their parents homes, and live independently for several years before marriage, Russian men tend to live with their parents until or even long after they marry. While girls are taught to do household chores like shopping and cleaning, boys are not. I realized the extent of this too late once, when, thinking I was talking with a very independent person, I made a joke to Rudak about how so many Russian men don't know how to do their own laundry. From a fleeting expression on his face, I realized that he was among this population of men-who-have-women-do-their-laundry, and that he was a bit embarrassed that in my American feminism I had assumed that he would not be.

In this sense, the normative Russian masculine domestic persona is highly interdependent on other - female - members of a household to reproduce the conditions of daily life. A man's inability to care for himself is considered charming, a mark of true masculinity. For instance, Vera told me a story about her husband:

when like, my husband leaves on a business trip, I don't even come out to the cafe, I just relax! I have to have the whole house cleaned up, everything in it's place, the dishes washed, everything else in order. Everything is perfect! *Vsyo Idial!* [then, in a dark voice] My husband comes home, and it's

"Vera, bring me something to eat! Vera, bring me something to drink! Vera, hand me that thing! Vera, where is the charger?! Vera, where is the --?! [laughs]

But actually in terms of cooking, my husband is a very good cook.

[then, pausing, because she's set up a joke]

BUT, the way he cooks, it's like it cancels it out: he cooks for two hours, but then it takes three hours to clean the kitchen! Because the dishes will ALL be dirty! The kitchen will be a total mess! On the table, on the floors, on the walls, everywhere! [laughs]

Soo. So yea. No, cooking is cooking. I have like, it worked out for me with husbands, that I have men that can cook. But in order to clean up after them -- you lose even more time than if you did it yourself. It's just unbelievable!!

This story, at face value, is intended as a joke - it's funny when someone makes so much of a mess that it takes longer to clean that it did to cook! On the other hand, her tone is one of commiseration between women, and in this way the story is way of bonding by offering an obvious stereotype - oh, men are so messy!! - which both the speaker and the listener can laugh and agree. It also positions Vera's husband as a "real man" - the type to do very little for himself, be very demanding to women, but who then must be very capable in domains of men's work - carrying things, drinking, building things, fighting, and so forth. Indeed, Vera's husband is a former soldier, a fact that she is proud of, even if her husband's gruffness scares her a little.

Of my male interlocutors, only Vakas desired more independence, clearly because of how his parents tried to keep him from leaving the apartment alone. In this way, even though Vakas is quite dependent on his family to help him with the tasks of daily living, he also feels a deep resentment toward them. Unable to play the tough guy by a long shot, Vakas executes artistic masculinity quite well, and he remains a hopeless romantic. Here is one passage that is particularly moving, from one of our in person interviews:

the 14th was the concert
that was a really unusual, since i went out
yeah. but this - outing - makes me
feel something
but today i asked -- it was beautiful -

let's go outside - he (papa) didn't want to
that's what i live for - seeing people
art
getting to know someone brings me joy

it's hard - since i almost
don't go outside at all and my parents
keep me at home, keep an eye over the place and i don't like it and
i tell them so
but there's already been so much uproar
about this

when i was going to the store
so, i used to talk with the salesgirl there
and i liked that
and when i got out and would get out of the house, so to speak,
i would always show up at the store.
and so i would be going to the weekend school and i was going
and i would ask them to let me out
by the store, and i would go in
and then walk home myself.

i found this really interesting salesgirl

-what store?

-it's in Capitol shopping center

-which one?

-it has kids' music stuff
i would go there often
a bunch of Sundays
it was always the same
salesgirl, and i liked her.
and one time when i
saw her i asked for
her to show me some things in
the store and i said, that i
liked meeting her there
but she was just at work
she looked at me and left
i wanted to give her
my book [of poems] - the first one, that
Fridrikh made in 2004
but it was a different person
i asked where is *that* girl
and no one could tell me
i didn't even know her name
and i couldn't even leave the
book for her
the next sunday i went back and
there standing there
was a different girl
i asked
where is she? she said, what's her name?

then i don't know who you mean
and then the next week -
a different salesgirl

so - this was, probably
a long time ago
around the time i bought a camera
two years ago

i wanted to give her my book and
i complemented her
these sorts of emotions
but i just liked her
how she looked
her face
i went every sunday
and asked someone
just to get to talk with someone
and obviously i shouldn't have
done that because
then she disappeared

-that's why you don't go out?

-no, my parents explain it like this:
so they let me out
on the street - when i started going
to the weekend school, it was
not in very good shape - three
or four years ago.
i met a new volunteer
this one was Olga (i forgot her last name)
it was nice talking to her
and i asked her to
take me outside in the yard
and there... the asphalt
and it got windy

-what happened, you fell down?

-So there was pavement with a
curb at the edge the
and for some reason thought
i'll step down
and because of the ledge
i just
fell right over
and my face - i swallowed a tooth
on the pavement

-she was standing right there?

-no she stepped away - she was
doing something with the kids,
up ahead
and so i come up with this

gorgeous mess with blood, without
teeth, and she (the girl)
was at the end --
so that, that - after that
that tooth - mama knew someone (who fixed it)- and then another time inside
the school - on a pipe, i tripped on
the linoleum
and broke it up to the nerve

-because of a *tooth* you're not allowed outside?

- well... there it is. (he says putting his hands up)

after that, i started to stay at home
and i told them so many times
but they -
you fall - your teeth! your head!
and we'll be sitting
by your hospital bed again
like after the accident
you can only go places in cars,
if you've called ahead
so that's what the 14th was -
i'm only allowed for things like that

In Vakas's description of these events here, he seems to depict his parents as utterly unreasonable, keeping him unjust captive. At the same time, the final lines of his narrative, in which he performs the emotional distress he imagines them deploying should he ask to go out unaccompanied. At from looking at the text alone, it might seem that he produced this imitation glibly, as a way of mocking his parents' overbearing protective ideas. At the same time, there is real emotional distress in the idea of his parents suffering over an injury that he sustained. A child's traumatic brain injury is particularly harrowing process to go through, and recovery is slow and entirely uncertain. Vakas told me that since his accident his *father* has never been the same again. In this way, even as Vakas is resentful of his parents, he is also unable to fully shrug off the weight of causing them emotional distress.

Conclusion

This chapter offered a brief overview of kinship, gender, sexuality, and reproduction as anthropological modes of inquiry, followed by a numerous examples of how different

interlocutors in my field site react differently to questions about sex, and how they imagine their futures as adults moving through the life course.

More research is needed to draw conclusions about how sexuality and disability come into play in the reproduction of ableism. Attention to gender and kinship patterns, however, reveals that because normative Russian masculinity includes a sort of performance of domestic helplessness, for adult men with disabilities, the drive to establish independence and to have one's own home, separate from one's parents, may be much lower for men with mobility impairments than for women. However, this could be an accident of my very sample; I have met several young men with disabilities who seem to be very independent - at least in the public sphere. Moreover, the complexities of gender performance should not be reduced to simple causal analyses, and I do not mean to do so here. Rather, I am curious about the ways that masculinity and femininity map on to disability in Russia. And I'm also extremely curious about who is having sex and with whom, but I don't know how to find out. But it seems that although in this study there are people with disabilities, still, there is not much sex at all.

CODA II *KHEPPI ENDINKS AND OTHER FUTURES*

One morning in early March of 2013, Sergei came to my apartment for an interview. Always a proper guest, he had a box of cookies tucked under his arm as he made his way carefully across the icy drive to the front door of the building.

Drinking tea in the kitchen, the cookies laid out on a plate, our interview meandered through his description of how he spends his days. He began talking about the movies he likes to watch: with unlimited internet, he can stream almost any film, dubbed into Russian, for free (pirated on the Russian internet, but with an array of click bait ads around them). The interview ended with him describing his recent predilection for watching war movies, and the difference between Russian and American films. He told me about a film in which the main character dies in the final frames: he gets, and then the credits role.

Sergei: With American movies, a lot of the time, the main character gets his motivation from fighting the enemy, and then he goes out of his mind from grief, andddd, then what? -- in the end everyone triumphs, right? In our Russian films, you know, it's more realistic. They tend show that even the enemy can be - sort of - we can do something deep with the character, right? So that you feel bad for them in the end. Our Russian film characters. And my mom, she says, "I don't understand it!" about this. They say that Russian films are grim (zhestokii). They say that Americans don't like grim films. And she says, that in American films, at the end, the main character always ends up with his hands raised in victory. Not, as a symbol of [relief of] having gotten through it, but just the opposite, the he has won without fail. [...]

C: Well, yes, in our American films, the word "hero" already means that not only is he the main character, but also that he will win, you know?

S: Yes, I think that's true. But in ours, there are often these shocking endings. [...]it's surprising when they do that. Especially in the very last moments. And everything is supposed to work out well -- [switches to heavily accented English] Kheppi Endink. [then, will glee] Nope! So that's the kind of films we have. But I watch them anyway. I like it. [...] But on the other hand, if I watch an American film, then I like it better than ours. So...

When I read this transcript, I picture Sergei in his family apartment, watching movies on his computer. I wonder if at this very moment he is watching an American film or a Russian film, and what effect each one has on his emotional landscape. Does watching a film with a Kheppi Endink shift his horizon of what is possible in the future?

I didn't remember it when I first read the transcript above, but several months before I had asked Sergei about his hopes for the future. It was actually in the first interview that I ever recorded with him. I brought up the question outright, some 45 minutes into our conversation.

C: And what are your plans for the future?

S: For the future? Well, what do I want? ... In the future... [pauses, thinking]. I don't even know what to say. ... it's a hard question in a way. Plans for the future... Well, in general, everything for me is... well, I work. What else do I need? I ... So what else? A ways off in the future, like? What will happen in a year or two?

C: Well, yes.

S: I don't even know.

C: Well, okay.

S: It's hard, but I'm interested in answering this question. Plans for the future... I'm living now, today, and it's good. I know what will happen tomorrow too, if... well, basically, it won't be worse. It will either be like today, or it will be better.

C: [laughs at the audacity of this response]

S: So, that's that. What will happen in a year will either be pretty much what's happening now, or it will be better, but about the same, not worse.

C: [laughs]

S: Well, a plan... Somehow I don't now. I guess I have some hopes and dreams, to travel somewhere, to go abroad... like, on some kind of trip. I would like, I don't know, a five day bus tour in Europe. So, that's something I want, that's a dream of mine, you could say. In general this is theoretically possible, but you'd have to plan for it.

I didn't yet know Sergei then, or his slow and methodical way of thinking, of circling around an idea again and again before finally locating himself in it. I asked him about his plans for the future more than 30 minutes into that first interview, and though he produced a short response right away, he continued to answer that question right on up to the end of that interview, twenty minutes later... and then, I suspect, at moments in subsequent interviews that took place months later. What he wanted me to know, it turns out, is that what happens in the future is less important to him than feeling connected in the moment.

CHAPTER XIII
CONCLUSION:
**ENACTING *INVALIDNOST*, DISABILITY THROUGH GLOBAL CONNECTIONS,
AND THE COMMODIFICATION OF ACCESS**

Anya:

The worst [part of talking with other people with disabilities] is when you run into this question: "What's the point of it all? All the same nothing changes..." You understand that if everyone talked like this, that nothing changes, then really nothing would change. So, I start from the beginning, explaining to everyone, so they don't decide it for everyone. ... It's a drop in the bucket. Take your little contribution and make it useful for something, and your little tiny drop in the bucket helps a stranger and then something changes. But if everyone will go around saying that nothing changes, then oops, nothing changes.⁸⁵

Why should the state be thinking about how to make it easier for us to live? [incredulous] The state doesn't need to think about anyone and it doesn't have to do anything for anyone. If you don't take care of yourself, no one else is going to take care of you... Why should you get used to the idea that someone should be looking out for you, if you have your own head to work from and you can look out for yourself? ... and then help someone, and look out for someone else... look out for someone who needs your help, or protection or support.⁸⁶

Every drop in the bucket counts, if each person will make their own little contribution. The laws are written, and if there are strange and not very honest people driving the bus, then you and your crew have to do something so that the laws work in your favor. And if you came and and met with resistance and you say, "Oh, I'm not doing that anymore," ... then it ends up that that side won and that's it. I understand that it doesn't have to be this way, but that's how it worked out and we can change it only with our own power.⁸⁷

⁸⁵ Самое сложное было тогда, когда натыкаешься на такой вопрос: «А зачем это надо?» всё равно ничего не изменится... И ты понимаешь, что если каждый будет так говорить, что ничего не изменится, тогда, действительно ничего не изменится. Вот и начинаю каждому объяснять, чтобы за всех не решали... «Внеси свою лепту в исполнение чего-то и твоя маленькая-маленькая лепта приложится к чужой и тогда что-то изменится. А если каждый будет говорить, что ничего не изменится, то оно и не изменится...

⁸⁶ (удивлённо) Почему государство должно думать, чтобы нам легче жилось?... Государство не о чём не должно думать и никто никому ничего не должен. Если сам не позаботишься о себе, то никто не позаботится о тебе... К чему привыкать к тому, что о тебе должен кто-то заботиться, если у тебя голова светлая и ты можешь сам о себе заботиться?... А потом помочь кому-то, тоже о ком-то позаботиться... О том, кто будет нуждаться в твоей помощи, защите и поддержке.

⁸⁷ If it worked out that way, that the laws are written in this way so that the other guy makes out with twice as much... well, what are you supposed to do? If he gets twice as much, then you have to work it out. And if you won't do that then everything will be exactly how the other side wants it, and that's it...

Всё будет накапливаться, если каждый человек внесёт свою маленькую лепту. Законы написаны и если у руля страной сидят не очень честные люди, тогда вы своей массой сделайте так, чтобы законы

Anya's mediation on the meaning and saliency of disability advocacy in contemporary Petrozavodsk is a fitting closing for this work. Even as Sergei's description of *kheppi endinks* suggests a Russian worldview in which heroism, justice, and resolution happen to other people in other countries, Anya suggests that a moral person, a Russian moral person, is obligated to continue to work toward justice, even when justice remains elusive.

The strategies and conceptual frameworks that my interlocutors - Anya, Alina, Vakas, Sergei, Rudak, and others - take up in order to make meaning of their lives as people living with disabilities and disability stigma in contemporary Petrozavodsk are myriad and varied. Conceptual realms of therapeutic rehabilitation, independent living, literary artistry and escapism, pop culture savvy, online friendships, rights and citizenship, transnational concepts of accessibility, local concepts of injustice, cultured patterns of speech and behavior, normative and transgressive models of kinship, imagined ideals of essential Russianness, imagined ideals of normal Europeanness, and more are deployed in various configurations with virtuosity and seamless integration.

The problem of seeking to unpack the cultural configuration of disability in contemporary Russia emerged very quickly upon my return from the field as a problem that

работали в вашу пользу. А если вы пришли, наткнулись на противостояние и говорите: «Ой, я больше не пойду туда» ... Получается, что та сторона победила и собственно всё... Я понимаю, что так не должно быть, но вот так сложилось и мы можем это менять только своими силами...

Если так сложилось, что законы написаны и они пишутся «в стол» (образное выражение) Если закон пишется так, что его можно рассмотреть двояко... Ну что делать?... Раз двояко, то нужно его в свою пользу рассматривать... А если мы не будем этого делать, то всё будет так, как хочет другая сторона, вот и всё...

could not be examined without contextualizing Russian discursive modes and performances of self in relation to global genealogies of ideas, technologies, and material worlds. The very impetus to attend to how the social exclusion of people with disabilities is reproduced, or, how the inverse, disability access is facilitated in contemporary Russia requires a recognition that with the body of the ethnographer, ideas and cultural as well as theoretical frameworks have moved across time, space, and cultural configurations.

So what happens when the idea of an accessible society moves into postsoviet spaces? Access, as we have seen in this work, is many things. It is the inclusion of minority or stigmatized groups in social and political life. It is an unhindered physical and material movement through space. It is both a metaphor and a literal expression of agency, and of social worth or neededness. It is a relational concept of interactions between complex networks of heterogeneous actors. It is peacefulness and comfort. It is the idealized normal.

As the notion of access has moved through networks of global connection, it has taken on new dimensions and meanings in local contexts. In the case of Petrozavodsk, standards of access and expectations about meeting those standards have moved across national, linguistic and cultural borders. It has troubled and been troubled by digital technologies and mediated communication.

Accessibility in public space means considering the social expectations about how individuals and groups are meant to move, gather, and communicate. While the American notion of *access* is predicated on a concept of civil rights guaranteed by the state and for which individuals, based on membership in a particular group or class, must actively lobby. In contrast, Russian concepts of self and society shift the emphasis of the concept: *dostupnost'* or *dostupnii* is related to something being within reach. Yet, the reach in question

is not strictly bounded to an individual human body (an arm reaching out). Rather, it is the reach of one's social network, how needed a person is, and how one's reciprocal relationships can turn up scarce resources. The necessity of a singular body moving through space is deemphasized, while a concept of social capital or embeddedness in a community is more present than in the English equivalent.

At the same time that these sematic domains of the literal translation of access do not match up, technologies that are considered to produce access in the West - wheelchairs, ramps, and building codes - also move into Russian material worlds. Material relationships and infrastructures of access and inaccess are coemergent with social forms. Standards, checklists, and other tools designed to allow technologies to move and be executed across borders facilitate movement but do not prevent friction. The globalization of accessibility standards gets caught up in the specificities of local material histories. Infrastructures, bureaucracies, businesses, and users weigh the importance of each element of a standard or checklist differently.

Meanwhile, although access is couched as a human rights issue in its English usage, its execution is intimately bound to the commodity values of material objects and technological development. Ramps, wheelchairs, and accessibility standards are embraced and executed according to logics of capital - from the social pressure to consume the latest technologies in order for states or municipalities to display prowess through savvy consumerism, to the incentives driving the production of new accessible public spaces. Even so, economies of inaccess or illiquidity, which rely on social networks and personal favors, rather than a free flow of capital, and profoundly woven into the material and social fabric of daily life in Petrozavodsk. Capital flows through and around stationary elements.

To think ethnographically about disability and access in Petrozavodsk in the twenty-first century requires thinking about global friction, and the ways that inclusion or access take on particular meanings in a specific time and place. This ethnography did not start out as an ethnography of globalization, or an ethnography of spatial relationships or infrastructure. It began with very simple questions about social and political participation, and the meaning of the word *invalidnost'* in contemporary Russia. Yet, by arriving in Petrozavodsk and raising these very questions, I was part of a much bigger flow of ideas about rights, knowledge, participation, and justice that has moved from the United States into postsoviet worlds. Yet, these ideas are taken up and take on meaning in vocabularies and lifeworlds in ways that would be unpredictable and difficult to parse from an American point of view.

Western discourse has frequently described democracy or political participation as inaccessible in a Russian context. Like Sergei's description of the *kheppi endink* that perpetually occurs in Hollywood plotlines, American dialogue has failed to stray from a rhetoric of just endings: the good guy gets the girl, and the bad guy slinks off in shame. The reconsolidation of social services and political power under the sovereignty of the Russian Federal government, and especially the annexation of Crimea and the upheaval in Donetsk, is perceived in the West to be an assertion of neo Cold War hostilities and anti-democratic totalitarian rule. The American media casts Putin as a villain, at once conniving, shrewd, inept, comical, and abusive.

But paying attention to flows of access, and to local perceptions of what is accessible and inaccessible, points to a different interpretation - one in which 1990 did not mark a Happy Ending to the Cold War and a time-limited transition to democracy and capitalism. Rather, Putin's reconsolidation becomes yet another stage in an unfinished experiment.

Access as a concept has been deeply theorized in disability studies, but has received insufficient attention in global studies, anthropology, and the broader humanities and social sciences, even as these disciplines have turned the focus to concepts like *mobilities*.

Conversations about supply chains, borders, social participation have all been related to the question of mobility, a conceptual question about how matter and bodies move through space. But, I would argue, *access*, as it has developed in disability theory, offers a more robust conceptual framework for addressing just these questions: it offers an opportunity to attend to *barriers* and conceptual and categorical omissions that prevent access or mobility.

Which is to say, that in this dissertation, I have worked to apply a question of access to problems of globalization in contemporary Petrozavodsk, explored through the lens of people with disabilities. I arrived in Petrozavodsk with questions about disability and access, but these ideas were revealed, through the course of this research, to be theoretical, rather than descriptive, terms. Interlocutors on the ground were willing and able to discuss and engage in discussion of these ideas - yet they remained always ideas or categories that floated above the surface of naturalized reality (even as stigma and internalized oppression naturalized the exclusion of people with disabilities from their peers in daily life). In this sense, this dissertation has come to focus on the ways in which ideas and concepts move globally. Where *mobile* concepts take on different shades of meaning in and between cultural contexts, these frictions offer or prevent *access* in specific ways to specific groups of people.

APPENDIX 1 DESCRIPTION OF RESEARCH

This dissertation focuses on a core group of interlocutors who actively participated in the formation of this project. Their stories are intended to be somewhat representative or generalizable. Research for this dissertation overall consisted of over 10 months in the field in Petrozavodsk, as well as extensive preparation in terms of previous related research projects. The overall research for this dissertation included interviews with over 70 interlocutors. The core group of interviewees on which the dissertation focuses are those people with whom I met and worked repeatedly and who expressed and sustained interest in participating in the project.

Many people were interviewed for this project, or allowed me to participate in activities and events as a participant observer, but do not appear in the final manuscript. Their absence here is either because they ceased to respond to inquiries indicating a disinterest in the project, or because their particular role was not immediately relevant to the stories told here but may be considered as part of the background research that supports the interpretation presented here. I am grateful to the many people who lent their time and attention to me during the course of this research.

The method, ethics, and intent of this project was thoroughly reviewed and remained for the duration of the research under the aegis of the Institutional Review Board of the University of North Carolina at Chapel Hill, with Dr. Michele Rivkin-Fish as the overseeing faculty member.

APPENDIX 2

A Note on Complimentary Texts & Media

This written dissertation is a companion to a series of non-text-based research outputs. That is, in the tradition of nontextocentrism (Conquergood), I have made a point to produce ethnographic outputs that might offer a chance encounter the subject matter of this research to a diversity of audiences with a range of sensory perceptions and degrees of interest in academic text. While the text of this dissertation stands alone as a piece of ethnographic writing, the reader is encouraged to consider it in conversation with the below-listed media.

Media and complimentary texts by Cassandra Hartblay:

1. [Do You Like This Installation?](#)

A digital installation, and accompanying commentary, part of the Crippling Cyberspace special issue of the Canadian Journal of Disability Studies

2. [Disabling structures: Perspectives on Marginalization in a Russian Cityscape](#)

A Photo Essay in the online journal Landscapes of Violence (2015)

3. **"I was never alone" or *Oporniki*: An Ethnographic Play**

A fully performable play script conceived as a companion to this dissertation; the text of the play is presented in side-by-side Russian and English, and is adapted from the transcribed interviews gathered during this research. More so than a scholarly ethnography, this work fully center the words and stories of interlocutors in the field. Readers of both works will recognize characters, voices, and segments of dialogue. In progress (in Joseph Megel's Performance Studies Advanced Projects workshop at UNC-CH) at the time this dissertation was submitted.

Media and complimentary texts by collaborators in Petrozavodsk:

1. The narrative films of Vladimir Rudak, including [Tough Guys Don't Dance](#) (*Krutye ne tantsuiut*, 2005)

2. ["A New Planet"](#): short documentary films about people with disabilities

A video project by Rudak and Aleksei Babenko, including episodes featuring Vera and Anya from this ethnographic account, available on YouTube (currently only in Russian).

3. *A Train Station Tale (Vokzal'naia Skazka)*

A play by Oleg Lipovetsky and Lidia Pobedinskaia, coauthored by children with disabilities, and produced with a collaborative group of volunteers

“Олег Липовецкий: «Мои Спектакли — Как Дети: Все Любимые» Губерния Daily.” 2015. Accessed March 18.

<http://gubdaily.ru/blog/sociology/interview/oleg-lipoveckij-moi-spektakli-kak-deti-vse-lyubimye/>.

“Социальный Арт-Проект «Добрый День» Рупор Петрозаводска.” 2015.
Accessed March 18. <http://rupor.sampo.ru/topic/65179>.

5. [The music & music videos of Okestr Kto Kak Mozhet](#)

Rudak's rock band, including [a recent collaboration with students and teachers at School # 21](#)

6. The poetry and prose of Vakas Milius

If you would like to be friends with Vakas, he will happily send you an electronic copy of his poetry chapbook and recent memoir (both in Russian). You can find him online via the Russian social network VK.

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