Affecting Neoliberal Public Health Care: Interdependent Relationality between Disabled Care Recipients and their Care Providers

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AFFECTING NEOLIBERAL PUBLIC HEALTH CARE: INTERDEPENDENT
RELATIONALITY BETWEEN DISABLED CARE RECIPIENTS AND THEIR CARE PROVIDERS

by

AKEMI NISHIDA

A dissertation submitted to the Graduate Faculty in Critical Social Personality Psychology in partial fulfillment of the requirements for the degree of Doctor of Philosophy, The Graduate Center, The City University of New York
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Abstract

AFFECTING NEOLIBERAL PUBLIC HEALTH CARE: INTERDEPENDENT RELATIONALITY BETWEEN DISABLED CARE RECIPIENTS AND THEIR CARE PROVIDERS

by

Akemi Nishida

Advisor: Professor Michelle Fine

In this dissertation, I trace the neoliberal turn of a public health-care program, Medicaid, and its effects on those who are involved in it: disabled care recipients and their care providers. Also examined is the emergence of an affective relationality between these individuals through their daily practices of care. In 1993, Medicaid went through a neoliberal turn that accelerated its privatization. I investigate the ways in which this turn—in company with the neoliberal transition of other welfare programs and the rise of a transnational care industry—further deployed a gendered, raced, classed, and immigration-based division of care labor that commodified and exploited the labor capacities of mostly lower-income women of color. Similarly, the neoliberal turn led to a reconfiguration of the Medicaid beneficiary criteria for disabled people such that their care needs became commodified and exploited in the interests of a maximized revenue for the care industry. As both populations come to be measured based on their capacities and needs, their wellbeing is overlooked and deteriorating. The narratives I have gathered from care recipients and providers of Medicaid long-term care programs illustrate how they are all turned into consumable and disposable populations for the industry’s capital accumulation and the state’s suppression of Medicaid expenses. Consequently, care recipients and providers are both
pushed to slow death: turning the neoliberal public health care into necropolitical one. Yet, a closer look at these narratives also tells a story more complex than total exploitation. As much as their care practices are embedded in injustices, recursive practices of care between recipients and providers allow them to slowly adapt to each other’s distinct body and bodily movements, capacities, needs, desires, and rhythms. They begin to recognize one another’s vulnerable situations as situated within the negligent care industry, and to share vulnerable moments together. Using affect theories, I theorize how this relationality moves beyond the cognitive, marking a proprioceptive connection between recipients and providers. Developing a notion of affective relationality, I end this dissertation by arguing that this embodied, interdependent, caring, and co-capacitative relationality destructs the flows of the neoliberal public health-care assemblage.
Acknowledgements

People write for different reasons. In the case of this dissertation, it was partially guilt which drove me to write. It is the guilt of leaving my family, particularly my mother, back in Japan and not fulfilling a daughter’s role to live nearby and take care of her and other family members. Therefore, my very first acknowledgement needs to go to my mother and other family members for allowing me to pursue my education despite the many sacrifices we have made together and individually.

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Indeed, it was a collective work (and we kept saying so) of many scholars and community activists. While all the faults of this dissertation are mine, all the credits belong to the New York City disability communities, disability justice activism, and domestic workers rights activism.

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Chapter 1
Introduction

Abstract

In this chapter, I set the groundwork for this dissertation. I begin the chapter by addressing the goals of this dissertation. Then, I share narratives that illustrate the ways in which this dissertation emerged from the dialogues and experiences I have had in disability communities and care justice activism. The overarching research questions are laid out next. Following those, I briefly contextualize this dissertation by describing the circumstances that deeply shape today’s public health-care sector: the care crisis, neoliberalism, and Medicaid. Finally, I present the intended contributions of this dissertation and the brief landscapes of the following chapters.

Care is fundamental to all life.
Put another way, everybody is dependent, and their\(^1\) life and bodymind\(^2\) are deeply interwoven with other lives and bodyminds.
Only through love, connection, and care, can we break the oppressive structures under which we live while imagining and practicing mutually co-capacitative, interdependent ways of living.

The above statement is nothing new and has been practiced always and already by many around the world (e.g., Ramose, 1999). This dissertation is an attempt to restate it. As axiomatic as it is, care has been, and is even more in today’s society, commodified and taken up by the globalized, capitalist, profit-making matrix and thus fueled by racist, sexist, classist, ableist,

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\(^1\) Throughout the dissertation, I use the gender-neutral pronoun “they,” instead of s/he, unless I intend to make a gender-specific statement.

\(^2\) A concept of “bodymind” is used throughout this dissertation, instead of separating body from mind, in order to emphasize their deeply intertwined nature. Please refer to Price (2011), for example, for a further conceptualization of bodymind.
sanist, ageist, heterosexist, and xenophobic ideologies. Simultaneously, though, some aspects of care resist being vacuumed into this agenda, and these escaping arrays of care underlie people’s everyday lives, rooting us to strive. This dissertation illustrates the landscape of contemporary care regulations—particularly of Medicaid Long-Term Services and Supports (LTSS)—and practices as co-engaged in by disabled people and their care providers in New York City (NYC). The profile of these care providers depicts it as an occupation largely reserved for and forced onto lower-income women of color who are often immigrants or former welfare recipients.

I document the neoliberalization of public health care, particularly of the Medicaid LTSS, and the development of the assemblage\(^3\) under the shift. I trace the psychological and physical impacts caused by the shifting health-care sector on those who are involved in the Medicaid LTSS: disabled care recipients and their care providers. Finally, I theorize the relationality between care recipients and providers that emerges from some of the care arrangements. I use the term “neoliberalization”\(^4\) in this dissertation to refer to the deregulation of and increasing privatization of the public health-care sector and other public sectors; development of the care industry inside and outside of the United States; commodification of care, care labor, and care needs; and individualization of care provision and reception responsibilities. Brown (2003); Fabricant and Fine (2013); Giroux (2014); and Goodley, Lawthom, and Runswick-Cole (2014b) among other scholars have written extensively about the ways in which the ideology of neoliberalism shapes not only the global political economy but also social ideologies, values, and beliefs as well as individual behaviors and psyches (e.g., desires). The neoliberalization of public

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\(^3\) This concept is further described under the section of “Key Terms” in chapter 2.

\(^4\) Neoliberalism is further described in the context section of this chapter.
health care has been ontologically experienced by those who are embedded in the health-care system, especially those who are most burdened and exploited in the system—care recipients and providers. Such experiences of theirs were evident throughout the focus groups, individual interviews, and participant observations I conducted for this dissertation. Nevertheless, in the process of data collection, the experiences of the research participants (disabled care recipients and their care providers) were often framed as individual narratives, with limited contextualization. To connect the narratives of care recipients and providers and embed them more explicitly in the larger, on-going shift toward neoliberalism, this dissertation asks the following:

- How has today’s public health care been shifted and shaped by the neoliberal political economy and its austere policy reforms?
- In what ways are the existing social injustices further deployed under the neoliberalization of public health care (e.g., sexism, racism, classism, ableism, sanism, and xenophobia that are inherent to care labors and practices)?
- What are the psychological and physical effects of the neoliberalization of public health care on those who are involved in it—particularly disabled people who receive their long-term care through New York State (NYS) Medicaid and their care providers?
- Does relationality emerge between care recipients and their providers, and if so, how?
- What does such relationality do?

These questions can be attributed to two origins. On the one hand, this dissertation sprouted theoretically as a response to a question Erevelles (2011)—critical race, disability, and transnational feminist theorist—asks, “How do we forge a collective struggle [between disabled people who receive care and their mostly female providers] without destroying the people we
really care for?” (p. 197). On the other hand, this dissertation primarily emerged from disability communities. Initiated through a principle of participatory action research, the above questions are formed through my engagement and conversations with friends who receive LTSS, through the collective care networks my friends and I have developed, and through my involvement in the national care justice campaign Caring Across Generations. I share snap-shots of these experiences below to show how this dissertation is profoundly community centered and personal.

**Sprouting of the Dissertation from Disability Communities**

The first snapshot of my experiences that led to the development of this dissertation is about a series of conversations—mostly via texting while we lay and sat next each other—I had with disability artist and activist Jon and feminist disability activist and community organizer Sonia, who are in a nonmarital partnership. Their knowledge regarding Medicaid LTSS comes from the everyday activism in which they engage to sustain social services for themselves and others with disabilities. Also, their wisdom is accumulated in an embodied manner, as Sonia receives several hours of personal care every morning, and Jon receives around-the-clock home medical care. They are experts of the public health-care systems across different states and tireless advocates for the disability communities general and also themselves as they spend most

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5 As has been expanded by Torre, Fine, Stoudt, and Fox (2012), participatory action research involves community-centered and -initiated projects where community members learn and gain research skills (usually in collaboration with university researchers) and use research to pursue justice for their community.

6 I am using pseudonyms to all the names used under this section to protect these individuals’ confidentialities.

7 Marriages between or involving disabled individuals who receive Supplemental Security Income (SSI) are subject to reduction or cuts of the social services they receive. Therefore, like many others who receive social services from different venues, marriage is not an option for these individuals without social service penalties.
of their day negotiating with public service authorities, searching for and training new nurses for Jon (due to the extremely high Medicaid care provider turn-over). Indeed, when I visit them, usually our conversation includes the frustration of the constant search for—and training and scheduling of—home nurses.

Their tiny one-bed-room apartment is a go-to place for disabled people living in or visiting NYC who want comfort, laughs, sci-fi show watching, food, and any resources on disability-related services as this power couple is more resourceful than any government-funded organization. I am no exception to those disabled people who are drawn to this magical space they create. My visits typically involve grocery shopping, cooking some Japanese food, and watching a film Jon has picked for Sonia and me. I do groceries with their food stamps to get ingredients for our film night dinner and whatever else they need. I cook Japanese foods in their small kitchen, which is attached to their living room, which functions as Jon and Sonia’s bedroom, Jon’s study, and a disability community space. Jon searches for a movie to watch over dinner; he carefully chooses the best film based on Sonia and my tastes. Sonia works in the tiny office next to the living room, taking care of the social service bureaucratic chores that consume most of her day. And Jon’s home nurse, Leroy, sits next to me in the tiny kitchen, filling out paperwork or engaging in conversations with me on what I am cooking.

When dinner is ready, I call Sonia and bring our bowls of food to the living room, which is filled with two beds and decorated from the last birthday party this space hosted. Medical supplies, a customized power chair, Hoyer lift, medical cabinets, and a tower of medical equipment that sends oxygen and food to Jon’s body all compete to occupy the space. Leroy follows me with a bowl of chopped foods for Jon. I sat on Sonia’s bed, which is attached to Jon’s; Sonia rolls in next to Jon’s bed, and Leroy sits next to Jon’s bed and in front of the tower
of equipment. All of us face a flat screen TV hanging on the wall, except for Leroy, who brings chopped food to Jon’s mouth with a gloved hand. Jon turns on the film. It is in this context that Jon and I occasionally text each other, me from my cell phone and Jon from his computer. We converse, often on the medicalized care he receives and his yearning for more humanitarian care.

He describes how some of his care providers come into their house in nursing uniforms, spitting out an unnecessary amount of medical terminology and radiating medical professional-like attitudes with unsolicited medical-sounding advice and suggestions on his body and care he receives. They ignore Jon and Sonia’s own embodied knowledge about themselves and the care they receive as well as their expertise on the disability service system. Sonia sometimes joins the text conversation from her phone or computer, inserting any changes in policies or bureaucratic updates to provide fuller context for the conversation. And the conversation usually returns to the hopelessly high turnover rate of Medicaid care providers and the constant challenges of opening themselves up to new providers, only to have the latter leave for a better-paying job after the trust has begun to bud between Jon and the provider. I ask them how research can contribute to the improvement of the public health care on which lower- or no-income disabled people rely.

He responds that research should reveal and raise awareness of the horribly medicalized long-term care disabled people receive under Medicaid.

Every week or so, I visit my friend Michelle, who is a disabled artist. Over the last few years, I have commuted in the evenings to her apartment every week or so, for conversation and updates while we engage in collective care. She is one of a few people who consistently provide major emotional care for me, and she is the English editor for my graduate school writing. I visit her around her bedtime; she welcomes me with a soft hug, asking me if I want tea, water, or
wine. She rolls and I walk the narrow hallway to her tiny Manhattan bedroom, which is connected to the bathroom. We talk nonstop, filling each other with stories, as I kneel down to take off her shoes and socks. As two Virgo besties, we share laughs and sarcasm. Michelle often offers me a hand massage, as my hands are tired from the academic labor of typing. I transfer her from her power chair to a bath chair or to her bed, and I help her take off or put on clothes, dry her body and hair after the shower, and do other tasks as they arise. After I help Michelle get into bed, I sit in her wheelchair as it charges next to her bed, and we continue to share every detail of our week, feelings, and sometimes tears. I recharge myself emotionally with Michelle’s help, as her chair gets charged underneath me. We talk about care labor and the never-ending questions of fair labor bartering, as she edits my academic writing in exchange for my physical care for her. We are part of larger Care Collective Michelle began with a group of her friends and, through recruitment, other people who provide physical care for her. Members of the collective take turns nightly, and each of the members develops their own unique relationship with Michelle as much as we develop friendship among the members. It is a collective experiment of interdependence, extending from Michelle. Every week, she offers me water, tea, or wine, fills me with emotional care, and restores me. This relationship will soon arrive at its third anniversary.

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In the activist sphere, disability rights and domestic workers’ rights groups struggle to build coalitions. I have attended a number of meetings of Caring Across Generations, a national campaign to build coalitions among domestic workers, senior citizens, and disabled people to change the face of care. It was initiated by the National Domestic Workers Alliance. Therefore, while the campaign is well-immersed in domestic work politics, it just began to grasp senior
citizen and disability rights politics. I am in full support of the domestic workers yet skeptical of how the campaign is organized and led by paid organizers who are not domestic workers, disabled, or senior citizens. And gradually my body becomes filled with frustration regarding the use of internalized ableist words within the campaign. One day, I was at a meeting in the office of the Service Employees International Union in Washington, DC, with two disability rights activists. We sat in front of twenty to thirty Caring Across Generations organizers, who had come from all over the United States. We challenged them to fully embrace disability politics and be disability communities’ allies to the extent that they ask disability communities to be domestic workers’ allies.

The continuing struggle to build solidarity among these constituencies seems to be largely about educating and convincing the intermediary organizers that the care-based injustice domestic workers experience is profoundly entangled with that of disabled people and therefore deserving of equal attention. Another necessary consideration is that many disabled people receive their long-term care through Medicaid and Medicare, and they are not necessarily situated in more financially privileged positions than their care providers. Indeed, the assumption that prevails in that campaign is that care recipients are financially more privileged than their providers and hold power as consumers of care services. The struggle I was part of to build the coalition within the campaign proved to be not solely a matter pertaining to the campaign, but one that is ongoing and rupturing throughout the United States. The Department of Labor’s current revisions of the Fair Labor Standards Act to include domestic workers (and therefore many home care providers) under its protection without increasing the Medicaid budget has been seen by disability rights activists as a threat to many disabled people who receive care in their own homes. While the legalization of labor protection—such as paid sick days, overtime payment, and more—will result in fairer
payment for providers, the lack of increase in the Medicaid budget to supplement the increasing wage has caused panic within some disability communities, as the transition can mean the reinstitutionalization of disabled people en masse to solve the financial gap (Greenhouse, 2013). As a result, a major disability rights organization has been protesting the way the Department of Labor is implementing the change⁸ (see, e.g., ADAPT, n.d.; Darling, n.d.). These continuing protests by some disability rights communities are interpreted differently even within disability communities, as some support the labor policy changes while some encourage signing the petition to delay the policy changes until the Medicaid budget issue is solved.

The above skits are part of my everyday life, shaping my perspectives, and consequently gave birth to this dissertation. This research is an attempt to understand care through the filter I have developed within disability communities, as both someone who receives care (e.g., English editing and emotional care) and provides care (e.g., physical care and cooking). It centers on the NYC disability activist, social, and academic communities as well as my on-and-off relationship with domestic workers’ communities, as they all have taught me how to read and synthesize writings done on care without compromising care recipients’ and providers’ perspectives and activism surrounding their equity and just treatment. Below, I illustrate a few key contextual elements that were crucial to the development of this dissertation and that contribute to a fuller understanding of care recipient and provider participants’ experiences within the care sector.

**Contextualizing the Dissertation**

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⁸ As of Dec 5, 2014.
One thing I seek to contribute with this dissertation is to contextualize care studies within the shifting sociopolitical context of neoliberalism. Below, I briefly describe key aspects of the context that are central to this dissertation: the care crisis, neoliberalism, and the history of Medicaid. These topics are further interrogated in the following chapters. This section serves, then, to set the groundwork to enter this dissertation.

This research primarily takes place in the United States and is based in particular on the NYS Medicaid policy and the geopolitics of NYC. It, for example, examines the political economy of care by tracing the histories of Medicaid and Welfare programs at the national and state levels, and all the research participants were recruited within NYC. Though this research sprouted within NYC, arguably the city is reflective of the direction the public health-care sector is heading across the United States. The globalizing care industry is particularly amplified in U.S. metropolises, making NYC a perfect geopolitical location within which to examine this international trend (Folbre, 2006; Glenn, 2010; Polson, 2013). Further, following the NYS governor’s prior endorsement for the deinstitutionalization of disabled people, NYC is more inclined toward community living (individuals living in their own houses or smaller-scale, community-integrated apartments with assistants, instead of segregated, large institutions) compared with other states (Polson, 2013). Anecdotal reports show that members of disability communities are moving to NYS in order to enroll in its rich community living programs. As the deinstitutionalization of disabled people is becoming a trend across the nation due to disability rights activism and suppression of the care budget, what is happening in NYC foreshadows what will happen throughout the country. In addition, NYS is the first state to pass the Domestic Workers’ Bill of Rights, which increases basic entitlements for many providers (e.g., Dean, 2013). As domestic workers’ political bargaining power is increasing, discourses and enactments
of domestic workers’ rights continue to spread throughout the United States. (Dean, 2013; Polson, 2013). In this context, NYC is an ideal location to examine for an understanding of U.S. care system transformations.

Care Crisis

Ask anyone. We all have our “care stories.” What we don’t tend to have is a plan for what we’ll do when someone we love needs care, or when we ourselves turn out not to be invincible. We don’t have a plan, and neither does our government, and yet a crisis looms. (Flanders, 2012)

Aging and debilitation hit every body, not equally, but surely—every body will require extensive care from other bodies sooner or later. The anxiety of a care crisis circulates and occupies bodies. In the United States, the Administration of Aging (2012) announced that, in 2010, a person turned 65 every 8 seconds, and the number of U.S. citizens in long-term care was projected to more than double between 2000 and 2050: from 13 million to 27 million. Elder care and disability services occupy nearly half of the projected employment growth between 2010 and 2020, that is, 45% compared with 31% of other health care and health assistance and 14% of all U.S. jobs (Paraprofessional Health Institution, 2012). A mass of baby-boomers multiplies the care recipient population and so does the rise of disabled veterans returning from multiple armed conflicts; the lives of both populations are saved by the improvement of medical technologies witnessed today (National Center for Veterans Analysis and Statistics, 2012; U.S. Administration on Aging, n.d). Nations of the Global North contemplate the unsolvable formula of the rapidly increasing number of people who require long-term care and the simultaneous decrease of

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9 California also passed the bill in 2013 (National Domestic Workers Alliance, n.d.).
traditionally unpaid care providers. Women who traditionally took on provider roles for their family members without pay are entering into public labor force (Daly, 2001). Care responsibilities are, therefore, outsourced or continue to be forced onto mostly female family members to take on as if they constituted a second job. Currently, almost one third of the adult population in the United States is already engaged in a care provider role in some capacity; the fraction of the population who takes care of their aging parents tripled between 1994 and 2001 (MetLife Mature Market Institute, 2011; National Alliance for Caregiving, 2009). Home-based care provision is the fastest growing occupation in the United States; it is expected to grow by 50% between 2012 and 2022, which is considered to be “much faster than average” (Department of Labor, 2014).

This rapid increase in the care recipient population has triggered more demands for the publically funded care programs Medicare and Medicaid. In the case of NYS, for example, Medicaid enrollees have increased by almost 190% in last 15 years (from 1998 to 2013; NYS Department of Health, 2014). Nevertheless, the neoliberal public policy of austerity and social service reforms introduce a cap to the Medicaid and Medicare budgets more often, dramatically shrinking the safety net once considered a public responsibility. Therefore, in the sphere of home-based long-term care, the care needs of Medicaid or Medicare beneficiaries are rarely met by the paid care providers alone. Instead, 90% of those who receive public long-term care also rely on their family members’ unpaid care work to fully meet their care needs (Greenber, 2011, cited in Polson, 2013).

The care crisis is not an issue only in the Global North. Yet the global economic inequality induced by globalizing capitalism brings a surge of people (especially women) from nations in the Global South to the Global North to take up the abundant care responsibilities.
Care-based occupations are, indeed, disproportionally reserved for im/migrant people, as evident in the 23%, or more than 50% in the case of NYC, of home-based care labor that is taken up by those who were born outside of the United States (while foreign-born people make up only 15.5% of the entire U.S. population), (Polson, DeFilippis, & Bernhardt, 2011; U.S. Bureau of Labor Statistics, 2010). The care crisis that began in nations of the Global North is extending to and involving nations of the Global South. Hochschild (2004) calls this chain reaction a “chain of care” and illustrates how the immigration of a care provider means the loss of an unpaid kin care provider for her family, which may cause the outsourcing of that care work to lower-class women from the countryside. This immigration and subsequent outsourcing of family care causes the loss of unpaid kin-care workers for the lower-class women’s families, who are left to attend to one another (Yeates, 2004). The care crisis of the Global North, therefore, profoundly affects the lives of many bodies across national borders, while continuing to loom (Daly & Standing, 2001).

**Neoliberalism**

Neoliberalism is a political, economical, and ideological system that privileges the market as the most efficient platform for distributing social goods, minimizes the role of government responsibility in assuring collective well-being and highlights instead personal responsibility for assuring individual well-being. (Fabricant & Fine, 2013, p. 4.)

Originally put together by a group of executive thinkers in the 1940s, the political theory of neoliberalism began to be experimented and practiced in the 1970s, under the dictatorship of Pinochet in Chile (Harvey, 2005). In the 1980s and onward, the transformation of political and economic spheres based on neoliberal ideology was aggressively pursued in the United Kingdom.
under the Thatcher administration and the United States under the Reagan administration. China set “out on a path of liberalization [in 1978]. The partial moves towards neoliberalization [occurred] in India in the 1980s and Sweden in the early 1990s” (Harvey, 2005, p. 9). Via these internationally powerful nations and global financial institutions such as the International Monetary Fund and the World Bank, the governing principles of neoliberalism spread and were taken in or forced on countries all over the world. Though neoliberalism varies from nation to nation regarding how such measurements have been implemented and its impact, it is undeniable that such a governing principle became hegemonic and shapes our lives today (Glenn, 2010; Harvey, 2005; Naidoo, 2008).

Neoliberalism is established on the bedrock of understanding that “human well-being can best be advanced by liberating individual entrepreneurial freedoms and skills within an institutional framework characterized by strong private property rights, free markets, and free trade” (Harvey, 2005, p. 2). In other words, already existing social virtues placed on individualism and a prototype of ideal citizens—rational, logical, and autonomous—are further privileged and enforced, with a heavy emphasis on the free market. Thus, under neoliberalism, every aspect of our lives—including our capacities, needs, and desires—is made into a profitable opportunity (Brown, 2003; Fabricant & Fine, 2013; Giroux, 2014; Goodley, Lawthom, & Runswick-Cole, 2014a; Puar, 2012). Puar (2012) states, “All bodies are being evaluated in relation to their success or failure in terms of health, wealth, progressive productivity, upward mobility, enhanced capacity” (p. 155). In this shifting terrain, what was once considered a social responsibility (and thus supported by the state) is no longer so. Instead, individuals are forced to take on increasing responsibilities while governments eviscerate themselves of their former responsibilities (e.g., decreasing quality public education and increasing educational inequality
between those who can afford quality education and those who cannot; Fabricant & Fine, 2013). The border between governments (whether federal, state, or county) and business industries is getting blurrier, as governments’ priority becomes to create and maintain “a good business or investment climate” (Harvey, 2005, p. 70) for these industries to flourish by producing “legislation and regulatory frameworks that advantage corporations” (p. 77). Thus, “in the event of a conflict, the typical neoliberal state will tend to side with a good business climate as opposed to either the collective rights (and quality of life) of labour or the capacity of the environment to regenerate itself” (Harvey, 2005, p. 70).

Consequently, individuals are left with increasing individualized responsibilities: “each individual is held responsible and accountable for his or her own actions and well-being. This principle extends into the realms of welfare… [and] health care” (Harvey, 2005, p. 65, emphasis added). One’s well-being (e.g., not being sick and disabled) is once again individualized and social supports—such as public health care—are drastically shrinking, while public institutions are heavily privatized. In such a context, inequality expands between those who can fit into the prototype of the ideal citizen and strive in the free market, and those who cannot. This point is further elaborated in chapter 4. Thus, in this context, those who do not or cannot fit properly into the neoliberal prototype are left to debilitate and to a slow death—both of which are explained in depth in chapter 5.

Medicaid

This dissertation focuses specifically on Medicaid LTSS. Reasons for the focus are twofold: One is because this dissertation sprouted from disability communities, particularly from the dialogues I have had with those who rely on the Medicaid LTSS for their care needs. Medicaid long-term care is a reality for many disabled people in the United States, as about 17%
of the entire disabled population are considered beneficiaries of Medicaid\textsuperscript{10} (as of 2011, there were 9,791,456 disabled beneficiaries of Medicaid; The Rehabilitation Research and Training Center on Disability Statistics and Demographics, n.d.; U.S. Census Bureau, 2012). Deeply rooted ableism and sanism in this society prevent many disabled people from holding any employment, let alone meaningful and well-paid employment with full benefits. Statistics show almost 50\% of adults with a “severe disability” were never employed between 2008 and 2010; 5 times more than the 9.2\% unemployed nondisabled adults in the same period of time (U.S. Census Bureau, 2012).\textsuperscript{11} In the circulation of ableism and sanism, many disabled people are left with no choice but to rely on public supports. Another reason for the focus on Medicaid LTSS is the shortage of care studies that focus on paid care work and public health care. Approached from care providers’ perspectives, mainstream care studies on paid care often proceed with their analyses in a context where those who receive paid care are financially more secure than their providers. Based on the financial inequality between care recipients and providers, paid care studies center their analysis around the highlighted employer-employee hierarchy, attributing it to the larger context of care-based injustices and the powerless position providers experience. Yet, not all paid care practices are built on a clear-cut class hierarchy. Many recipients of public health-care programs live in extreme poverty and in public housing that deeply influences them,

\textsuperscript{10} The calculation was done by comparing the U.S. population with disabilities and the number of disabled beneficiaries of Medicaid.

\textsuperscript{11} The number increases to 80\% if the calculation is done in terms of the number of those with ”severe disabilities” who did not hold a job for two consecutive years (U.S. Census Bureau, 2012).
their families, and their care practices. In this dissertation, instead, financial and other vulnerabilities of both care recipients and providers are recognized under neoliberal public health care. Thus, in order to expand care studies, this dissertation underscores a more complex and nuanced discourse and the ontological experiences of power and vulnerability as they are experienced by recipients and providers within their care practices.

Medicaid is one way to actualize the right to receive care, and it became a law in 1965. It was considered as a “government’s insurance,” designed to lift “a great burden … from the shoulders of all Americans. Older citizens [would] no longer have to fear that illness [would] wipe out their savings…. For every family… [it] mean[t] relief from the often-crushing responsibilities of care” (Johnson, 1965). The Kerr-Mills program, said to be the precursor of Medicaid and which supported the medical needs of elderlies, was criticized, since the “Medicare hospital insurance program for the aged alone was not sufficient to meet the many medical needs of the aged, blind, and disabled or the mothers and children receiving aid for dependent children” (Moore & Smith, 2005–2006, p. 47). Against the backdrop of the failing Kerr-Mills program, the increasing care recipient population, rising medical costs, and a lack of affordable health insurance, Medicaid was established. In 1965, Medicaid and Medicare were legislated, as an amendment of the Social Security Act (Pub.L. 89-97, 79 Stat. 286), after a long period of advocacy by citizens’ organizations (e.g., nurses unions) as well as a number of presidents: Franklin D. Roosevelt, who failed to include health care under the original Social

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12 Though this point is not highlighted in this dissertation, many care provider participants of this study described the fear of visiting their care recipients’ homes, which are often public housing, and the sadness of witnessing the poverty their care recipients endure, such as a lack of food in their fridge.
Security Act; Harry S. Truman,\(^{13}\) who was a strong advocate and started to draft a health-care law; John F. Kennedy, who was also a great advocate for the bill; and Lyndon B. Johnson, who ratified it into a law (The Henry J. Kaiser Family Foundation, n.d.).

Medicaid is a means-tested social health care program jointly funded by state and federal (and county, in the case of NYS\(^ {14}\)) governments, and it is administered by the state. This division of the funding and administrative authority means that it is ultimately up to each state to be on board with Medicaid. Indeed, it took close to two decades for every state to begin to provide Medicaid (GoMedicare, n.d.). Medicaid provides health care and LTSS to certain children and adults with low income and resources. Eligibility for the program has been under constant revision, yet it has steadily provided medical supports to those who are blind, disabled, pregnant, and children. Today, Medicaid covers over 66 million Americans, more than 1 in every 5, and it is the largest budget that flows from the federal to state governments (Kaiser Family Foundation, 2014; Kaiser Family Foundation, 2013). Thus, with the current development of the Affordable Care Act, the eligibility is expanding dramatically to be open to anyone (including nondisabled men) who has low income and resources.\(^ {15}\) While Medicaid continues to provide a safety net for some\(^ {16}\) underprivileged populations with care needs, it does not mean that such provision is

\(^{13}\) He was the first to enroll in Medicare.

\(^{14}\) Due to the unequal distribution of Medicaid beneficiaries across NYS, this state has its own Medicaid funding system which includes counties alongside the state and federal governments.

\(^{15}\) This point, again, varies from state to state.

\(^{16}\) Throughout the dissertation, I continue to describe “some” or “certain” minority people as being covered under Medicaid in order not to overlook people who are not receiving such services because, for example, they experience difficulty applying to such a program due to their disability and obstacles to gaining the information, or the program does not cover general care for noncitizen immigrants (it covers emergency care of undocumented immigrants).
always secure and of quality. In the era of austerity and under the neoliberal regime, the Medicaid budget is constantly under threat of major cuts (ADAPT, n.d.), and this point is further elaborated in chapter 4.

**Goals of this Dissertation**

With this political and historical backdrop, I developed this dissertation with the following goals and purposes in mind:

- To reveal that public health care is currently arranged to be profit centered and not human centered.

This goal comes directly from the requests and hopes members of disability communities shared with me when I asked how research could contribute to the end of ableism and sanism in relation to the care sector.

- To identify how the care-based injustices care recipients and providers experience are intertwined.

While care studies in general approach the topic of care exclusively from either recipients’ *or* providers’ perspectives, and care justice activism often prioritizes care-based justice for recipients *or* providers, I strive to bridge the disciplinary gap by arguing that these care recipient and provider populations are *both* negatively impacted and exploited by the neoliberal public health-care assemblage. Thus, these care providers and recipients cannot achieve care-based justice for themselves without also achieving justice for their care partners.

- To theorize that care is profoundly relational and fundamental for ethical collective living.

A major part of this dissertation is about unveiling the commodification of care and the exploitation of care recipients and providers. Simultaneously, I state that care is a necessity for people to be able to strive; in particular, interdependent, co-capacitating, and caring relationality
is key in order to work toward social justice and to live ethically with every body: material or immaterial.

Roadmap of This Dissertation

This dissertation begins by providing background of ways in which this research was developed. Chapters 2 and 3 provide a literature review on care studies, and the methodologies used. Chapters 4 through 6 move from the macro to micro units of analysis. Chapter 4 lays the foundation of this dissertation by mapping out the neoliberal public health-care assemblage within a historical analysis of the political economy of care. Chapter 5 argues that the public health-care assemblage is necropolitical by foregrounding the psychological and physiological consequences care recipients and providers experience within the assemblage. Chapter 6 develops a concept of affective relationality emerging from care practices co-conducted by a disabled care recipient and their carer. Finally, chapter 7 is spent imagining and strategizing what care justice entails and how such justice can be actualized.

Chapter 2

In this chapter, I lay out the literature review of care studies and definitions of key terms used in this dissertation. I deconstruct concepts of care as developed by different scholars to explain how I approach and conceptualize care in this dissertation. Feminist studies and disability studies of care are juxtaposed to illustrate the current state of care studies and to articulate how this dissertation makes its intervention. Then I describe in detail how I intend to build on existing care studies with this dissertation. Finally, terms that are used repeatedly in this dissertation are defined: long-term care, care practice/labor/relationship/work, division of care recipient and provider, care agencies and industries, capacitation and debilitation, and assemblage.

Chapter 3
In this chapter, I describe the processes of data collection and analysis done for this dissertation. Starting with a brief review of how this dissertation emerged, I lay out (1) data collection methodologies—archival research, focus group, individual interview, and participant observations, (2) descriptions of participants and the recruitment process, (3) data collection procedures, and (4) data analysis methods and procedures. Besides sharing examples of the step-by-step process on coding and theme organizing, the data analysis section also includes theoretical frameworks that shape my understanding of the data. Within this context, I explain the qualitative research foundation of this dissertation. The chapter ends with charts of questions used in the focus groups and individual interviews as well as demography of the participants.

**Chapter 4**

In this chapter, I map the neoliberal U.S. public health-care assemblage. I identify the neoliberal turn within Medicaid, which brought about the privatization of the public health-care sector, as well as the relating rise of the transnational care industry and the neoliberal turn of the welfare program for single mothers. By doing so, I describe whose labor capacities and needs for care came to be commodified in the public health-care assemblage. Thus, I examine the ways in which race, gender, and immigration status as well as the types of care one requires came to be further deployed within neoliberal public health care. With the review of Medicaid’s history and the related development of care industries and a welfare program, this chapter theorizes how certain bodies are capacitated for their labor power, while others are debilitated for their care needs—both to profit the care industry and to suppress the state’s Medicaid budget. In the neoliberal public health-care assemblage, health-care institutions, reform policies, care industries, and the bodies of disabled people and lower-income women are deployed to create a
flow of labor capacities, socially legitimated needs, and funds among these parts of the assemblage.

**Chapter 5**

In this chapter, I examine how the public health-care system under the neoliberal regime shapes the realities of those who are involved in care practices: care recipients and providers. Tracing narratives collected from Medicaid care recipients and providers illustrates how they enter the public health-care sector, how they are treated in the sector, and the consequences of their involvement in the sector. Using theories of slow death and necropolitics, I describe the ways in which under the neoliberal public health-care assemblage these people are exploited and consumed based on their labor capacities and care needs. The consequence of such consumption is their psychological and physical deterioration: slow death. Not only they are exploited, the abundance of people who require public long-term care and who take low-wage care labor turns them into disposable populations. I argue that as a result of neoliberalism, public health care is not biopolitical but necropolitical.

**Chapter 6**

This chapter takes a close look at relationship between disabled care recipients and their providers. Using Spinozian and Deleuzian conceptualizations of affect and the body, this chapter develops a concept of *affective relationality* that is interdependent, caring, and co-capacitative. I argue that the recursive encounters and practices of care co-conducted by the care providers and recipients gives rise to affective relationality through their adaptation to each other’s distinct capacities, needs, desires, and rhythms. In the recursive practices, also, the vulnerability care providers and recipients individually experience, and hold against each other at their first encounter, slowly turn into shared vulnerability, which ignites sympathy and intimacy between
them. This positive connection between these individuals turns their relationality into a capacitative one. In the following, I provide a theoretical description of affective relationality, which is followed by the narratives of care providers and recipients to enrich the theoretical development. Finally I explore what affective relationality does in the neoliberal public health-care assemblage by contrasting it with the psychological studies of solidarity building and by describing it as the *undercommon* of the neoliberal public health-care assemblage.

**Chapter 7**

This final chapter is a reflection upon this dissertation. Provided herein are summary responses to the research questions I pose at the beginning of this dissertation. Then, I lay out limitations of this dissertation: one, which is methodological and the other, which is theoretical. My assessments of what constitutes “care justice” is documented next. In this section I explore both macro and micro ways of actualizing and practicing care justice. Finally, I end this chapter and dissertation by describing how the actual writing and editing of this dissertation is an embodiment of affective relationality. By applying what I have developed in this dissertation to the practice of academic writing, I describe ways in which my friends and I share the task of editing this dissertation for English grammar and usage (particularly when needs, such as English editing, are not institutionally supported in the university). Based on my experiences asking for English editing and negotiating ways to barter this necessary labor, I list questions of differently embodied capacities and needs as well as power and privilege to re-consider ways bartering of a labor is discussed and practiced.
Chapter 2

Literature Review: Defining Care and Other Key Terms

Abstract

In this chapter, I lay out the literature review of care studies and definitions of key terms used in this dissertation. I deconstruct concepts of care as developed by different scholars to explain how I approach and conceptualize care in this dissertation. Feminist studies and disability studies of care are juxtaposed to illustrate the current state of care studies and to articulate how this dissertation makes its intervention. Then I describe in detail how I intend to build on existing care studies with this dissertation. Finally, terms that are used repeatedly in this dissertation are defined: long-term care, care practice/labor/relationship/work, division of care recipient and provider, care agencies and industries, capacitation and debilitation, and assemblage.

This chapter lays out the basic premise of this dissertation. It includes a brief review of how the term care is conceptualized, how care is studied in different disciplines, and other key terms used throughout this dissertation. Also underscored in this chapter is the intervention this dissertation makes in current studies on care. As repeatedly acknowledged in this chapter, care is often conceptualized and studied exclusively from care providers or recipients' perspectives. In such an approach, care providers and recipients are not only divided but also put into (false) antagonism, as though one could investigate or advocate for only one party’s circumstances and not the other’s. Instead, this research commits to taking both perspectives and highlighting how experiences of and justice for care recipients and providers are intertwined. This dissertation analyzes and theorizes circumstances in which care providers and recipients are situated, as well as their experiences from multidimensional units and perspectives, to actualize care studies which embodies the commitments and analysis of critical transnational feminist, disability, and race studies. By doing so, this dissertation is set to push the boundaries of existing care studies.

Defining Care
Care manifests in various modes. Care transgresses time and space. The word care is used to cover a wide range of behaviors and mental states. Japanese feminist sociologist Ueno (2011) analyzes the various actions the English word “care” entails. She explores the different words corresponding to different types of care in Japanese: *Kaigo* (介護) as assistive care for elderly and disabled adults; *Ikuji* (育児), as care for infants and children; and *Kango* (看護), as medical care for sick people. The lack of such compartmentalization of care in the English language and its housing of various behaviors and mental states under the term is related to the challenges of conceptualizing care. Scholars, as a result, come up with diverse definitions. On one end of the spectrum, a definition by Fisher and Tronto (cited in Tronto, 1993) widens the potential of care by including care among “any” body—beyond human and non-human boundaries. This is the definition on which this dissertation is built:

On the most general level, we suggest that caring be viewed as a species activity that includes everything that we do to maintain, continue, and repair our “world” so that we can live in it as well as possible. That world includes our bodies, our selves, and our environment, all of which we seek to interweave in a complex, life-sustaining web (Fisher and Tronto, cited in Tronto, 1993, p. 103).

On the other end of the spectrum, Daly (2001) describes how care is “conventionally defined as the activities and relations involved in caring for the ill, elderly, handicapped [sic] and dependent youth” (p. 34). As much as these definitions suggest what actions a concept of care entails, they also shape and determine the subjectivities of those who are involved in care. Fisher and Tronto suggest an object of care is “our world” including “our bodies, our selves, and our environment.” On the contrary, Daly explains recipients of care by the conventional definition are limited to humans who are socially conceived as vulnerable. In other words, these definitions come with
assumptions about one’s capacities to be a care provider or a recipient. By defining care as “a species activity,” Fisher and Tronto suggest that all species are capable of caring as much as they are capable of being recipients of care. This definition aligns with scholarship that positions dependency as part of human nature (Kittay, 2001; Lynch, et al., 2009; Price, 2011; Standing, 2001), except that Fisher and Tronto’s definition includes non-human bodies in the circulation of care. The definition Daly offers, emerging primarily from labor studies, highlights the inevitable and idiosyncratic care needs of the elderly, disabled, and young (infants and children) and how such care needs are met by the labor of others. As much as the Daly’s definition underscores the often ignored reality that care provision entails the labor of some bodies, simultaneously, this definition situates elderly, disabled, and young people exclusively as care recipients and overlooks the care these populations provide (e.g., grandparents taking care of their grandchildren, disabled people taking care of their family members or service animals, and children take care of their siblings). This combination of definitions means that, while everyone is dependent and simultaneously has a capacity to care for one another through different modalities of care, the latter’s conceptualization often captures limited aspects, which are heavily biased by whose standpoint is prioritized in the conceptualization (Lynch et al., 2009). The commodification of care, for example, clearly illustrates this point, as within it care is seen as a marketable object (see, e.g., Hardt & Negri, 2004). Reflecting on these realities of care, feminist sociologist Bubeck (1995), for example, raises the importance of using the term service to distinguish the service-based care labor largely women are forced into from the restorative and affective aspects of care. Care work is certainly classified as what Fisher and Kang (2013) call a dirty job, as in, “physical labor that involves cleaning and caring for the human body, its products, and its environs, particularly where doing so involves handling body parts or products
that are intimate, messy, or possibly contaminated” (p. 165). In contrast, disability studies advocated for the use of the term, *assistance* instead of care. With the rise of the independent living movements, the care disabled people receive is minimized as mere assistance in order to highlight disabled people’s capacities and to recognize their rights for self-determination (Watson, McKie, Hughes, Hopkins, & Gregory, 2004). I fully recognize the significance and necessity of these terminologies to compartmentalize care during the time activists advocated for these words. However, in this dissertation I use the term *care*.

Folbre and Wright (2012) review the divide within care studies between the association of the motivation to care with either money or love: “[W]e challenge this [divide], emphasizing the ways in which love and money often combine and intersect, sometimes (though not always) in complementary ways” (p. 21). Similarly, I use the word care to recognize its multiplicity—as a space, practice, and relationship—and how it contains a number of discourses, meanings, and intentions, including services and confinement as mentioned above. The point that care cannot be simplified as either service or assistance is evident in narratives by care recipient and provider participants of this study, too. While care provider participants of this study described care work as their job, for example, they also agreed that it is more than just a means to earn living. They echoed each other by telling me that care work is about caring and attending for those who need their care. Also, as this dissertation strives to interweave experiences of care providers and recipients, I require a term which reflects both parties’ perspectives, and hence I turn to the word

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17 Indeed, the question on the use of different terminology—care or assistance—was brought up by disability rights activist and scholar Adrienne Asch at a disability studies conference in 2013. As Adrienne was facilitating the panel I was part of, she questioned my use of the term *care* in my presentation, and we discussed in length about the terminology: where she advocated for the use of *assistance* and I for the term *care*. 
care. I build this dissertation on the definition of care offered by Fisher and Tronto and use the term to capture the more complex, nuanced, and multidimensional aspects the term entails.

**Care as Emotional/Material/Physical/Cognitive/Spiritual**

Though care is often exclusively conceptualized and measured based on its physical labor aspect, it takes more than a physical form. The broadening of the recognition that care occurs in various modes helps to demonstrate that care circulates, countering the idea that it is exclusively a one-way action from provider to recipient. Care comes in physical, material and financial, emotional, cognitive, and spiritual formats and is practiced through a combination of these.

Examples of physical care include lifting, transporting, or feeding someone, holding hands, or being present. Material and financial care include providing necessities such as food, water, electricity, or cookies when they are needed, or offering financial support such as paying rent for others. Emotional care can manifest in conversations or checking in on another’s wellbeing.

Emotional care also manifests through physical care during acts such as hugging and holding hands, or making a phone call to a friend across the globe. It can also be practiced in a subtle way such as looking after the neighborhood so children can play safely. Cognitive care can entail collectively solving problems and making decisions, or planning out physical care logistics. It can occur outside of the recipient’s presence such as a provider looking into the nutritional values of foods to serve the next day. Or it may be that care recipients negotiate their care schedules with care agencies to accommodate their providers’ needs. Spiritually, one can provide care by collectively meditating, sharing spiritual conversations, or praying for one another. In many ways, “care work often goes beyond fulfillment of basic needs to develop the capabilities of its recipients—their health, their mental abilities, or skills that will be useful to themselves and others” (Folbre & Wright, 2012, p. 7). These modes of care are continuous, overlapping, and
thus used simultaneously to form care practices. Also, such categorization largely relies on the interpretations by care recipients and providers; what a provider provides as emotional care may not be received as such by their care recipient. Though there are different modalities of the practice of care, it is often physical care that *counts*. In reality, physical care is often centralized, since it is a relatively easy and standard way to measure labor care providers offer. Care offered to recipients and assigned to providers, indeed, takes the form of the Activities of Daily Living (e.g., feeding) and/or Instrumental Activities of Daily Living (e.g., preparing meals). For those who are involved in care practices, though, the emotional aspect of the care is evident (Ehrenreich & Hochschild, 2004; Folbre, 2008; Standing, 2001). Many accounts reveal that the emotional aspect of care determines the quality of care (Folbre & Wright, 2012; Ungerson, 1999). Folbre and Wright (2012) explain that “the quality of an output such as health or skill often depends more on the relationship between care provider and recipient than on the individual characteristics of either” (p. 9). Physical care without a positive attitude or attention is less likely to be felt as care by recipients (Power & Oschwald, n.d.). Also, I argue that lack of emotional care and attention from recipients to their providers can cause those providers to feel unappreciated, or can circulate negative affects between a recipient and their provider.

Despite the crucial contributions of immaterial care (e.g., emotional, cognitive, spiritual) that make up the quality of care, the difficulty or impossibility in measuring these often leads to these factors being unrecognized. Thus, the lack of an effective method to measure different forms of care (e.g., emotional) is said to be a cause for unfair compensation for providers (Daly, 2001; Ehrenreich, & Hochschild, 2004; Folbre & Wright, 2012). Indeed, care is often understood, measured, and compensated through physical care: by its typology (medical care or daily assistive care) and through time (wage is calculated hourly based on providers’ physical
presence with their recipients). In the process, the complex and layered nature of care is simplified and overlooked. Thus, the prioritization of physical care erases the care contribution a disabled person makes; the emotional care recipients contribute to their providers, for example, is not considered legitimate care.

**Literature Review of Care Studies**

Feminist and labor studies as well as disability studies have led the scholarly work on care. A tracing of these disciplines, as laid out below, illustrates how care studies have been developed taking exclusively *either* the care recipients’ *or* the providers’ perspectives and concerning injustices recipients *or* providers are affected by. The literature reviewed here is primarily social science empirically based research.

**Feminist Studies of Care**

Daly, in her edited book *Care Work* (2001), describes feminist and labor studies as the two leading fields for care studies. Both fields enter care studies by articulating the sexist, exploitative nature of care labor as well as care as undervalued labor. Ueno (2011) describes how women’s capacity to bear children is used to naturalize care responsibilities as women’s work. Hence, the care women provide to their family members and others are overlooked: “As a society that enshrines the virtue of independence, defines instrumental work as superior to emotional work, seeks to distance itself from basic life events, and devalues the activities of women, we have tended to ignore the experience of caregivers” (Adel & Nelson, 1990, p. 4). Thus, such downgrading of care providers’ or women’s contributions is deeply interwoven with the undervaluation of care. People see practices of care, in the various modes described in the section above, Care as Emotional/Material/Physical/Cognitive/Spiritual, as involving no skills and are pushed into a domestic domain. As a result, women’s labor to fulfill care responsibilities
for others (e.g., cases of family care, nannying or nursing) are often conducted without pay or under unjustifiable wages and undesirable working conditions (Beasley & Bacchi, 2005; Dorros, Card, Segrin, & Badger, 2010; Gibson, 1998; Hollingsworth, 1994; Hooyman & Gonyea, 1995; Kirkman, 2011; Poole & Isaacs, 1997). In this context, care is understood as a manifestation of sexist oppression and exploitation, which prevents women from entering a more desirable public work force or living their own lives (Abbott, 1994; Lee & Porteous, 2002).

Not only is the degradation of care work and women’s labor a discursive matter, it also dovetails with the physical and emotional costs for the providers. Feminist psychologists Lee and Porteous (2002), for example, study care labor related to stress on women who conduct unpaid care for their chronically ill, disabled, or frail family members and friends. Their secondary analysis of a longitudinal survey, *The Women’s Health Australia*, reveals how those who are involved in unpaid care work are less likely to have paid full time jobs, thus experiencing poorer physical and mental health over all (e.g., chest pain or constant tiredness) and their experienced level of stress is higher than that of women who do not engage in care labor.18 Their qualitative data illustrates a wide range of themes including participants’ critiques of unjust health and welfare services as well as mixed feelings of being exploited and the internalization of the ethics of care: “[W]omen have a natural ethics of care” (p. 89).

In terms of paid care work, Baine’s (2006) qualitative study identifies gendered stress, violence, and workload issues that workers experience at non-profit organizations that provide various services (e.g., group homes and day programs) for people with intellectual disabilities. While men are increasingly entering the care labor field through residences for intellectually

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18 All other variables are controlled.
disabled people,\textsuperscript{19} it is women who are expected to and actually take unpaid overtime and volunteer their labor more often than their male colleagues. Even as early as the hiring process, managers of these agencies seek out women who display “a woman’s caring and empathetic nature”: “all my staff are great but lots of times clients want a mother figure to cry on. Isn’t that what we all want?” (Baine, 2006, p. 144). The researcher also analyzes the “violence” happening at the workplace as targeting specifically women in “a complicated mix of opportunity (physical proximity), ideology (which gender is expected to be warm and empathetic and which gender might hit back and which gender warrants violence when frustrations overwhelm) and the normalized notions of women as targets for relationship-based violence” (p. 146, emphasis original). While these women experience gender-related stress and violence at the workplace, their responsibilities as care providers do not stop there. Being primary care providers for their family members in their private lives, their responsibility to care for others continues outside of this paid work. The border between work and private spheres is blurred and exploited, as these workers are routinely “stretched to the breaking point” (Braine, 2006, p. 141). In other words, women’s roles as care providers transgress specific contexts.

While these two studies are explored here as prototypes of care studies done in the social sciences, these studies are limited in terms of their lack of analysis extending beyond the gender bias within care practices. In the larger sphere of feminist care studies, more scholars, though still in the minority, are adding race, class, and global analyses (e.g., Ehrenreich & Hochschild, 2004; Erevelles, 2011; Flores-Gonzalez, Guevara, Toro-Morn, & Chang, 2013; Folbre, 2013; A study by Armstrong (1996), as cited in Baines (2006)', explains how more men moved into care industry jobs in the late 1980s and 1990s, as employment in other more traditionally male jobs (e.g., manufacturing works) diminished. Among the care industries men are entering, the developmental disability service sector employs a higher proportion of men (35%) than other sectors (18%) of the social services.
Glenn, 2010). Ueno (2011), for example, discusses how even in the time of the Roman Empire, care labor was reserved for women of color. Erevelles (2011) connects the history of slavery in the United States and current care labor to reveal the latter’s undeniable racial component. It was Folbre and others who untangled global labor trafficking in relation to increasing care-related occupations in the nations of the Global North. These scholars assert that it is not just any women who are pushed to do care work, it is always women of color, working-class women, and women from the Global South who are disproportionately forced into care labor. That care labor is racialized, class-based, and geopolitically based—as well as gendered—is highlighted throughout this dissertation. In sum, these works by feminist studies scholars approach care from care providers’ perspectives by highlighting and analyzing how gender inequality manifests and enables current care practices. Consequently, care justice is imagined based on the emancipation of women from gendered labor.

**Disability Studies of Care**

Though, Daly (2001) does not include disability studies in the list of leading fields for care studies, and disability studies is often marginalized in mainstream care studies, I argue that disability studies’ analysis of care practice is indispensable. Approaching care practice from the standpoint of disabled people, who are often exclusively situated as care recipients, disability studies radically questions elements of being human that are often taken for granted (e.g., Goodley, Lawthom, & Runswick-Cole, 2014b). It deconstructs concepts such as independence and dependence, agency, care, and expectations attached to a care recipient role. Disability studies of care, by and large, conceptualize care as a site of management operating within the medical model of care; therefore, it emphasizes the importance of liberating disabled people from this form of ableism (Gibson, Brooks, DeMatteo, & Kind, 2009; Meyer, Donelly, &
Weerakoon, 2007; Morris, 2004; Shakespeare, 2000b; Stewart, Harris, & Sapey, 1999). Relying upon the social model, this set of studies analyzes care and dependency as socially constructed by individualizing and biologizing disabilities. This essentialization of disability and disabled people causes ableist categorization—that is, seeing disabled people exclusively as dependent and incapable of being valuable citizens. Such an understanding is supported by the social virtue assigned to and norms imposed on people regarding rationality and independence, and thus obscures the inevitable dependent nature all people embody. In the sphere of care, the dependency of disabled people is solely amplified, often situating disabled people as the root of the care burden their family members experience:

Broader debates in the area of social policy also reflect the tendency to view disabled people as an inevitable burden on their families, and to biologize and individualize the problem of disablement… People who receive care are conceptualized as dependent … [and] blamed for their situation. It may ignore the fact disabled people can be carers … [and] the fact that “normal” life involves mutual aid and that everyone is in some measure dependent on others tends to be ignored. (Shakespeare, 2000a, pp. 53-55)

Thus, not only are disabled people conceptually made into burden, they are also forced to perform the incapability in order to receive the social services they require. Disabled people have no choice but to perform social stereotypes of an “incapable and dependent disabled person” so people—particularly those in positions of authority—recognize them as legitimately needing and deserving of social services. Consequently, disabled people’s agency as well as expertise over their own bodyminds, lives, and experiences are stripped from them (Gibson, Brooks, DeMatteo, & Kind, 2009; Meyer, Donelly, & Weerakoon, 2007; Morris, 2004; Shakespeare, 2000b). In this paradigm, many disabled people regard care with suspicion as “medical control,
institutionalization and confinement” (Gibson, Brooks, DeMatteo, & Kind, 2009, p. 318). Therefore, Shakespeare (2000b) suggests that “it is more appropriate and more just to seek to remove disabling barriers and structural disadvantage, than to provide services to deal with the consequences of oppression” (p. 58). Thus, in this context, while injustice toward providers is acknowledged, Shakespeare (2000b) insists that “it is a priority to consider and research the voice of people placed in a situation of dependency (disabled people)” (p. 57).

To resist this ableist view of care, in the late 1960s, disability rights activists launched the independent living movement, which continues today, originally in the United States and United Kingdom and then around the world (Fleischer & Zames, 2001). The principles of the independent living movement include: equal opportunities for disabled people to live as fully and without social barriers as their nondisabled counterparts are granted, with choices and control over the care they receive as well as their bodyminds and lives. At its core, the independent living movement challenges the binary concepts of independence and dependence (Morris, 2004). Contrary to the medical model of care, the independent living movement situates disabled people as experts of themselves, as well as care they receive. The independent living movement is generally known to have empowered disabled people’s social statuses and themselves, thus independent living came to be seen as an essential right for disabled people.20

Stainton and Boyce (2004) report the effects of the implementation of the independent living program (in this context, the direct payment program in the United Kingdom) based on a

20 An important point worth noting here is how this literature distinguishes social independence from physical independence. Advocates of the independent living movement are not striving for the physical independence of disabled people, in the way that many rehabilitation professionals or therapists do. Yet, these scholars as well as disability rights activists strive for disabled people’s social independence and self-determination in making their own choices and having control over their own bodies and lives. In other words, personal assistants or care providers are fundamental for disabled people to practice independent living.
two-year evaluation study. Interviews with the users reveal that “the experience [of the direct payment program] had been overwhelmingly positive” (p. 444). In this descriptive study, Stainton and Boyce provide background on why some choose to use this program despite the complicated processes it requires. Behind the reported improvement of self-esteem, users pointed out the capacity to control their care arrangements and lives with less restriction as the single most important benefit of and reason to use the program. Compared with the conventional care provided by a third agency (e.g., a non- or for-profit care agency that determines care programs and sends government-paid staff), a direct payment program (as the government funding goes directly to disabled people) allows disabled people to train their care providers and schedule care service when they want. The time flexibility, especially, provides more opportunities and possibilities for disabled people to engage with their friends and/or to spend time on what they desire. Beyond users gaining control over their care and lives, one of the other reported positive impacts is the fact that many directors of the direct payment program (who train disabled people to be more effective employers) are disabled themselves. Many interviewees identify working with these directors as a benefit of this program, as these directors understand ableism firsthand, and are potential role models who encourage users to be advocates for themselves and others. Another positive impact is that by having more control over training and scheduling of their care practices, users see the possibility of having better and more egalitarian relationships with their providers.

In sum, centered in disabled people’s experiences of care, disability studies depicts discourse of care as an ableist site where disabled people are managed under the name of care. Also, disability studies scholars initiate conversations on how all humans are dependent, and thus the need to examine the social construction of virtuous independence. Therefore, in disability
rights movements, activists have asserted that what disabled people need is assistance that prioritizes disabled people’s self-determination and participation in the public sphere, and not pity care. Such a view, however, has been critiqued in recent years, since it widens the divide between care recipients and providers and undervalues providers’ agency and labor (Fritsch, 2013). Below, I expand on this critique by underscoring the need to understand care as a relational practice.

**Intervention of this Dissertation: Care as Relational**

As laid out above, care studies has developed in two strands. Feminist studies untangles the sociopolitical and cultural ideologies that situate women as care providers and devalue care work. Disability studies works to reclaim the agency of disabled people, who are often situated exclusively as passive recipients of care, by highlighting the socially constructed notion of dependency which create ignorance of disabled people’s agency. Such a notion enables care to turn into confinement and management of disabled people’s bodyminds and lives. While such exclusive focus on either the care recipient’s or provider’s perspective offers a space to deepen the analyses of gender, race, class, and global inequalities in care labor or in ableist and sanist practices within care, it also highlights the (false) divide between care recipients and providers, ignoring the relationality which emerges from care practices (Folbre & Wright, 2013). A quote from Abbott (1994) underlines this divide: “The cost of normalizing life for mentally handicapped [sic] children is to de-normalize it for their mothers … The burden is particularly heavy where the dependent is an adult” (p. 300). Shakespeare (2000b) echoes this sentiment, as quoted above, that it is more urgent to remove barrier and structural disadvantage disabled people face, first. As described in the previous chapter, such a divide is witnessed in domestic workers’ rights and disability rights activism, where it manifests as more than a divide and
instead as a false antagonism. Such an extreme focus on one side of care within care studies limits the imaginative possibilities of envisioning care justice for both care recipient and provider populations.

Instead of choosing either the care recipient’s or provider’s perspective, this dissertation takes into consideration both populations’ circumstances by theorizing how recipients and providers are both woven into and exploited in the public health-care sector, which is increasingly privatized. Thus, the holistic approach inserts the notion of care as a relational practice and concept. Care recipients’ and providers’ fates are intertwined and inseparable. Care takes more than one body—one who cares and an object of care, whether these are human or nonhuman (e.g., the environment). Thus, as is elaborated in chapter 6, I argue that care circulates among these “bodies.” In other words, one of the ways I contribute to care studies is by freeing the concept of care from its primary conceptualization as a package passed from one person to another down a one-way street. I do not ignore the reality that care is commodified and care labor is intended to be delivered from a provider to their care recipient; I simply promote the multifold nature of care. This dissertation acknowledges social constructionist readings of care as much as it emphasizes the ontological experiences of care; it illustrates oppression attached to care practices, as well as care relationships that are lines of flight or potential forces of destruction in the neoliberal public health-care structure, where various injustices interlock.

This point that care is relational is certainly not a new idea, particularly within more recent care studies that work to expand its potential. Watson et al. (2004), for example, advocate for interdependence rather than independence, as they theoretically bridge feminist studies’ and disability studies’ views on care. Also, Kittay (2001) asserts interdependency and shared vulnerability as the care relationship’s nature: “[I]nterdependencies of caring relationships are
not only possible, they are common” (p. 31). Touching on the topic of shared vulnerability, she describes care recipients’ vulnerability to their providers, which stems from the differences in physical strength and cognitive functioning as well as recipients’ profound dependency on others to receive the care they need. Kittay (2001) further describes how providers experience vulnerability: “Because of the charge’s [care recipient’s] dependence upon her [care provider], and because of the ties formed through that relation, the dependency worker herself becomes vulnerable to the abuse of having her substance grafted onto another” (p. 35). Highlighting the affective relationship and emphasizing the multiple ways to practice care (e.g., physical, emotional, cognitive, spiritual), Erevelles (2012) advocates for the conceptualization of care as dialectic between a care recipient and their provider. Even within the discipline of psychology, especially in health psychology, the concept of interdependence is recognized and investigated, mostly in the context of care practices between aging couples (Paulin et al., 2010; Reid, Moss, & Hyman, 2005; Williamson, Shaffer, & The Family Relationships in Late Life Project, 2001). Psychological studies of relational care often rely on the positivistic experimental tradition and understand care practices and their influences solely via the care providers’ perspectives. A quantitative study by Poulin et al. (2010), for example, looks into aging couple’s care practices. The researchers examine how the types of care a spouse provides, as well as their perception of their relationship with their spousal care recipient, influence the emotional well-being of the provider. Integrating data collected using various scales, including the scale of fitness interdependence (Brown & Brown, 2006), their study concludes that the more a provider recognizes the mutual need and shared dependency with their spouse who is a care recipient, and the more time the provider spends on direct care of their spouse, the better the care provider feels about providing care. This dissertation draws from and builds upon these perspectives by
conceptualizing care as dialectic and deeply relational. Particularly by utilizing the framework offered by affect theory, chapter 6 of this dissertation describes in depth how care circulates between care recipients and providers, connecting them and nurturing their relationality.

**Defining Key Concepts**

With the brief review of care studies laid out above, this chapter ends with describing key concepts used in this chapter. Below, I define long-term care, care practice/labor/relationship/work, division of care recipient and care provider, care agencies and care industries, capacitation and debilitation, and assemblage.

**Long-Term Care**

Care needs in general are assessed based on the incapability of an individual to fulfill their self-care (Folbre & Wright, 2012). Commonly, Activities of Daily Living and Instrumental Activities of Daily Living are used to measure care needs. In this dissertation, the concept of long-term care is used in contrast to the acute care Medicaid also provides. Long-term care includes the daily care people receive in what is anticipated to be a longer period of time. As explained by Folbre and Wright (2013), the definition of long-term is often unspecified and what such care entails varies from a person to person. Specifically, the term Long-Term Services and Supports (LTSS) is used in this dissertation, as it is an official term in Medicaid and therefore also used by care agencies and care recipients and providers.

**Care Practice/Labor/Relationship/Work**

In this dissertation, I intentionally use the term care practice to depict care conducted by care recipients and providers in order to keep the concept of care neutral and open to different interpretations. I also borrow from Wetherell’s (2012) interpretation of the word: “Practice has old and familiar connotations in the social sciences, and these are useful and still extremely
valuable. But, practice is also capacious enough to extend to some of the new thinking available about activity, flow, assemblage and relationality ... Practice conjures forms of order but recognizes their ‘could be otherwise’ qualities” (p. 4).

Unlike Folbre and Wright (2012), who refuse to use the word commodity, as it limits the concept of care to money exclusively and negates the affective nature of it, I use terms such as *care labor* and *care work* that highlight the commodification of care. I use these terms in order to emphasize situations in which people (mostly women) are forced into or exploited under care-related occupations. In contrast, *care relationship* is used to address the relational nature of care. For example, I may use the term care practice to describe the care coconducted by care recipients and providers at the beginning of their care arrangements, when they engage in care merely because it is their job (for providers) or because it is indispensable assistance for conducting their daily life (for recipients). Yet as the care practices are repeated and their narratives include genuine affective care—more than a job or assistive routine—I may start using the term care relationship in order to differentiate the care from mere practice.

**Division of Care Recipient and Provider**

Care relationships and practices emerge due to the care needs of *care recipients*, and the role of *care provider* is assigned to respond to these needs. People are all dependent beings; yet differences in people’s capacities, social expectations (disabled people as dependent or women as “natural” caretakers), and the care industry (which commodifies care labor) all play a role in dividing care recipient and provider categories. As much as Lynch et al. (2009) emphasize the rights to both give and receive care, and I conceptualize care as circulating—rather than given and received unidirectionally—people’s capacity to take care of themselves independently varies from person to person and throughout the lifetime. Some embody idiosyncratic care needs.
While care circulates and is exchanged, the circulation and exchange do not happen equally among all members of society. There are gender-, race-, and class-biased care responsibilities. When care includes work and labor, the labor needs to be recognized and compensated, and a firm categorization of the care provider becomes necessary. However, in order for disabled people to receive social services, it is requirement for their needs to be legitimated, and the category of care recipient becomes crucial. To acknowledge individuals’ differences in capacities and needs, as well as the construction of strict care recipient and provider roles by the industry, I use the terms care recipient and care provider.

Care Agencies and Industries

I define the care industry as the aggregation of economic systems that make their revenues by providing health care. It includes the for- and nonprofit managed care organizations, or care agencies, as participants in this study call them. I use the terms care industry and care agencies with the connotation of the capitalist involvement in the public health-care sector, which is increasing dramatically with neoliberal reforms, as explained in chapter 4. Care agencies function as the intermediary in care arrangements. Their tasks include hiring and training care providers. They, through contracting social workers, assess and determine the course of care recipients receive. They arrange for providers to visit their consumers (recipients) and follow up with the consumers periodically to assess the quality of care they receive. They also set the guidelines of “do’s and don’ts” for providers to follow. They intervene in care arrangements when issues arise and take care of billing Medicaid and paying providers. Most of

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21 Care as work and labor refers to situations in which care is no longer an activity whose responsibilities are shared by many equally but instead a responsibility of a few. Thus, the intense amount of care responsibility restricts care providers from pursuing their life goals, and care occupies their everyday life as if it were a formal occupation.
their revenue comes from Medicaid, whose budget is allotted by federal, state, and (in the case of NYS) county governments. Finally, I would like to note that, although agencies claim to fulfill these tasks, how effectively the work is getting done is a controversial topic, as brought up by participants of this study and further investigated throughout this dissertation.

**Capacitation and Debilitation**

I use concepts of *capacitation* and *debilitation* as they are deployed in Puar’s work (e.g., 2012) and which she describes as deeply rooted in affect studies (2015). Conceptualizations of capacitation and debilitation are rooted in Spinoza’s and Deleuze’s work on body and affect, which studies ways in which a body’s “power of acting is diminished or blocked … [or] increased or enhanced,” depending on the bodies it encounters (Deleuze, 1988, p. 27). Following the genealogy and adding to Berlant’s conceptualization of “slow death,” Puar (2012, p. 153) describes the neoliberal demands for bodily capacity as well as the profitability of debility, both functioning as central routes through which finance capital seeks to sustain itself.…. Capacity and debility are seeming opposites generated by increasingly demanding neoliberal formulations of health, agency, and choice—what I call a “liberal eugenics of lifestyle programming”—that produce, along with biotechnologies and bioinformatics, population aggregates. Those “folded” into life are seen as more capacious or on the side of capacity, while those targeted for premature or slow death are figured as debility. In sum, capacitation includes the ways in which bodily capacity is manipulatively heightened and exploited, mainly for the progress and maintenance of the neoliberal political economy. Debility consists of the ways in which bodily capacity is manipulatively decreased in order to, again, produce profit out of the debilitated body.
Assemblage

Developed by Deleuze and Guattari (1977; 1987), the concept of assemblage refers to “ad hoc groupings of diverse elements, of vibrant materials of all sorts. Assemblages are living, throbbing confederations that are able to function despite the persistent presence of energies that confound them from within” (Benett, 2010, pp. 23–24). Thus the assemblage is composed of interwoven molar and molecular activities, formations, and temporalities:

There are fundamentally two poles: but we would not be satisfied if we had to present them merely as the duality of the molar formations and the molecular formations, since there is not one molecular formation that is not by itself an investment of a molar formation. There are no desiring-machines that exist outside of a molar formation. There are no desiring-machines that exist outside the social machines that they form on a larger scale; and no social machines without the desiring-machines that inhabit them on a small scale. Nor is there any molecular chain that does not intercept and reproduce whole blocks of molar code or axiomatic, nor any such blocks that do not contain or seal off fragments of molecular chain. (Deleuze & Guattari, 1977, p. 340)

Globalization is an assemblage, for example, which requires a new way of understanding its part-whole relationship: “The parts of this giant whole were both intimately interconnected and highly conflictual…, the coexistence of mutual dependency with friction and violence between parts … but somehow functioning [as] whole” (Bennet, 2010, p. 23).

The concept of “assemblage” is used in this dissertation to describe the formation of public health care under neoliberalism. The concept allows me to connect and describe influences among the U.S. government; the NYS government; and the neoliberal turns in Medicaid, the welfare program for single mothers, and international and domestic care
industries; and care providers and disabled people, to name a few. Thus, neoliberal public health care is simultaneously part of the larger globalizing, neoliberal assemblage. The notion of assemblage highlights the multiple positions and spaces these institutions, industries, policies, and individuals occupy.
Chapter 3

Methodologies

Abstract

In this chapter, I describe the processes of data collection and analysis done for this dissertation. Starting with a brief review of how this dissertation emerged, I lay out (1) data collection methodologies—archival research, focus group, individual interview, and participant observations, (2) descriptions of participants and the recruitment process, (3) data collection procedures, and (4) data analysis methods and procedures. Besides sharing examples of the step-by-step process on coding and theme organizing, the data analysis section also includes theoretical frameworks that shape my understanding of the data. Within this context, I explain the qualitative research foundation of this dissertation. The chapter ends with charts of questions used in the focus groups and individual interviews as well as demography of the participants.

As much as the focus groups and individual interviews were conducted to collect narratives of Care Recipients and care providers’ interdependent care relationships, such relationship was evident and embedded in focus groups with disabled people. As disabled participants began to fill the conference room and gather around a big white table, it became clear that this focus group was quickly turning into a multi-generational disability community gathering. As many used power chairs, others moved chairs that were already in the room to create a space for them. We took turns to open the door, when people moved in and out of the room. As we all identify as part of disability community, interdependence is our nature; our way to share a space together. People worked together to interpret and help passing messages across the table, when some participants’ speech was affected by their disabilities. We took turns filling out demography questionnaire as some of us read and others do not; some of us write and others do not. Some read and write in English and others in different languages. After the focus group and during our group lunch, we took turns feeding each other, so everyone’s stomach was filled. We were the seasoned experts to create warm, supportive, and affirmative space to welcome anyone...
and everyone regardless of our developmental and/or physical disabilities: including those who were super vocal and friendly as well as those who were shy and needed some time to warm up.

It was particularly memorable when an elderly man with cognitive disability answered to my question, “In what ways do you (care recipient participants) provide care to others,” by telling us, “No, I am a care recipient and not giver.” A number of other participants immediately disagreed with him by telling the group how he taught them—younger advocates of disability communities—how to work in this complex disability service system. They together embodied interdependent care for one another. As we all helped each other, we transgressed care recipient-provider binary where disabled people are often situated exclusively as recipients of care.

Similar things were evident during the participant observations of care practices. When they worked together, they worked as a team beyond given roles as a recipient and a provider. After years of working together, they worked in sync without overshadowing each other’s individuality. Even without communicating, they knew what each other needed and how each other worked. It was as if they were part of one big force which makes things happen: whether it is a preparation for music class the care recipient gives or experimenting a chocolate cake baking together.

—Excerpts from my data collection notes

Initial Development of the Dissertation

Topics of this dissertation emerged from my own experiences being a care provider for children and disabled adults, witnessing how my disabled friends who receive Long-Term Services and Supports (LTSS) are treated by their care providers, and getting involved in disability rights and domestic workers’ rights activism. Following the principles of participatory
action research—developing and conducting research with community members based on their needs and interests—this dissertation was designed reflecting opinions and input from disability communities. As described in detail in chapter 1, to start this dissertation, I asked disability community members, “In what ways can research contribute to improvement of care quality?” A summary of the responses is as following: (1) proving and raising awareness of how care became a profit- (and not people-) centered practice and (2) challenging medical models of care. These responses provided direction for this dissertation. With the entry point offered by the communities, this dissertation came to ask the questions listed in chapter 1.

In the following space, I describe data collection methodologies, the first of which includes archival research, focus groups, individual interviews, and participant observations. Next, I share a brief description of participants and the recruitment process. Third, I lay out the detailed data-collection procedures. After that, I explain the processes of data analysis, with charts that depict these processes in detail. Finally, this chapter ends with a description of the ways in which my own subjectivity possibly affected the construction of this dissertation. Below is the quick summary of methodologies.
<table>
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involved in it—particularly disabled people who receive their long-term care through New York State (NYS) Medicaid and their care providers?

| 6 | Does relationality emerge between care recipients and their providers, and if so, how? What does such relationality do? | Focus group and individual interviews | Content analysis and Grounded Theory with the theoretical framework | Affect theories and conceptualization of body (Deleuze, 1988) |

Table 1: Summary of chapters and corresponding research questions, methodologies, and theoretical frameworks

Data Collection Methodologies

Archival Data on Medicaid and Welfare Programs

In order to answer the research questions, the first set of data that was sought includes archives on policy changes applied to Medicaid and the welfare program for single mothers. They also include data on changes in labor protections for domestic workers, developments of Supplemental Security Income (SSI), and general information on the care crisis such as the rise of care industries in and outside of the United States. The data was collected through governmental documents, research institutes’ reports on these policies, newspaper articles mostly from The New York Times, academic scholarship on these social service programs, policy reports.
by the national activist campaigns that work on care in/justice, and personal conversations with two experts on the NYS public care system. Examples of sites where the governmental documents were sought include websites of U.S. Departments of Health, Labor, and Aging; Social Security Administration; census reports; and Medicaid services as well as the NYS Department of Health. These websites offer updates on reforms of these social services as well as basic descriptions and guidelines, histories, and application processes. Alongside the governmental websites, reports from research institutions—such as the Kaiser Family Foundation—are reviewed. Many activist organization and campaign websites also provided useful information on policy updates and interpretations of them based on their constituency’s interests. Activist organization websites reviewed in this dissertation include the National Domestic Workers Alliance, ADAPT (disability rights organization), Center for Disability Rights, and Caring Across Generations. Academic scholarships are reviewed for historical analysis and timelines, particularly of the welfare program for single mothers (e.g., Glenn, 2010; Gordon, 1994). Additionally, I had several conversations and consultations with experts on Medicaid: Mariette Bates, the director of disability studies at the City University of New York, and a well-known advocate for those with cognitive disabilities and mental illness; and Nick Dupree, who is a disabled disability rights and Medicaid activist. Though participants of this research are also experts based on their daily experiences in public health-care system, Dr. Bates and Mr. Dupree—whose professional interests and activism involve the policies of public disability services—offered me an in-depth, layered understanding of public LTSS from multiple perspectives, alongside their perspectives as the program’s recipient or provider. As we are currently experiencing the U.S. care crisis and transition into aging society, as well as dramatic shifts in social health-care programs, what started as a quick review of the context of this
dissertation ended up as a massive volume of data, from which chapter 4 emerged. While the archival research method was used to elicit contextual information for this dissertation, data collected from this method is used in particular to answer the first question of this dissertation: How has today’s public health care been shifted and shaped by the neoliberal political economy and its austere policy reforms?

In contrast, the following methodologies—focus group, individual interview, and participant observations—are employed to gain access to care recipients and providers’ understanding of the care system as well as the ways in which they are treated under the system and by one another. These three methodologies are used to respond the rest of research questions: In what ways are the existing social injustices further deployed under the neoliberalization of public health care (e.g., sexism, racism, classism, ableism, sanism, and xenophobia, that are inherent to care labors and practices)?; What are the psychological and physical effects of the neoliberalization of public health care on those who are involved in it—particularly disabled people who receive their long-term care through New York State (NYS) Medicaid and their care providers?; Does relationality emerge between care recipients and their providers, and if so, how?; and What does such relationality do?

**Focus Group**

The focus group method has been selected for its ability to elicit discussion and opinions from participants in ways that build knowledge *within* the group itself (Steward, Shamdasani, & Rook, 2007). This internal knowledge building is critical because it means that—since the focus group is comprised of those with the expert knowledge born of similar experiences—unexpected topics may arise that may not surface in individual interviews. Also similarities between participants will provide a way for them to more safely explore their experiences regarding such
a private matter as care. Finally, because both disabled people and care providers are known to be isolated from other community members (e.g., Francisco, 2012; Linton, 1996), my hope was for these focus groups to provide a space for resource sharing and community building by demonstrating that the challenges and issues participants may have experienced within care practice individually were actually shared and common among others who occupy care recipient or provider roles.

Focus group interviews were conducted in order to gain in-depth understandings about:

- the processes disabled people go through in order to receive Medicaid LTSS and how they experience these processes;
- the nature of job training care providers are required to take by their employer agencies, and the providers’ views on these trainings;
- the guidelines created for care recipients and providers and enforced by care agencies to regulate their care giving and receiving, and their opinions on these guidelines;
- examples of pleasant care relationships where care recipients and providers feel that they are cared by one another;
- examples of challenging care relationships where care recipients and providers find the relationships to be negative or even abusive; and
- the everyday practices care recipients and providers already engage in order to care for each other despite the restrictions placed by the care agencies.

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22 As described in chapter 2, definition of care ranges widely. “Everyday practices of care,” as used in here and in focus groups, are understood by research participants as care routines assigned by care agencies to care providers. Disabled people and their care providers are usually notified in the documents what care routines (e.g., making bed, cooking breakfast) are assigned and their frequencies.
These themes were developed reflecting the larger research questions of this dissertation, and they became the basis for interview questions. Interview questions are attached in Appendix A at the end of this dissertation.

Originally, focus groups for care recipients and providers were scheduled to be conducted separately, so that participants could share their experiences without the feeling of being judged by those who were situated on the other side of care relationships. In total, two focus groups with mainly disabled care recipients were conducted. These focus groups also included a few care recipient participants’ providers upon these recipients’ requests to have the former in the conversation. They suggested that their care providers join the focus group so that I could gain both care recipients’ and providers’ perspectives. I asked for and gained consent from all recipient participants to include these providers in the focus group prior to the focus group interviews.

**Individual Interviews**

Initially, I planned to have focus groups and participant observations to collect data from both care recipients and providers. In reality, though, most of provider participants who responded to join the focus groups could not show up to them, due to the last-minute work schedule changes—a point elaborated on below in the section called “Difficult Recruitment.” Due to the extreme difficulty in setting up a focus group for care providers, care provider focus groups were turned into individual interviews. A set of interview questions prepared for the focus group were directly applied to individual interviews, except for the opening art activity, which was used as an icebreaker for the focus groups (Appendix A). While individual interviews do not have the same benefits as focus groups, such as building knowledge within, I would like to note that my experiences as a care provider as well as my teaching experiences with students
who are mostly care providers in the NYC disability service sector contributed to the knowledge building within individual interviews and allowed me to offer care-related anecdotes to develop deeper conversations with these provider participants. In total, 5 individual interviews were conducted with providers of Medicaid LTSS.

**Participant observation**

Participant observation was used to document care practices between two pairs of care recipients and providers as they unfolded in naturalistic settings. Unlike focus groups and individual interviews, which allowed me to collect narratives and opinions from the participants, participant observation allowed me observe the details of care practices, which take the form of nonverbal communication and interactions between a care recipient and their provider, that are often left out of interviews. Also, this methodology was a way for me to experience ontologically the care participants were practicing and embedded in, even though it was not as authentic as what they were experiencing. During participant observations, particular attention was given to recording how they treated one another and negotiated their needs and capacities as they engaged in the joyous and difficult moments in their care practices. I also took notes on my own experiences and reactions in the space where their care practices took place, sometimes interacting with them and offering help.

**Participants**

Participants of this dissertation are 12 adults with disabilities—10 of them who receive daily Medicaid LTSS at their residence—and 10 care providers who work full-time to provide care for disabled adults under the Medicaid LTSS program. All the participants live in NYC. The nature of disabilities the recipient participants embody varied, though it was mostly physical disabilities.
The selection criteria for care recipient participants was based on their Medicaid home-based LTSS beneficiary status, their age (over 21), and having any kind of disability that made them require LTSS. In terms of criteria for the Medicaid LTSS beneficiary, this study included those who have received support to conduct Activities of Daily Living or Instrumental Activities of Daily Living for at least two years. The selection criteria for provider participants included those who provide LTSS to disabled adults at least four days a week, more than four hours per day, for over a year at least, and whose payment comes through Medicaid.

At the end of the recruitment, I had 10 disabled people and 9 providers of care who participated in the focus groups and individual interviews. Two disabled participants who currently do not receive LTSS showed up to the focus group, as it was an important topic to them. One of them joined the first focus group. He came because he had witnessed the care his best friend who uses LTSS received and wanted to work for care justice for disabled people. Another person participated in the second focus group who told us that he needed services such as SSI and Medicaid, yet due to his learning disabilities, he had been having an extremely difficult time going through the bureaucratic process. All the other participants welcomed these two people to participate in the focus groups. Detailed descriptions of all the participants are cited at the end of this chapter, in Appendix B.

Difficult Recruitment

Recruitment for this research was done relentlessly. In terms of care recipient participants, I used connections I had gained through years of work organizing various disability community events and activism. For provider participants, I contacted various gatekeepers of disability LTSS programs in NYC: directors of care agencies and policy makers at disability care services. From their recommendations, I visited a number of health organizations (e.g., a
physical therapy center for disabled people) and care agencies that provide LTSS for disabled people and who also host many social gatherings, workshops, and events for their consumers (disabled care recipients). While volunteering at these events, I recruited provider as well as care recipient participants.

Despite the continuous recruitment, bringing these participants to a focus group was a major challenge, and reasons for the difficulty varied. One reason was the very private nature of this research. The research questions focus directly on these disabled people’s everyday lives— involving possibly embarrassing, vulnerable, and intimate aspects of these. For providers, participation could mean revealing their care practices and work ethics that may have contradicted the expectations of their employers, care agencies, and policies. One care provider participant requested that I not tape-record the interview, for example, for this reason. Another reason for recruitment difficulties—a major one, I assume—was the nature of ever-shifting schedules, particularly for providers. These care providers often work 12 hours a day and 5 to 6 days a week. Thus, their work hours are directly affected by their care recipients’ well-being as well as how smoothly their appointments with medical and bureaucratic authorities proceed. Indeed, many participants called me right before the scheduled focus group time to tell me that they were stuck at their care partner’s appointment with doctors or in an Access-A-Ride with their care recipients, or they had been asked to stay extra hours in the evening. These unpredictable work hours prevented them from participating in the focus group on time. Even outside of work hours, their schedules are often determined by others’. Care providers described how their free time often involved taking care of their family members, particularly their children or aging parents; therefore, the priority given to participation in research interviews was next to zero. Their concerns for the topic of this dissertation, though, moved many to stretch
themselves to participate in this research. One participant told me, “Look, I have only one day off. And I have been running around with laundry and grocery shopping all day already. I usually don’t have time for something like this [research interview]. But you seemed nice. That’s the only reason I came here. Because you looked like a nice person at the Karaoke party [where you volunteered].” Regardless of my effort to increase incentive to compensate their participation (with payment and Japanese homemade lunch), the reality is that care providers are often buried under multiple jobs, tasks, and responsibilities and that disabled people tend to have less access to leave home and attend meetings (due to the lack of accessible and reliable transportation or difficulty securing care providers who can travel with them, for example), which prevented many from participating in this research and made recruitment extremely difficult.

**Procedure of Data Collection**

**Focus Group Procedure**

Two of the focus groups with disabled care recipients were conducted in a conference room at the Self Advocacy Association of NYS, an organization located within the NYS Office for People With Developmental Disabilities. The space was chosen for its convenience, as many participants work in the building or visit there to receive services. Both focus groups proceeded in the same manner, and began with my description of my intentions with this research and their rights as participants. All participants signed consent forms. Then, I asked if the group would be comfortable with and consent to including a few care providers (whom a few care recipient participants had invited) and a disabled person who currently does not receive LTSS. I solicited consent on this matter because the original call for these focus groups said that only disabled people who received LTSS would be present. After I had received everyone’s consent, the focus groups began with an ice-breaking art activity in which participants were asked to express what
care meant to them. On the table, there were multiple art supplies including paper, colored pencils and markers, and playdough. The icebreaker lasted 10 to 15 minutes and was filled with chatting among participants. The chatting included support for each other’s brainstorming regarding how to express their thoughts on the paper as well as prompts for those who needed extra encouragement. The formal focus group conversations started with each participant introducing themselves and sharing what care meant to them by describing what they had created with the art supplies. The focus group continued with the set of questions listed in Appendix A. The focus groups did not proceed in a linear manner, as the protocol may suggest. Instead, they were filled with follow-up questions; multidirectional conversations among participants (instead of me asking a bunch of questions to them unidirectionally); shared laughs, frustrations, and sympathy; and resource building. As excerpts from my research notes shared at the beginning of this chapter suggest, I witnessed budding micro-community and friendships in the focus groups. Many got excited as they learned about their mutual friends, that they had gone to the same summer camp for disabled children, or that they shared loopholes within services and systems of which they were intimately a part. Also, when some shared their difficulties in applying for services, others with more experience consulted with them right away, and the rest of the group provided lots of encouragement and support (that often included loud cheering for one other as well as cursing at the system and the government).

After the focus groups, participants were asked to fill out a demographic questionnaire. Some filled it out on their own—as they could read, comprehend the questions, and write on their own—while others filled it out with me. Each focus group lasted 2 hours and was followed by a group lunch. All participants received a little monetary compensation. Some received it in
the form of a check, and some in cash in order to avoid SSI income penalties. All conversations were tape-recorded and transcribed afterward. Many participants left their artwork with me, as they had no need for it.

**Care Provider Individual Interview Procedure**

As most care provider participants could not join their focus groups, individual interviews were conducted instead at each participant’s convenience. The length of these interviews varied from 40 minutes to 2 hours depending on the participant’s availability. Interviews took place at convenient locations for participants, including the back rooms of a nonprofit organization where an event for disabled consumers was going on, a corner table of the McDonald’s in their neighborhood, and a conference room at the City University of New York. These individual interviews started with my explaining the purpose of the research and their rights as participants, followed by signing consent forms. Unlike my original plan for the focus group procedure, these interviews jumped directly into the interview questions after a few minutes of chitchat, instead of starting with an art project. The art project was skipped because the individual interviews were not like focus groups, which require icebreakers and participant introductions to build trust and connection among them to safely share their experiences and opinions. I replaced the icebreaker activity with chitchat, to build a friendly atmosphere, wherein we talked about a variety of things including participants’ family, their day, or their old friends from Japan.

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23 All the disabled participants who receive Medicaid long-term care are also recipients of SSI, which limits each recipient’s saving to below $2000 in order for them to maintain their eligibility. In the case that the limit is breached, the excess income is taken away by the Social Security Administration or the person may lose their eligibility.
A set of interview questions (Appendix A) guided the interview, which included occasional interruptions by phone calls from their families or colleagues who needed their help. Similar to the focus groups with care recipients, the individual interviews proceeded in a conversational way, with many follow-up questions, rather than as a unidirectional question-and-answer session. Indeed, interviews were filled with various emotions as well as sharp critiques of the care agencies and governments who regulate Medicaid. Sometimes, provider participants relayed the positive and affirming care relationships they had developed with their care partners; some of these relationships remain strong years after the care arrangement has ceased (because the care recipients moved to another region, for example). Sometimes participants’ eyes got teary when they recalled their past care recipients who were deceased. As all the participants had worked in care work for nearly or more than 10 years, interviews with them were filled with their own rich life stories as well as those of the care recipients with whom they worked.

After the interview, participants filled out a demographic questionnaire: some of them filled it out on their own, while others needed my help to read and write. All interviews but one were tape-recorded and transcribed afterward. One participant did not want her interview to be recorded yet gave me a permission to takes notes during the interview. All participants received a little monetary compensation. One participant refused to receive such compensation, as she expressed that she had participated in the interview not for money but to contribute to the improvement of care and employment quality as well as to help me out.

**Participant observation**

Participant observation was initially planned to be done with five pairs of care recipients and providers as they engaged in their daily care practices. Yet, due to the participants’ availabilities and the very private nature of this data collection method—observation of their
daily care routines—the original plan was modified, and the participant observations were done with two pairs of care recipients and providers. The first observation was with Amy (recipient) and Patricia (provider), and I joined their morning routine for 3 hours: from when Amy woke to the end of her brunch or when Patricia shift was ending. I visited Any’s apartment two mornings for observation. Their morning routine included Amy taking a shower, using the toilet, dressing, and eating brunch, as well as Patricia assisting with Amy’s showering, dressing, and hair braiding; cleaning the kitchen, living room, and bathroom; as well as cooking brunch, late lunch, and dinner for the day. In addition, as they both enjoy cooking, they collaboratively cooked chocolate and baked a chocolate cake on the first day of the observation and a cake on the second day.

I observed the second pair, Maria (recipient) and Isabella (provider), for 2 hours as they prepared for a music class Maria teaches for fellow disabled people at a nonprofit care agency that coordinates LTSS for Medicaid recipients, including Maria. The observation included their collaboratively setting up a space by laying eight electric pianos across six plastic tables, choosing music books for the lesson, and hanging around and socializing with clients and employees of the agency. In the participant observation, I asked questions during their down times and provided help when it was needed.

I took as many notes as possible during the observation, and I wrote additional notes directly after each observation. I paid attention to how they interacted and communicated with one another. Of particular interest was how each pair both individually and collectively navigated the power dynamics within their care relationships. Such dynamics were apparent every moment, for example, when recipients asked their providers to do things for them, and
how providers responded to the requests. Also, I took notes on what I was feeling in the moment in relation to the care practices taking place.

**Data Analysis**

Data analysis was done following principles of grounded theory and by using content analysis (Glaser, 2001; Braun & Clarke, 2006). While these analytical methodologies provided me tools for interacting with and organizing the data, various theories I was reading about at the time of data analysis lent me perspectives through which I read and analyzed the data. In particular, I incorporated concepts of assemblage (Deleuze & Guatarri, 1972 & 1987) and capacitation and debilitation (Puar, 2012) in chapter 4; and concepts and theories of disposable population (Giroux, 2004), biopolitical labor (Hardt & Negri, 2004), necropolitics (Mbembe, 2003), and slow death (Berlant, 2011) in chapter 5. Chapter 6 is shaped by theories and concepts of affect and body developed by Deleuze (1988), Spinoza (as interpreted in Deleuze, 1988 and Bignall, 2011), Venn (2010), and McCarthy and Prokhovnik (2014), as well as the concept of the undercommon as introduced by Harney and Moten (2013). These concepts and theories are further explored and described in the corresponding chapters and chapter 2 (assemblage, capacitation, and debilitation). In sum, reading these works made me aware of how society—especially under the neoliberal hegemony—is constructed in a specific way, and how citizens are situated in certain positions and roles circulating power dynamics within the structure. Simultaneously, though, these writings assert lines of flight or revolutionary hope and potential always and already happening on the micro level. These theories heavily influenced how I understood the data. Feminist and disability studies’ theorization of care also reminded me that there are multiple ways to interpret data and that narratives of care practices are always embedded in the historical and political contexts. Finally, the same set of data I collected through
focus groups, individual interviews, and participant observations are used for both chapter 5 and 6. As these chapters are organized to respond to different research questions, the same set of data is analyzed through different lends for each chapter. This means that the same quote might be used in both chapters, but to reach to different theses and theorizations.

**Process of Data Analysis for Chapter 5**

Tape-recordings of focus groups and individual interviews were transcribed first. Transcripts were coded, and codes were organized to form themes based on each interview transcript. Braun and Clarke’s (2006) guide for thematic coding was used to navigate the process. Also following the principles of the grounded theory, codes and themes were developed based on what was repeatedly brought up in the interviews as well as what stood out in relation to the research questions. From there, themes that emerged from five care provider individual interviews were compared and merged to come up with common themes of providers’ narratives. The same process was taken to organize care recipients’ narratives.
<table>
<thead>
<tr>
<th>Quotes</th>
<th>Codes</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alisha (provider): They’re (care workers) not different from McDonald’s, fast food workers, they’re no different [in terms of] the amount of pay you get. First of all, you’ve gotta have um, certain days, you know. We see all different kind of things. You never know what case you gonna come upon, where it may just be too much. You know, people pass away, oh that happened to me. People died.</td>
<td>Frustration with low wage care work Unexpectedness of work Intense nature of care work Facing death of their care recipients Emotional effects of care work</td>
<td>Low wage care work Intense nature of care work Emotional toll of care work</td>
</tr>
</tbody>
</table>
| Ty (recipient): I get people (providers) from agency, you can automatically tell when you first come to your house, what kind of person it’s gonna be. Because some people come in and tell you what they NOT gonna do. You know, I don’t sweep and mop early in the morning, … They are on the phone and talk all day, or people | Agency hiring anyone who comes to the office Provider who does not follow assigned work Encounters with untrained care providers | Agency’s failure to gatekeep unqualified providers Deterioration of providers due to the lack of care from the agency Agency’s failure to provide rigorous high-
watch TV all day. You know, they sent me someone who can’t cook at all.

quality training to its workers

Table 2: Examples of code and theme developments (Chapter 5)

After the initial coding and theme forming, themes were all drawn to see connections among them and to come up with umbrella themes.

Then, it was once again theoretical frameworks that guided me to make sense of these themes and build a main thesis.
For chapter 5, codes and themes are organized based on how providers and recipients enter the public health-care sector (or what I call the neoliberal public health-care assemblage), how they are treated in it, and the consequences of being part of the sector. The use of the concept of assemblage (Deleuze & Guatarri, 1987; 1982) is helpful, here, to recognize the public health-care sector on a longer scale and beyond the immediate state-recipient-provider relation. How care recipients and providers are situated in the health-care realm is certainly shaped by neoliberal austere social reform policies, the larger transnational care industry which manifests in the form of care agencies, and much more. Thus, care providers and recipients are simultaneously part of other assemblages or realms beyond the care industry alone. The concept of assemblage comes in handy to indicate the multiple positions and spaces these individuals occupy. With these rationale as a backdrop, the codes and themes were organized as below.
### Narratives of care providers

<table>
<thead>
<tr>
<th>Framework</th>
<th>Themes</th>
<th>Examples of codes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Entering into care labor</td>
<td>Care work is only available job</td>
<td>• Previous experience as family’s care provider</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Desperation for a job due to living in poverty and being a single mother</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Abundant amount of care jobs</td>
</tr>
<tr>
<td>Characteristics of care labor under the assemblage</td>
<td>Low-wage job</td>
<td>• Agency and Medicaid pay providers extremely low-wages</td>
</tr>
<tr>
<td></td>
<td>Extended hours of work</td>
<td>• Long hours of work</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• No time to spend with family</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• No holiday break</td>
</tr>
<tr>
<td></td>
<td>Intensified care work</td>
<td>• Unsafe work environment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>o Agencies not checking the work environment periodically</td>
</tr>
<tr>
<td></td>
<td></td>
<td>o No information about their care recipients from agencies, prior to the providers’ visits to them</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Individual responsibilization of agencies’ shortcomings</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Abuse of care providers</td>
</tr>
</tbody>
</table>
| Consequences of laboring in the assemblage | Emotional and physical deterioration | • Frustration of not being able to spend time with family  
• Emotional toll of the intensified care work  
• Physical deterioration due to the intensified labor and lack of health care |

Table 3: *Examples of framework building from narratives of care providers (Chapter 5)*
<table>
<thead>
<tr>
<th>Framework</th>
<th>Themes</th>
<th>Examples of codes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Entering into public health care</td>
<td>Long, defeating, and ridiculous bureaucratic process</td>
<td>• Proving one’s disability, its permanency, and care needs</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Forced poverty to receive social services</td>
</tr>
<tr>
<td>Characteristics of care reception under the assemblage</td>
<td>Agency’s failure to gate-keep unqualified providers</td>
<td>• Agency hiring <em>anyone</em> who comes to the office</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Recipients’ experiences of their belongings being stolen</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Mistreatment of care recipients by providers</td>
</tr>
<tr>
<td></td>
<td>Agency’s failure to provide rigorous high-quality training to its workers</td>
<td>• Encounters with un-trained care providers</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Agency’s rejection of having care recipients contribute to provider training</td>
</tr>
<tr>
<td></td>
<td>Deterioration of providers due to the lack of care from the agency</td>
<td>• Burnout of care providers (regardless of their motivation and qualifications)</td>
</tr>
<tr>
<td></td>
<td>Intensification of care vulnerability</td>
<td>• Not receiving any information about their care providers</td>
</tr>
</tbody>
</table>
### Table 4: Examples of framework building from narratives of care recipients (Chapter 5)

<table>
<thead>
<tr>
<th>Consequences of being “beneficiaries” in the assemblage</th>
<th>Lack of choice regarding letting strangers into their homes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Life-threatening (lack of) care</td>
<td>Direct connection between lack of care or mistreatment to their death or acute deterioration of their health</td>
</tr>
</tbody>
</table>

**Process of Data Analysis for Chapter 6**

Similar to that in chapter 5, data analysis of chapter 6 involved data from focus groups and individual interviews and was conducted based on content analysis as laid out by Braun and Clarke (2006). Centering its analysis on the topic of *relationality*, coding was done on any encounters between care recipients and their providers, co-conducting of care by recipients and providers, and factors that influenced their care practices and relationship.
<table>
<thead>
<tr>
<th>Quotes</th>
<th>Codes</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>The problem is the agency. The agency keeps telling them (providers), you’re not supposed to engage with your client. You’re supposed to keep your distance. (Rick, care recipient)</td>
<td>Control from care agencies</td>
<td>External factors that initially shaped the encounter of care recipient and provider</td>
</tr>
<tr>
<td>They don’t want you to get familiar, they don’t want you to. They don’t want you to really like each other. (Keisha, recipient)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>What they going through is not easy. It takes sometimes, it takes a lot for people to ask somebody to wash them up. That’s not something to get easy adjusted to do. That’s, total stranger somebody you don’t know have to come into do everything from you. Got to you don’t know yet. Got to see your whole entire. You know, your body is a temple, it’s private. You have to use a bathroom. You have to do certain things</td>
<td>Witnessing and acknowledging each other’s vulnerability Sympathy for one another</td>
<td>Sympathy for one another Transformation of feelings</td>
</tr>
</tbody>
</table>
that you, you know. It’s a lot for them as well. (Alisha, care provider)

Table 5: Examples of codes and theme developments building (Chapter 6)

As the figure above demonstrates, themes were developed following the guidelines of the grounded theory (Glaser, 2001), and organized into frameworks suggested by theories incorporated into chapter 6. In the creation of themes, it became clear that there are two lines of development between care recipients and providers: adaptation to each other’s body and circulation of feelings between these two bodies. First of all, their first encounter with each other is filled with and shaped by expectations and assumptions that are largely induced by external factors. Such external factors include “previous care experiences,” “internalization of social norms around disability and care services,” and “control from the care agencies.” From there, care practices begin. On one hand, the “co-engagement of care practices” brings the bodies of care providers and recipients closer. Under the framework of “co-engagement of care practices,” I included themes such as: “time as an element to bring them closer,” “learning about their care pair through repetition of care practices,” “compromising and adapting to their care pair,” and “necessity of patience.” One the other hand, the development of the care relationship is also enabled by the transformation of feelings circulating between care recipients and providers. In particular, it was clear in the transcript that the feeling of vulnerability is emphasized across different focus groups and interviews. The “transformation of feelings” begins with care providers’ and recipients’ “individually experienced vulnerability.” And slowly, they start “witnessing and acknowledging each other’s vulnerability,” which turns into “shared vulnerability.” Thus, such sharing of vulnerable moments sometimes brings “sympathy for one another.”
After these lines of development are described, I lay out a framework and themes that are illustrative of affective relationality. Such relationality is described as “embodied relationality,” and characterized as the “development of their own unique ways to communicate and care for one another” and the “care recipient and provider building their own care practices and transgressing their agency’s rules.”
<table>
<thead>
<tr>
<th>Framework</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vulnerability at the door and against each other</td>
</tr>
<tr>
<td>Vulnerability inside of the door and learning to share it together</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>External factors that initially shaped the encounter of care recipient and provider</td>
</tr>
<tr>
<td>Co-engagement of care practices</td>
</tr>
<tr>
<td>Transformation of feelings</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Examples of codes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Previous care experiences</td>
</tr>
<tr>
<td>Internalization of social norms around disability and care services</td>
</tr>
<tr>
<td>Control from care agencies</td>
</tr>
<tr>
<td>Time as an element to bring them closer</td>
</tr>
<tr>
<td>Learning about their care pair through repetition of care practices</td>
</tr>
<tr>
<td>Compromising and adapting to their care pair</td>
</tr>
<tr>
<td>Necessity of patience</td>
</tr>
<tr>
<td>Individually experienced vulnerability</td>
</tr>
<tr>
<td>Witnessing and acknowledging each other’s vulnerability</td>
</tr>
</tbody>
</table>
Table 6: Examples framework building from narratives of care recipients and providers

(Chapter 6)

**Conclusion and Researcher’s Subjectivity**

As I mentioned briefly at the beginning of this chapter, this dissertation emerged largely from my own experiences of providing care for others and being disabled as well as witnessing and hearing about my friends’ experiences in care as providers and recipients. Therefore, this dissertation is heavily influenced by my own subjectivity—from its questions, to the theoretical framework and methodologies of data collection and analysis. Particularly, my politics and everyday experiences of being disabled, a care provider, and friends with those who receive care determined the course of argument and epistemology this dissertation takes. For example, it was this occupation of the dual space of being disabled (thus, requiring some care, as minor as it is)
and a care provider that allowed me to have some insights into both care receiving and providing, and made me commit to bringing both perspectives to this dissertation. Indeed, this occupation of the dual-space as well as involvement in both domestic worker rights (including care providers’) and disability rights activism made me painfully aware of blurred line between these two communities. Many providers are exploited and becoming sick and disabled. Thus, many disabled people become each other’s resources and provide care and support to collectively maneuver the bureaucratic system.

As care studies is often conducted from either a feminist or a disability studies perspective—which often situates disabled care recipients and providers in a false sense of antagonism, as if one is causing the oppression of the other—it was particularly challenging to keep the balance between these two different populations’ perspectives and experiences. It was particularly difficult when the narratives of these participants included critiques of their care partners. There were many comments on abusive care providers from the recipients as well as how care recipients mistreat their providers. Addressing and writing about the larger care-based injustices they are embedded in as well as the agency and accountability of these individuals in the occurrence of mistreatments was challenging; some of these occurrences are documented in chapter 5.

Also, being an organizer in NYC disability communities and a faculty member in the disability studies program at the City University of New York allowed me to access different spaces (e.g., social events at the care agencies for the providers and recipients as well as NYC-wide disability rights activist meetings) to conduct recruitment. Besides these leadership positions I have taken, I certainly see how the intersecting identities I occupy affected the recruitment and data collection of this dissertation. My experiences as a care provider, certainly,
facilitated some vibrant conversations between care provider participants and myself. Also, the fact that I have a disability and am often present at NYC disability rights activism and protests (some participants had seen or met me prior to the focus groups) helped me and disabled care recipient participants to initiate conversations. Also, another large factor that affected the data collection is my foreign status in this country. As I was not born and raised in the United States—which was somewhat evident to these participants with my nonfluent and heavily-accented English—many participants seemed to be more compassionate to teach me details about the care sector in this country. Thus, my status as a graduate student and young adult created a dynamic in the data collection space that reminded me of an educational setting in which they were there, again, to teach and educate me. While my foreign status seemed to bring out more detailed information from these participants, it also meant an extra hurdle to communicate sometimes. As many care provider participants use English as their second or third language, like myself, individual interviews with them were filled with body language that required detailed note taking after the interviews. Furthermore, this communication hurdle meant that sometimes I had difficulty understanding disabled care recipients’ narratives, when their disability affected the way they spoke. When this difficulty came up, other participants in the focus groups helped to me to understand what was said. Indeed, this is one of the moments I witnessed interdependence in the focus groups, as noted in the anecdote shared at the beginning of this chapter. These are the several points I recognize as moments when my research procedure was influenced by my own standpoint, identity, needs, and capacities.
Chapter 4

Political Economy of Care: Mapping the neoliberal public health-care assemblage and capacitated and debilitated bodies

Abstract

In this chapter, I map the neoliberal U.S. public health-care assemblage. I identify the neoliberal turn within Medicaid, which brought about the privatization of the public health-care sector, as well as the relating rise of the transnational care industry and the neoliberal turn of the welfare program for single mothers. By doing so, I describe whose labor capacities and needs for care came to be commodified in the public health-care assemblage. Thus, I examine the ways in which race, gender, and immigration status as well as the types of care one requires came to be further deployed within neoliberal public health care. With the review of Medicaid’s history and the related development of care industries and a welfare program, this chapter theorizes how certain bodies are capacitated for their labor power, while others are debilitated for their care needs—both to profit the care industry and to suppress the state’s Medicaid budget. In the neoliberal public health-care assemblage, health-care institutions, reform policies, care industries, and the bodies of disabled people and lower-income women are deployed to create a flow of labor capacities, socially legitimated needs, and funds among these parts of the assemblage.

All bodies are being evaluated in relation to their success or failure in terms of health, wealth, progressive productivity, upward mobility, enhanced capacity (Puar, 2012, p. 155).

Each individual is held responsible and accountable for his or her own actions and well-being. This principle extends into the realms of welfare … health care (Harvey, 2005, p. 65).

Introduction

In the 1980s and thereafter, the transformation of the political economy based on the neoliberal ideology spreads rapidly across the globe. “Privileg[ing] the market as the most efficient platform for distributing social goods, minimiz[ing] the role of government responsibility in assuring collective well-bring and highlight[ing] instead personal responsibility”
(Fabricant & Fine, 2013, p. 4.), neoliberalism came to shape and apply monetary value to every aspect of a society. Public health care is not an exception. In a society where “neoliberal embodied citizens” becomes a prototype, people’s capacities are measured and exploited and their values are determined based on this model. Human bodies are turned into yet another parts of the neoliberal public health-care assemblage, creating flows of profit for the care industries and the state (Goodley, 2014). Thus, such exploitation and valuing of one’s capacity is deeply shaped by factors such as disability, race, gender, and immigration status. This neoliberal turn shifts the ways in which care is practiced and conceptualized and demands the further development of care studies. In this neoliberal era, methods of care delivery and reception are shifting. The main role of this chapter is to map the shift in order to further contextualize this dissertation.

Additionally, such mapping of the neoliberal shift in the care sector is done with a particular attention to the ways in which race, gender, immigration status, and disability are further deployed in the shift. In particular, I discuss the reconfiguration of the disabled Medicaid beneficiary population through a case described in The New York Times. Then, I discuss further the enforcement of the race-, class-, and immigration status based division of care labor with the rise of the transnational care industry and the neoliberal turn in the welfare program for single mothers. I end this chapter by describing the ways in which, in the neoliberal public health-care sector, certain bodies are capacitated (manipulatively and exploitatively forced to expand their labor capacities) based on their labor capacities, and some are debilitated (manipulatively forced to stay sick, disabled, and weak) based on their care needs. All of this serves to accumulate revenues for care industries and suppress governments’ Medicaid expenses.
By tracing the neoliberal turn of Medicaid, the corresponding rise of the care industry, and the subsequent reconfiguration of care recipient and provider populations, this chapter addresses the first two questions of this dissertation. How has today’s public health care been shifted and shaped by the neoliberal political economy and its austere policy reforms?; and In what ways are the existing social injustices further deployed under the neoliberalization of public health care (e.g., sexism, racism, classism, ableism, sanism, and xenophobia, that are inherent to care labors and practices)? To answer these questions and tie in arguments developed throughout this dissertation, I incorporate the concept of assemblage (Deleuze & Guattari, 1977; 1987).

As described in chapter 2 in details, an assemblage is composed of both molar and molecular activities, formations, temporalities, and flows (Deleuze & Guattari, 1987). The U.S. public health-care sector is an assemblage involving various policies, institutions, domestic and international industries, bodies of care providers and recipients, and more. Within the assemblage, Medicaid funds, care needs, labor capacities, desires, and much more flow among the elements. The U.S. public health-care assemblage is also a part of the larger neoliberal globalization assemblage. And, as an assemblage is gregarious and its elements are dynamic and always in reconfiguration, what I map in this chapter, and in the dissertation at large, is only one aspect of the ever-developing assemblage. To map this assemblage, I first lay out the history of Medicaid and its neoliberal turn. From there, I illustrate the development of the care industry (both domestic and transnational) and the reform of the welfare program for single mothers. Finally, I describe the capacitation and debilitation of certain populations in relation to their members’ race, gender, immigration status, and disabilities, and based on their labor capacities and care needs. Information shared below reflect the results of the reviews I have conducted based on the governmental documents on Medicaid and welfare policies (e.g., NYS Department
Care as a Human Right: The History of Medicaid

“Reception of care is a basic human right”—this is an ideology with which many would agree. Yet, how such an ideology will be actualized—who is responsible for providing care, where the budget for care provision comes from, and who deserves the protection of their right to receive care—often brings disputes. This conflict is evident in the current controversy over the Affordable Care Act, for instance. At a glance, care for “socially vulnerable populations” seems to be promised by the nation. Public health care (including Long Term Services and Supports, LTSS) for blind, disabled, elderly, or pregnant people, and children, for example, are secured to a certain extent. Nonetheless, as we are still in the middle of the implementation of national health care and facing its many pitfalls and criticisms, it is too early to assert that such a right is promised to everyone. Thus, the quality of health care to which one has access is deeply correlated with a person’s class background (e.g., Erevelles, 2011). Additionally, Lynch et al. (2009) demand that not only reception but also provision of care should be a socially supported right (e.g., basic labor protection assured by the Department of Labor). Rights for those who provide care, certainly, have a long way to go, and many continue to advocate for care workers’ or domestic workers’ rights²⁴ (e.g., the National Domestic Workers Alliance, Caring Across Generations).

²⁴At the point when this dissertation is written, labor protection for domestic workers (which includes the majority of home-based care provider population) is not promised under the Department of Labor’s Fair Labor Act.
Medicaid was developed as a way to actualize the right to receive care for those who are considered “socially vulnerable” and was implemented in 1965. As briefly described in chapter 1, Medicaid is a means-tested social health-care program jointly funded by state and federal governments (and county governments in the case of NYS\textsuperscript{25}). Medicaid promises health care, including LTSS, to those with minimal resources and who are blind, disabled, pregnant, or under-age. Today, Medicaid covers over 66 million Americans, more than one in every five people. The health-care budget is the second largest national budget in the United States (and Medicaid occupies the largest fraction of it), as well as the largest budget that flows from the federal to state governments (Jones & Hazel, 2013). Medicaid accounts for 62% ($19 million) of expenditures for all LTSS (National Health Policy Forum, 2012, cited in Paraprofessional Health Institute, 2012c). Furthermore, with the current development of the Affordable Care Act, eligibility for Medicaid expanding dramatically—available to anyone (including nondisabled men) who is low income and low resourced. While Medicaid continues to provide a safety net for some\textsuperscript{26} underprivileged populations with care needs, such provision is not always secure and of quality. In the era of austerity, under the neoliberal regime, the Medicaid budget is constantly under threat of major cut. Fighting for the Medicaid budget, therefore, continues to be the main

\textsuperscript{25} Due to the unequal distribution of Medicaid beneficiaries across NYS, the state manages its own Medicaid funding system, which includes counties as well as the state and federal governments.

\textsuperscript{26} Throughout the dissertation, I continue to assert that merely “some” or “certain” people are covered under Medicaid in order not to overlook people who do not receive such services because they experience difficulty applying to such program, or because the program does not cover general care for non-citizen immigrants (it covers emergency care for undocumented migrants).
target of activism for disability rights communities, as an activism banner of Figure 2 illustrates (ADAPT, n.a.).

![Image of activism banner]

**Figure 2:** “My Medicaid Matters” logo used at ADAPT actions.

**Implication of Neoliberalism in the Care Sector**

The shift to the neoliberal state and its valuing of the free market and individual freedom and responsibility continues to bring about austere social policies and reforms to minimize governmental responsibilities (e.g., Harvey, 2005). Using a concept of *neoliberal ableism*, Goodley, Rawthom, and Runswick-Cole (2014a) theorize the phenomena in which neoliberalism incubates, promotes, and accelerates ableism. The neoliberalization of the public health-care sector, which is characterized by the austere social policy reforms (as explained later in this chapter), is one example of such phenomena. This theorization is, thus, applicable to a wide range of other social injustices, since the neoliberal state and its valuing of the free market intensifies the existing social hierarchy and injustices by disguising the deeply rooted historical injustices and structural inequality under its emphasis on the individualization of responsibility.
According to Harvey (2005), “each individual is held responsible and accountable for his or her own actions and well-being. This principle extends into the realms of welfare … [and] health care” (p. 65, emphasis added). Among the many brutal characteristics of neoliberalism, the one I highlight here is the responsibilization of well-being. Being “not well,” which can be translated as being disabled, sick, or fragile due to impairments, aging, or being a child, is responsibilized onto an individual bodymind or on the family of the “not well” individual. Under this responsibilization of individuals, inequality is expanding between those whose needs and dependencies are naturalized (e.g., affluent people’s dependence on domestic workers or domestic partners [e.g., wives] to take care of their daily chores) and those whose needs and dependencies are seen as a social burden (e.g., lower- or no-income disabled people’s need for LTSS), as well as those who can afford quality care and those who cannot (Harvey, 2005; Polson, 2013).

With its emphasis on individual responsibility, neoliberalism erases decades of work disability rights activists have done to spread the social model—that is, attributing disabled people’s incapacity to participate in society to inaccessible and exclusionary social structures. One of the primary agendas of the disability rights movement has been precisely about lifting the stigma which is attached to individuals’ bodyminds, as their disabilities are seen as biomedical deficits and the sole reasons for their inability to participate in society. The movement challenged the social factors that privilege rational, logical, and autonomous citizens and discriminate against those who do not fit this prototype. Under the movement, disability

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27 Soldatic and Meekosha (2012) describe the disability rights agenda as being appropriated in the neoliberal political economy. Disabled people’s demands to work backfired, as many disabled people are pushed out of social welfare and into often underpaid and un-meaningful labor forces.
communities won civil rights for disabled people in the United States with the Americans with Disabilities Act, which legally promises need-based accommodations. Nevertheless, under neoliberal ideology, disability is, yet again, turned into biomedical deficits that require fixing, cuing, or rehabilitating to maximize the individual’s capacity to function and participate in the labor force. This model gives birth to and fuels medical and other related markets to sell medical operations, medicines, behavioral trainings, and rehabilitation. Also, failure to fix and cure one’s own disability becomes a business opportunity for some to open and regulate institutions such as group homes and prisons, to manage the lives of disabled people or those who are deemed unfit for society.

This neoliberal turn also un-does the work of feminists who fought to liberate women from gendered care responsibilities. Responsibilization of individuals’ care needs has tremendous impacts on families, and in particular women, who are traditionally situated as care providers for their family members. As described in details below, the reform of Medicaid led to re-configuration of eligibility for it and the amounts of LTSS beneficiaries are granted, and it left many former beneficiaries without the LTSS they require. Families of these former recipients (who received the service in the first place because of their low- to no-income status) consequently often have no choice but to fulfill the care needs themselves. A survey by the National Alliance for Caregiving in collaboration with AARP (2009) reveals that almost one third of adult Americans provide some form of long-term care for their family members. And even when people receive LTSS from the state (e.g., Medicare), a study shows that 90 percent of such recipients also receive informal care from their family members, as the care offered by social programs is not enough (Greenber, 2011, cited in Polson, 2013). Consequences of the neoliberal shift induced by the reform include female family members quitting their jobs to be
the full-time care providers for their families, or keeping their jobs and fulfilling care labor needs when they get home as if it is their second shift or hiring care providers (largely lower-income women of color who are often immigrants) who will take care labor with a lower wage (Glenn, 2010). Either way, feminist scholars agree that it is women—and largely lower-income non/immigrant women of color—who are pushed to take the un/paid care responsibilities that are discounted and discontinued by the state. This move toward the individualization of responsibility under the austerity of neoliberalism yet again re-conceptualizes care needs of the recipients as the “burden” of family members and societies.

**Neoliberal Turn in the Public Health-Care Sector: Introduction of Managed Care**

In the middle of neoliberalism’s spread and the care crisis (described in detail in chapter 1), Medicaid underwent a neoliberal turn toward deregulation and privatization. Medicaid traditionally took—and keeps taking, in some states and under some types of care—a form of fee for service, wherein medical practitioners are reimbursed for the medical and other care services they provide for Medicaid beneficiaries. This form of the Medicaid service provision has been critiqued for its difficulty to standardize types and costs of treatment each beneficiary needs and is entitled to. *Managed care* was introduced as an alternative to fee for service, which states have been implementing more frequently for Medicaid in past 15 years, according to the Centers for Medicare and Medicaid Services (n.d. a). Managed care is a care delivery system under which “people get most or all of their Medicaid services from an organization under contract with the state” (The Centers for Medicare & Medicaid Services, n.d. a, emphasis added). This transferring of Medicaid provision and much of its administrative authority to managed care organizations
(or what I call the care industry\(^{28}\) in this dissertation) was actively induced by the state because such a transition was considered to “improve access (to health care) and reduce costs (of Medicaid) by eliminating inappropriate and unnecessary services and relying more heavily on primary care and coordination of care” (Kaiser Family Foundation, 2001). Managed care organizations\(^{29}\) are a mixture of non- and for-profit organizations, which are given major authority to coordinate care for enrollees of Medicaid. Under managed care, the Medicaid budget, which is jointly funded by federal and state (and county, in case of NYS) governments, flows to care industries. Almost half (49\%) of these organizations’ revenues are said to come from the Medicaid fund (U.S. Census Bureau, 2010, cited in Polson, 2013). Such managed care organizations, or the care industry, multiplied in the last few decades and became the norm.

The transition to managed care drastically took over Medicaid across the nation in the 1990s, triggered by the Section 1115 waiver\(^{30}\) the Clinton Administration granted to Tennessee and Oregon in 1993. Section 1115 of the Social Security Act is a waiver that grants states the “flexibility to design and improve their [Medicaid] program” and to carry out “experimental, pilot, or demonstration projects” (The Centers for Medicare & Medicaid Services, n.a. c). The waiver gives states permission to implement managed care, which accelerated the privatization

\(^{28}\) The aggregate economic systems that make their revenues by providing health care.

\(^{29}\) A variety of for-profit and nonprofit organizations are considered to provide managed care. In 2007, 350 health plans offered Medicaid care and 147 of them were Medicaid-focused health plans. All states (except for Alaska and Wyoming) have all or some part of the Medicaid enrollment under managed care organizations (Kaiser Family Foundation, 2013).

\(^{30}\) Though there are three basic types of federal authority programs that allow states to implement managed care program—state plan authority (Section 1932(a)), and waiver programs (Section 1915(a) and (b) and Section 1115)—Section 1115 was commonly used waiver to transfer the majority of authority over Medicaid to states (Medicaid.gov, n.a.).
of Medicaid. The federal government promoted this waiver to the states as advancing “innovative service delivery systems” that were supposed to “improve care, increase efficiency, and reduce costs,” and thus “relieve state fiscal pressure” (The Centers for Medicare & Medicaid Services, n.a. c; Kaiser Family Foundation, 2004). The Section 1115 waiver allows a state government (and eventually the care industries) to “make very broad changes in eligibility, benefits, or cost sharing” of Medicaid “in ways that do not meet federal standards and still receive federal matching funds” (Kaiser Family Foundation, 2004).

This waiver spreads throughout the nation in 1990s, particularly in conjunction with section 1915 which “permits states to enroll Medicaid beneficiaries in mandatory managed care” (Kaiser Family Foundation, 2004, emphasis added). When managed care was initially implemented, enrollment in managed care was voluntary, but with the extended authority to mandate the enrollment, 21 states and D.C. have used the 1915(B) waiver to mandate managed care to many of their Medicaid beneficiaries as of 2001 (Kaiser Family Foundation, 2001).
Figure 3: Growth in the share of Medicaid beneficiaries enrolled in managed care, 1991-2000 (Kaiser Family Foundation, 2001)

Figure 3 (Kaiser Family Foundation, 2001) illustrates, enrollment in managed care increased almost 7 times in a decade—from 2.7 million people in 1991 to 18.8 million in 2000 (Kaiser Family Foundation, 2001). All states but Alaska and Wyoming have had some portion of their Medicaid recipients enrolled under managed care as of 2001 (Kaiser Family Foundation, 2001). Today, almost 50 million people are enrolled under managed care, voluntary or mandatory, while the total number of Medicaid beneficiaries is 66 million (The Centers for Medicare & Medicaid Services, n.d. a).

In terms of care for disabled people, while managed care implementation started with health care for nondisabled beneficiaries, it is rapidly changing, because the cost for disabled and elderly people’s care accounts for up to 65% of Medicaid expenditures (compared with 25 percent of low-income children and adults; Kaiser Family Foundation, 2001). As of 2013, “roughly one in four nonelderly Medicaid enrollees with disabilities are in managed care and
majority of these are in mandatory, capitated plans” (Kaiser Family Foundation, 2001). Also, as of 2014, all but a few states do managed care, and 26 of them have contracts with care industries to deliver LTSS for disabled people (ibid). The number of states that use managed LTSS increased from 8 in 2004 to 16 in 2012 and 26 in 2014; the number is only increasing (The Centers for Medicare & Medicaid Services, n.d. b).

As the aging population increases and the need for LTSS continues to increase, the trend toward managed LTSS is only getting more popular. In other words, the privatization of the public care sector is becoming commonplace today, and it is carried out by “put[ting] billions of public dollars into privately managed long-term care plans” (Bernstein, 2014). The reconstruction of Medicaid by the industry is, however, never without concerns and critique. The Kaiser Family Foundation (2001) states, “Enrollment of elderly and disabled populations into managed care is increasing, but is complicated by difficulties in setting appropriate capitation rates [and] limited plan experience in providing specialized services” (p. 1). The negative impacts of such privatization on those who are involved in the care practices, care recipients and providers, are further investigated in next chapter.

**New York State Medicaid Reform**

It is of compelling public importance that the State conduct a fundamental restructuring of its Medicaid program to achieve measurable improvement in health outcomes, sustainable cost control and a more efficient administrative structure (Governor Cuomo, 2011, cited in New York State Department of Health, 2014c).

Medicaid has long served as a safety net for disabled people who cannot afford necessary long-term and other types of care on their own. While it has shortcomings, this program has played a pivotal role in realizing community and independent living for many disabled people and has
lifted care responsibility from their families. Although a number of social services underwent reforms in the past few decades, public assistance for disabled people is often left alone due to the politically sensitive nature of the topic (Soldatic & Meekosha, 2012). Nonetheless, under the care crisis—with an ever-expanding care recipient population and the associated care costs—Medicaid LTSS came to be examined. In terms of NYS, this examination led to Medicaid LTSS becoming “managed” care and the Medicaid budget being “capped,” as Governor Cuomo announced in 2011.

Some of the very first jobs newly inaugurated NYS Governor Andrew M. Cuomo initiated, in 2011, were within the Medicaid Redesign Team (Cuomo, 2011). Since then, the team has implemented the Medicaid Global Cap to limit the Medicaid budget, which currently makes up 25% of NYS’s public spending and serves 5 million people (one in four New Yorkers; NYS Department of Health, n.d.). It does not make sense, indeed, to limit the Medicaid budget, when the care recipient population continues to grow rapidly. In the last 5 years, NYS Medicaid enrollees increased almost by 25%: from 4,106,785 in 2007 to 5,097,920 in 2012 (NYS Department of Health, 2014a). Following the national trend, NYS implemented managed care to suppress Medicaid costs by “streamlin[ing] the delivery of long-term services to people who are chronically ill or disabled” (NYS Department of Health, 2014b). As of 2014, NYS is still in the process of implementing the mandatory enrolment of Medicaid Managed Long Term Care; however, the implementation of NYC’s home-based LTSS is already completed.

**Rise of the Care Industry**

The neoliberal turn within public LTSS and its privatization are deeply entangled with the care crisis currently experienced by many nations of the Global North. As described in chapter 1, between the rapidly increasing care recipient populations (e.g., aging baby boomers)
and the entry of women into the public labor force, who have traditionally been the unpaid family care providers, care is increasingly outsourced; the care crisis of the United States and other Global North nations accelerated development of transnational care industries under the globalizing capitalism. Care industries have emerged and multiplied in last few decades. Such an industry flourishes across national borders, involving nations of the Global South, which are often perceived as a source of low-wage laborers. In this era’s global economy, the impact of the care crisis experienced in the Global North experiences is far-reaching.

**Development of the Transnational Care Industry**

While the spreading of neoliberalism in the nations of the Global North is described in chapter 1 as having been indulged by these nations’ leaders (e.g., the Reagan administration), neoliberal ideologies are enforced in the Global South via international financial intuitions, such as the International Monetary Fund and the World Bank, in exchange for financial support or debt forgiveness (Glenn, 2010; Harvey, 2005). This enforcement has led to the expansion of international corporations in the business and financial spheres of those nations and converted local people’s means of living—such as agriculture for their own consumption and sale—into mass-scale exportation businesses (e.g., rice fields of many Southeast Asian nations being turned into fields for exportation-purposed flowers, while local people have no choice but to buy imported rice for their own consumption). Without their traditional means of livelihood, “many people have turned to migration to find work in more prosperous areas. Significant portions of migrants, especially women, find jobs in low-wage service sectors in the global north” (Glenn, 2010, p. 153). Indeed, care labor, in the United States, which was once unpaid labor provided by female family members, is handed down to immigrant women who will work for minimum or lower than minimum wage.
The care crisis of the Global North has changed lives of many women (and beyond) in the Global South. Hochschild (2004) introduces a concept of a *chain of care* to illustrate how the care crisis of the Global North has long-lasting, globe impacts. In order to provide care for people in the Global North, for example, Filipina middle-class women who live in urban areas in the Philippines are brought to the United States. In order to fill the care responsibilities these women had for their family members, women from rural regions in the Philippines are brought to the urban areas. Consequently, family members of the migrating rural women have no choice but to look after one another. At the every step of this chain, there is an industry. For instance, the Philippines, which was turned into a major exporting country of nurses and other care providers under the post-colonial agenda, witnessed the multiplication of for-profit educational institutions from which a mass number of nurses graduate and whose main drive is said to be profit rather than quality education to train nurses who can provide quality care (Folbre, 2006). While the quality of education provided by those institutions is continually under critiques, the critics or opponents are silenced and these institutions continue to function (Overland, 2005). Indeed, according to Daly and Standing (2001), care work is the Philippines’ prime exportation business. At the U.S. end of the chain, Congress has been advocating to ease the immigration process for care providers by increasing the number of visas provided and lowering the care provider certification requirements (Folbre, 2006). In 2002, for example, the United States welcomed more than 7,500 nurses with temporary working permissions. Not only nursing but home-based care labor jobs are increasingly taken by im/migrant women. While foreign-born people make up only 15.5% of the entire U.S. population, they occupy 23% of the home-based care provider population nationally, or more than 50% in case of NYC, who are mostly women (one study estimated the number up to 88.7%; Polson, DeFilippis, & Bernhardt, 2011). The immigration of
women as care laborers is induced and endorsed structurally by the care industry and the state. As the state is eager to tighten ever-increasing public care expenses and the care industry extorts more revenues via people’s care needs by lowering care wages, they both benefit from the immigration of care provider and continue to accelerate the immigration process.

**Development of the Domestic Care Industry: Case of NYC**

Similarly to the growth of transnational care industries, rapid growth of the care industry is evident within the United States. With the rise of managed care, and in particular *mandatory* managed care, Medicaid enrollees have no choice but to join care programs organized by the industry. The care industry, in the shape of an “agency,” takes a third-party or broker role by coordinating provision of care; thus, they hire and train care providers, assess the care needs of recipients (based on the Medicaid reports and by their contracted nurses and social workers) and send providers to recipients’ homes according to the assessed needs. Seavey (2011) reports that while only 7 percent of Medicaid certified home care agencies were for-profit in 1980, this number had increased to 70% in 2007. As of 2012, almost 80% of general home health agencies were for-profit (Harris-Kojetin, Sengupta, Park-Lee, & Valerde, 2013). Thus, home-based care provision is the fastest growing occupations in the United States. The U.S. Department of Labor (2013) predicts that such an occupation is expected to grow by nearly 50% between 2012 and 2022.

**Commodification of Care Needs**

One of the consequences of this transition to managed long-term care has been the reformation of Medicaid LTSS eligibility. As the administrative authority over Medicaid LTSS is transferred to the care industry from state governments, LTSS is no longer a public health-care program but a profitable opportunity for care industries. To suppress care expenses and increase
revenues for the care industry, therefore, a drastic revision of LTSS, including its eligibility, is in
order. For example, *The New York Times* reports a case of Mr. McClanahan who has become
blind as he ages. With the onset of blindness, he became a beneficiary of Medicaid LTSS, under
which he has received a few hours of care every day from paid care providers for last few years
(Bernstein, 2014). As he continued to age, he developed dementia and other health issues, and
therefore he came to require more hours of daily care. When his family applied for more hours of
home care or to enroll him in a nursing home under the new managed long-term care plan, his
application was denied. Not only were the additional hours of care or entry to a nursing home
denied, but his LTSS was cut all together—including what he was already receiving. Under the
reformed Medicaid, he is considered no longer eligible for LTSS. Mr. McCanahan who needed
LTSS more than ever, fell off of his bed on his face the morning after his LTSS was terminated,
and he was left with a huge scar across his face. After much confrontation by his family, the
agency that manages Mr. McCanahan’s LTSS suggested that as an alternative his LTSS could be
continued but with only half of the original funding. This means that the only way for him to
continue his LTSS is by either relying more on his family members for unpaid care or hiring
providers who will take care labor with lower wages. As elaborated below, this is one place
where care recipients’ and providers’ paths cross, as the well-being of both becomes secondary
to the care industry, whose focus is on maximization of revenue and minimization of
expenditures. Under such circumstances, the only way for disabled people to receive care at their
home is by participating in the exploitation of providers. And even if disabled people find
providers who will take care labor with a lower wage, the providers are more likely to be over-
working to earn a minimum living wage, and the quality of care the recipients receive may be
low.
Under the Medicaid reform and reconfiguration of Medicaid LTSS eligibility, disabled people who require public LTSS were re-examined, re-valued, and re-divided. This reform, therefore, symbolizes how bodies came to be reorganized based on their capacities to strive in the free market and contribute to the labor force, or, when unable to do so, the commodification of their need for LTSS for the industry to receive funds from the state (e.g., the Medicaid premium). This reconfiguration capacitated some disabled people while debilitating others, in order to make disabled bodies and their needs profitable. Many are capacitated, as they are newly labeled “work-able” and pushed into the labor force and out of Medicaid protection. Under the reconfigured eligibility, they are considered to be not disabled enough to be eligible for Medicaid services. In the labor force, overwhelming numbers of disabled people are pushed into more casual, short-term jobs that rarely provide benefits, justifiable wages, or meaningful tasks: this kind of labor force resembles early asylum factories where disabled people’s labor was exploited (Soldatic & Meekosha, 2012). The advocacy of the disability rights movement for the right to work has been co-opted, as their activism mantra used to put disabled people into an undesirable labor force and eliminate them from the Medicaid realm. Thus, as they are no longer on Medicaid, it is extremely difficult to return to it. Therefore, now they have no choice but to stick to these underpaying and often un-meaningful jobs in order to collect income and rarely provided benefits.

Those who are incapable of entering such a labor force are further divided based on the amount and kind of care needs they embody, as well as the associated care costs. Those who are disabled enough to receive Medicaid LTSS but who are not “too disabled” and do not require extensive care are kept in their own homes to receive care from paid providers, as this is a cheaper option than institutionalization. Home and community care is generally 3 times cheaper.
than the institutional care (Bernstein, 2014). Yet those who are considered to be “too disabled,” and whose care is more costly due to its extensive hours and medical care requirements, are debilitated and put into institutions such as nursing homes because it is cheaper to provide extensive medical care en masse (Bernstein, 2014). Bernstein (2014) describes the careful calculation—debilitation and capacitation—of disabled people’s needs and capacities as constituting how care agencies make a profit. Disabled people’s care needs become tokens with which to receive funding from the governments. The disabled care recipient population, which was once treated more as a homogeneous group, is re-examined and further divided based on each individual’s capacity to contribute to the labor force and on the cost of care they requires. Fritch (2013) and others note that the re-creation of hierarchy within the disability community, as its members are capacitated or debilitated, reinforces the idea that some are more worthy of disability social services than others.

**Welfare Reform and the Commodification of Labor Power**

Home health care as a social welfare service developed as part of the New Deal legislation to place unemployed African American domestic workers with low-income families whose mothers were incapacitated in some way. Originally, domestic workers were directly employed by welfare departments … [and] Post-World War II, the need for home health care grew … the 1962 Public Welfare Amendments, the Older Americans Act and Medicare/Medicaid were the public policies that “established a foundation for a social services labor market within the welfare state” (Boris & Klein, 2006, cited in Polson, 2013, p. 133)

Neoliberal discourses of care are increasingly used as a technology of control, to both reify normative constructions of the heterosexual middle-class family and to morally,
socially and culturally regulate poor people with care responsibilities, for themselves and others, under workfare structures and programmes (Soldatic & Meekosha, 2012, p. 57)

The reconfiguration of disabled beneficiaries of Medicaid makes it clear that it is not anyone with care needs who is protected by Medicaid and promised such social services. The right to receive care seems more and more precarious in the era of austerity. This “right” is increasingly pushed to be individual and household responsibility to fulfill—dragging women back to the familiar role as the family care providers. Under neoliberalism, where individuals’ entry to the free market is encouraged (or enforced) and people are valued based on their capacities, it is no longer any women who are pushed to take care responsibilities. While women, in general, enter the labor force, it is women from lower-income—and largely non/immigrant women of color—who enter the care labor force. Care responsibilities that once belonged to the public are now converted into a profitable opportunity for the care industry. Care is once again low-wage labor, overwhelmingly undervalued, and reserved for a specific set of women. Census reports from 2000 demonstrate that those who occupy paid personal- and home- care aide jobs are almost all women (91.8%), among whom more than half are of color (52%—weather foreign-born or U.S. born; Paraprofessional Health Institute, 2012d; Polson, DeFilippis, & Bernhardt, 2011). Immigrant people disproportionately occupy the statistics, 24.9%, compared with the fact that only 15.5% of the entire U.S. population are foreign-born (Glenn, 2010, p. 179). Fifth-six percent of providers rely on public assistance such as Medicaid or food stamp in their households; nearly 70% of employer agencies do not provide health insurance; and nearly 37% of care providers are without insurance (Paraprofessional Health Institute, 2014a; 2012b). Fifty-eight percent of them have no postsecondary or little high school education, and those older than 55 are in the fastest-growing care provider age group (Paraprofessional Health Institute,
Twenty-five percent of care providers are from households living in the 100% of the federal poverty level, and 56% of them live in the 200% of federal poverty level (Paraprofessional Health Institute, 2014a). These numbers show that low- and minimum-wage care labor has been reserved for women of lower classes. Partially, this statistic is due to the engraved stereotypes that women, particularly of racial minority, are suited to be care providers (Mohanty, 2003). And it is also socio-politically enforced. As described above, global economic inequality pushes women from the Global South to take care labor in nations of the Global North. Furthermore, historical reforms of welfare programs for lower-income single mothers in the United States also reserved care labor specifically for lower-income single mothers of color.

In her book, *Forced to Care*, Glenn (2010) adds racial and immigration status-based analyses to studies of care, and one way of doing so is by tracing the history of welfare reforms. Many traditional and mainstream care studies homogenized women by documenting that one of the major factors triggering the care crisis was the increasing entry of women (who used to be their families’ care providers) into the public labor force. What was often under-documented (which is fortunately more documented nowadays) is that it is women of the lower-class—who are disproportionately women of color and immigrant women—who have been always pushed to care labor and who continue to take on abandoned care responsibilities. Glenn (2010) uncovers often unsaid assumptions around care: “[Family] care labor is [considered to be] only properly carried out when it occurs within a self-sufficient male-headed household and … poor women’s and women of color’s unpaid caring for their families has little value and does not deserve public support” (p. 162). Further, tracing the history of welfare, Glenn (2010) questions who was socially supported to stay at their home to care for their children and who was forced to work outside of the home, including tending others’ children, as well as on whose shoulders low-wage
care labor lands. Since the earliest form of public supports for single mothers, “Mothers’ Pensions”—first implemented in Chicago in 1911—there has been a tendency to exclude African American and Mexican American single mothers from receiving its benefits, with the reasoning that there were jobs available to these populations (such as domestic work and field work, which are often reserved for women of color), and therefore they did not need public assistance. A common tendency in welfare programs—the requirement for beneficiary mothers to enter the labor force and the exclusion of lower-income single mothers of color—is said to have been inherited by other major welfare programs such as Aid to Families with Dependent Children and Temporary Assistance for Needy Families (TANF). Gordon (1994) also adds to the racial analysis of welfare programs by describing how the fact that majority of welfare recipients are white people is obscured, and welfare came to be stigmatized as a tool for and associated with specifically African American single mothers to avoid working. Thus, welfare came to be an indicator of individuals’ moral failures used to characterize African American single mothers (Gordon, 1994). The emergence of TANF in 1996, which limited the welfare recipient period to 5 year maximum, highlights the transition of welfare to workfare (Soldatic & Meekosha, 2012), as its recipients were strongly encouraged, or forced, to enter the work force. The introduction of TANF and the cap for the welfare recipient period dropped the number of welfare recipients by 6.5 million, more than 53%, in the first 4 years after the TANF was implemented (Glenn, 2010). This statistic is not necessarily an indicator of TANF’s success in supporting the independence of mothers—it more accurately describes how the state came to cease supports for certain women and removed their rights to receive social supports to care for their families. Among those who were dropped from the TANF include the “disconnected,” who were unemployed, without welfare, and had no choice but to depend on their family members if they had any. Also, in the
first few years after TANF’s implementation, 60% of its former beneficiaries gained employment—employment which led them to constant poverty. Jobs that were available to those former welfare recipients paid low to minimum wage (Glenn, 2010). A study shows that though these women formerly receiving welfare worked 35 hours in an average week, their income average was two thirds of the federal poverty line at the time (Glenn, 2010). This data suggests that the introduction of cap for the welfare reception period created a large pool of lower-income single mothers who had no choice but to work any job available, including low-wage care jobs.

What is unsettling here is the fact that TANF was implemented only 3 years after Medicaid took the neoliberal turn that opened door to managed care. The neoliberal turn, or austerity reform, of Medicaid caused a rapid increase of the for-profit care industry. Consequently, there was an increase of care labor jobs, particularly low-wage care labor so that the industry could maximize its profits.

Corresponding to The New York Times coverage of Mr. McCanahan laid out above, Medicaid reforms inevitably alter providers’ work environments as well. The opposite side of the service cut Mr. McCanahan experienced is the lowering of care labor wages for providers. This unjust compensation, for example, is highlighted in the restructuring of the “live-in” program under Medicaid long-term care—under which disabled people receive around-the-clock care in their own homes. This arrangement means that providers are expected to live-in their care recipients’ homes. Alisha, one of provider participants of this study, told me that

they (agencies) used to have 12 hours and 12 hours [shifts], and break it into half to two people (each care provider takes one 12-hour shift). But then, [the Medicaid] cut course. … They’ve cut a lot of hours, so they [agencies] started having the live-in. … I used to come in Friday morning and I’d leave Monday morning. And the person that comes in
Monday morning, she would leave Friday morning. That means you are not [at your own] home all the time [when you are doing live-in work]. You gotta bring your own food, you gotta bring clothes, you gotta carry the travel bag that pulls, put all your belongings, all your personal whatever … You only get paid for 12 hours, but you’re there for 24 [hours]. Even though it kinda, provides the care for the client, but [as] far as aide, it cheats them. Because somebody is there 24 hours, but you only gonna pay for 12 … [I used to get] paid 120 dollars a day [for working 24 hours].

Continuing to share her critique on the live-in program, Alisha said, “I think that’s kind of … slavery. I don’t wanna use the term, but that’s kinda like [slavery]. Someone is working extra amount of hours, and they are not getting paid. I think that’s a big rip off.”

It is not only disabled people who are capacitated and debilitated for their profitable care needs. Through the welfare structure, global capitalism, and cultural ideologies, certain women are capacitated for their labor power. As Alisha’s quote clearly depicts, she was pushed to work double shifts for half the money. As much as she is aware of the unequal nature of the care work, as will be described in next chapter, her status as a single mother with a high school education keeps her going back to the care work.

Care work, after all, does not fall on all women’s shoulders—it is distinctly framed within lines of race, class, and immigration status and relies on the capacitation of these bodies. Economically, enlarging the care industry excels the migration of women from the Global South to take care labor in the Global North. Politically, welfare reforms, represented by TANF in this case, created care work particularly for lower-class women who were former welfare recipients (and who are disproportionately women of color).

Conclusion
The 1990s witnessed two major neoliberal turns or insertion of austerity reforms, to Medicaid and welfare; both uncannily fulfill the goals of the rising care industry. Medicaid reforms revised beneficiary eligibility to solidify Medicaid expenses, and welfare reforms enabled the industry to save its budget by creating a large pool of lower- (or no-) income single mothers who are required (or forced) to take any job available to them, including low-wage care work. A non-profit agency in Bronx, the Cooperative Home Care Associates (which takes many Medicaid LTSS cases) symbolizes this eerie “coincidence.” One of the selling points of Cooperative Home Care Associates is to connect those who needs LTSS and “women wanting to leave welfare” through care work the association organizes and manages (Glenn, 2010, p. 175).

Under the neoliberal regime, care—which was once considered a human right and supported by the state—is under a huge transition. Despite decades of work by disability rights activists and feminists to turn care responsibility into a social responsibility, care giving and receiving are once again framed as individual and family responsibilities. The neoliberal turn in Medicaid—which was initiated by approval of the Section 1115 waiver in 1993—opened the public sector of care to the for-profit care industry. Against the backdrop of an on-going care crisis, the reform of Medicaid was immediately followed by a neoliberal turn in welfare, TANF, which eventually created a large labor force for Medicaid care provision. Thus, these political shifts triggered the further deployment of a mostly female immigrant population from the Global South into the abundant care responsibilities of the Global North. These political and economic forces re-shape a concept of care and widen the gap between those who are legitimated to receive publicly funded care and those who are pushed out of the service or pushed back into institutions. Also strongly enforced was on whose shoulders the care responsibility fell. Neoliberal reforms of these social programs capacitated some bodies (lower-income women of
color who are often migrants) for their labor power and debilitated some other bodies (lower-class disabled people) for their socially legitimated care needs. The commodification of care resulted in the commodification of labor power and care needs, thus creating categories of exploitable provider and profitable recipient—all in order to maximize the care industry’s profits and suppress the state’s expenditures on social services. Thus, such a mechanism of profit-making deeply relies on factors such as race, disability, gender, and immigration status.

This chapter started with quotes by Puar and Harvey, both of which highlight the new ways in which individuals and their bodies are measured and valued. Under the same logic of neoliberalism, the current U.S. public health-care assemblage is constructed. Parts of the larger whole indeed coexist with “mutual dependency with friction and violence between parts” (Bannet, 2013, p. 23). Bodies, capacities, and the needs of care provider and recipient populations are re-evaluated and positioned strategically to create flows of capacities, needs, and most importantly funding between governments and industry. As much as this chapter began with the molar development of the assemblage, the following chapters further examine what the assemblage does to these care provider and recipient populations, as well as how these molecular elements of the assemblage (providers and recipients) develop their own relationality and what this relationality does to the larger assemblage.
Chapter 5

Necropolitics of Neoliberal Public Health Care: Creation of Consumable and Disposable Populations

Abstract

In this chapter, I examine how the public health-care system under the neoliberal regime shapes the realities of those who are involved in care practices: care recipients and providers. Tracing narratives collected from Medicaid care recipients and providers illustrates how they enter the public health-care sector, how they are treated in the sector, and the consequences of their involvement in the sector. Using theories of slow death and necropolitics, I describe the ways in which under the neoliberal public health-care assemblage these people are exploited and consumed based on their labor capacities and care needs. The consequence of such consumption is their psychological and physical deterioration: slow death. Not only they are exploited, the abundance of people who require public long-term care and who take low-wage care labor turns them into disposable populations. I argue that as a result of neoliberalism, public health care is not biopolitical but necropolitical.

The right to give and to receive care is underpinned by a right not to be obliged to provide care…. This is not a plea for social irresponsibility; it is an assertion that care is precious, and therefore suffers if it is treated as something close to forced labour (Daly & Standing, 2001).

Introduction

On the most general level, we suggest that caring be viewed as a species activity that includes everything that we do to maintain, continue, and repair our “world” so that we can live in it as well as possible. That world includes our bodies, our selves, and our environment, all of which we seek to interweave in a complex, life-sustaining web (Fisher & Tronto, cited in Tronto, 1993, p. 103).

Care is, in short, a practice to keep its recipient—whether human, animal, or environmental—not only surviving, but striving. However, care is also a precarious concept and practice. Feminist
scholars repeatedly bring up how such a practice, or at times duty or forced labor, is distributed unequally across gender lines in addition to race, class, and immigration statuses (Daly, 2001; Dodson & Luttrell, 2011; Ehrenreich & Hochschild, 2004; Erevelles, 2011; Folbre, 2006; Glenn, 2010; Kittay, 2001; Lynch, et al., 2009; Tronto, 1993). Additionally, disability studies scholars articulate how the practice of care is used to confine care recipients’ lives, instead of assisting them to live the lives they desire (Morris, 2004; Power & Oschild, n.d.; Shakespeare, 2000a; Watson et al., 2004).

Building on the previous chapter, which traces the development of the assemblage, in this chapter, I investigate what the neoliberal public health-care assemblage does, based on the perspectives of care providers and recipients. I engage with the second and third research questions of this dissertation:

- In what ways are the existing social injustices further deployed under the neoliberalization of public health care (e.g., sexism, racism, classism, ableism, sanism, and xenophobia, that are inherent to care labors and practices)?

- What are the psychological and physical effects of the neoliberalization of public health care on those who are involved in it—particularly disabled people who receive their long-term care through New York State (NYS) Medicaid and their care providers?

As a way to respond to the above questions with the narratives of disabled care recipients and care providers for disabled people, I theorize that the neoliberal assemblage converts a care practice into a necropolitical one, as both care providers and recipients are turned into consumable and disposable populations: subjects of slow death. In the assemblage, I argue, the meaning or function of care is shifted from mutual restoration to a commodified, profit-making tool for the industry (which is directly connected to saving state expenditures on health care)
where care practice, care labor capacities, and convincing care needs (that therefore arose social responsibility) become the property of the assemblage. They are all circulated among its elements, often in exchange with funding. With the shift in meaning of care, priority within care practice has shifted as well, to profit making, where the well-being of care providers and recipients becomes secondary. These people (disabled care recipients and lower-income female care providers), who were already marginalized in society, are now consumed by the care industry and disposed of, as the populations who require long-term care and those who would take up the care labor are considered to be excessing. A consequence of being turned into consumable and disposable populations is slow death\textsuperscript{31} (Berlant, 2006). I argue that the care arrangements within the neoliberal public health-care assemblage are a matter of not only biopolitical labor, as described by Hardt and Negri (2004), but also necropolitical (Mbembe, 2003).

**Necropolitics and Slow Death**

Mbembe (2003) describes necropolitics and necropower as “the power and the capacity to dictate who may live and who must die. Hence, to kill or to allow to live constitutes the limits of sovereignty, its fundamental attitudes” (pp. 11-12, emphasis added). Thus necropolitics and power are “contemporary forms of subjugation of life to the power of death” (p. 39). Bringing up cases of slavery and colonization, he describes the transformation of ways in which power is exercised on people, particularly regarding the relationship between sovereignty and death. He highlights how minority bodies are not only marginalized, but also consumed:

\textsuperscript{31} Though the question of slow death or fast death are brought up, I am using “slow death” here, instead of “fast death.” My intention is to differentiate the deteriorating care these disabled people receive from mercy killing. To me, mercy killing is fast death and the low quality care many participants receive is slow death.
As an instrument of labor, the slave has a price. As a property, he or she has a value. His or her labor is needed and used. The slave is therefore kept alive but in a state of injury …, treated as if he or she no longer existed except as a mere tool and instrument of production…. If power still depends on tight control over bodies (or on concentrating them in camps), the new technologies of destruction are less concerned with inscribing bodies within disciplinary apparatuses as inscribing them, when the time comes, within the order of the maximal economy now represented by the “massacre” (ppp. 21-22-34).

Though the case in this dissertation is not directly about slavery or colonization (though the word slavery was used by one research participant to describe the conditions of care work) and focuses primarily on the U.S. contemporary neoliberal context, Mbembe's analysis is helpful in understanding the circumstances of people who are situated as care providers and recipients in the neoliberal public health-care assemblage. In Particular, I combine Mbembe’s necropolitical analysis with a concept of slow death, introduced by Berlant (2006), to further enhance the necropolitical argument in this chapter. According to Berlant (2006), slow death is the “physical wearing out of a population and the deterioration of people in that population that is very nearly a defining condition of their experience and historical existence…. the phenomenon of mass physical attenuation under global/national regimes of capital structure and subordination and governmentality” (p. 754). In contrast to the “sovereignty” Mbembe engages with, Berlant (2007) points out the limitations of the ways in which sovereignty can be applied to today’s society and instead emphasizes that “experience is simultaneously at an extreme and in a zone of

32 Though, this study is not directly about the slavery or colonization that Mbembe uses as cases, the current care labor structure is deeply endorsed by the post colonialism of Global South nations as well as long legacy of slavery and its racial division of labor.
ordinariness, where life building and the attrition of human life are indistinguishable” (p. 755, emphasis added). In the following sections, these concepts are applied and further expanded to describe experiences of disabled people and their care providers under Medicaid.

Materialist-based Marginalization

In this neoliberal era, the marginalization of certain populations is deeply marked by their capacity to contribute to capitalism (Erevelles, 2011; Goodley, 2014). In the neoliberal era, people are measured “in relation to their success or failure in terms of health, wealth, progressive productivity, upward mobility, enhanced capacity” (Puar, 2012, p. 155). The prototype of a person desired in such society, and who flourishes in it, is the “embodied neoliberal citizen” who is disciplined to strive in the free market by taking responsibility for their needs (Goodley, 2014). Under such a measurement, for example, even the construction of a mental health evaluation manual (DSM 5) is deeply influenced by and based on the prototype of the neoliberal subject, which consequently pathologizes those who do not fit into it (Goodley, 2014). In Berlant’s word, “sickness is defined as the inability to work” (2007, p. 754). The Social Security Administration defines disability based on a person’s “inability to work” (Social Security, n.d.). Such economic and materialist measurement is, certainly, entangled with social injustices (e.g., racism, sexism), as these injustices shape social stereotypes as well as the opportunities one is granted.33 In this evaluation of people in contrast to the prototype of “neoliberal citizen,” lower-income women of color with a minimal education background—who are also largely former welfare recipients or immigrants from nations of the Global South—are capacitated for their labor power, while

33 As described elsewhere (e.g., Mohanty, 2003), occupational segregation is heavily constructed with gender, race, class, ethnicity, age, and ability-based ideologies, limiting many minority people from occupying highly valued (and thus well-paid) jobs.
paradoxically their labor is devalued and forced into the public health-care work, which is undervalued and low-waged. Similarly, when disability is defined based on one’s “inability to work” (Social Security Administration, n.d., emphasis added), some disabled people are capacitated to enter the often undesirable and underpaid labor force and no longer receive social services (since they are not disabled anymore). Others who are legitimately disabled (incapable of working) and living with lower- (or no-) income are, therefore, further marginalized within the materialist and capacity-based evaluation of people and put under the state’s management, through the system of social services including social security and Medicaid. In the neoliberal era, therefore, even those who are deemed to have an “inability to work” are put to use.

Disposable and Consumable Populations

The rise of the care crisis and neoliberalism turned public health care into an incubator for the health-care industry. Borrowing Mbembe’s words, lower-income women are turned into an instrument of care labor: “[H]er labor is needed and used.” And therefore these women are “kept alive but in a state of injury” and treated as if they “no longer existed except as a mere tool and instrument of production” (pp. 21–22). While the narrative laid out below further describes it, in the neoliberal public health-care assemblage, mostly female care providers are needed strictly for their labor capacities, and particularly because they take care labor regardless of its lower wages and undervalued status. Thus, such women who desperately need employment are excessing, particularly in the context of global labor trafficking. In the assemblage, these excess women are not only turned into a “disposable” population (Giroux, 2004), they are “consumable” for the labor market.

This commodification of care and its deteriorating consequences on care providers have been partially acknowledged in the academic sphere. At the turn of the century, in the middle of
globalization and neoliberal transitions, scholars Hardt and Negri (2000; 2004) described the transformation of industry from material to immaterial labor, which produces products such as “ideas, images, affects, and relationships” (2004, p. xvi). In their book, they pay close attention to the development of the affective labor industry, such as the entertainment and care industries, defining affective labor as “labor that produces or manipulates affects such as a feeling of ease, well-being, satisfaction, excitement, or passion” (p. 108). For example, care providers are trained specifically to provide an affect of safety and satisfaction to their care recipients (Ducey, 2007). In this line of theorizing, Hardt and Negri (2004) further elaborate affective labor as biopolitical labor “that creates not only material goods but also relationships and ultimately social life itself” (p. 110). Thus, care providers’ domestic labor “involves producing affects, relationships, and forms of communication…. Biopolitical production directly produces social relationships and forms of life” (p. 110). In other words, care providers are expected to provide and shape the lives of their care recipients.

Hardt and Negri (2004) use the concept of biopolitical labor in their book primarily to emphasize the type of products this labor is expected to manufacture: affect. Nonetheless, here I am expanding the notion of biopolitical labor with further emphasis on Foucault’s (1990) conceptualization of biopower: “a power to foster life or disallow it to the point of death” (p. 138). This definition suggests that, when care providers are expected to provide and shape lives for their disabled care recipients, they are not merely shaping lives of recipients but also disciplining their lives: in disability studies’ words, confining a life and ignoring the right to self-determination. In addition, I argue that biopolitical labor, in the case of care labor particularly, can be described as the labor through which care recipients are made to live at the expense of their care providers’ deterioration. This point is implied in the writing of Hardt and Negri (2004)
as well, as the well-being or agency of the biopolitical labor producer (in this case, care
providers) is overshadowed by the continual emphasis that biopolitical labor places on about
recipients of such labor (care recipients, in this case). Berlant’s interpretation of biopower
highlights this point: “The power to *make* something live or let it die, the power to regularize
life, the authority to *force* living not just to happen but to endure and appear in particular ways”
(2010, p. 756, emphasis original). Biopolitical labor, therefore, not only produces affective, life-
making effects, but also determines whose lives are made alive and whose are left out. This
echoes feminist care studies' sentiment regarding how female care providers' lives are sacrificed
for their care recipients (e.g., Abbott, 1994). I would expand such a sentiment further, though, by
arguing that these care providers' labor is sacrificed not for their care recipient, but for the care
industry; thus, such sacrifices are caused by the lack of social supports from the state.

Also, as the premise of this dissertation is to take *both* care providers’ *and* recipients'
accounts to understand the public health-care assemblage, I build the argument of biopolitical
labor further by adding the accounts of disabled care recipients. It is not only these female care
providers whose labor is commodified and exploited. Disabled care recipients of public health
care are also commodified and exploited via a different route. Once disabled people are doomed
as nonworkable or incapable of contributing through their labor capacity, they are consumed—
their needs are put to use, instead of their labor capacity—by capitalism through the disability
service sector, medical institutions, and the prison industry, as these industries require disabled,
sick, and mad bodies in order to accumulate revenue. In terms of the public health-care sector,
what the assemblage needs is disabled people's legitimated care needs that arose sense of social
responsibility from public (which pressures the state to support such needs) to create a flow of
Medicaid funding from the state to the industry. And as the number of people who legitimately
need such social services is skyrocketing against the backdrop of an increasing aging population and shrinking social services, the population is considered to be excessive and becomes consumable and disposable.

Not only is care providers' well-being disregarded, but so is disabled care recipients’. This notion of disregard for the well-being of both demands the expansion of the concept of biopolitical labor as described above. In the context of the neoliberal public health-care assemblage, disabled care recipients are not cared to be made live. Instead, both care provider populations and disabled care recipient populations are consumed and disposed. Returning to the earlier description of necropolitics and slow death, I argue that the current neoliberal public health-care assemblage is the embodiment not of biopolitical labor but, rather, of necropolitical labor. As both care providers and recipients are turned into consumable and disposable populations, they are converted into subjects of slow death. What follows are narratives from focus groups and individual interviews, organized to further illustrate this point. These data serve to strengthen the thesis of this chapter:

- The neoliberal public health-care assemblage is necropolitical.
- Lower-income and racialized women—many of whom are immigrants or former beneficiaries of welfare—as well as lower- (or no-) income disabled people who require LTSS are turned into excess populations, prepared for consumption and disposal, and thus become subjects of slow death.

**Narratives**

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34 All quotes from interviews are cited as they are. This means that these quotes may include grammatical mistakes and be in more conversational English.
The following narratives were gathered through focus groups and individual interviews with disabled people who receive LTSS from NYS Medicaid and those who work as care providers for disabled people under LTSS Medicaid. Methods of data collection as well as data analysis are described in chapter 3. In the following pages, I lay out care provider narratives first and care recipient narratives second. Each narrative is organized as follows: (1) The participant’s participation into the neoliberal public health-care assemblage (care labor force, for care providers, and Medicaid LTSS, for care recipients), (2) their descriptions of the assemblage, and (3) the consequences of being part of the assemblage.

**Narratives of Care Providers**

**Participation in care labor**

The entrance to paid care labor is paved by enforced gendered and racialized occupational divisions (Erevelles, 2011; Folbre, 2006; Glenn, 2010; Tronto, 1993). In other words, most of the care provider participants entered care labor because they had previous experience in care work as unpaid care providers for their family members. Alisha\(^{35}\) (care provider), for example, explains, “I had a grandmother who was invalid, and she couldn’t do anything…. I was living with her, so I had to kind of tip in and help.” Tia (provider) echoes this narrative: “When I was younger, before I came to this country, I take care of my aunt…. I used to bathe her, I used to clean and do everything for her. When I come here (U.S.), I say, ‘You know, maybe I could do it [care work]. Try and do it.’” In addition to care workers’ previous experience, care work is the fastest-growing occupation in New York City (NYC) and rarely poses any eligibility criteria (Polson, 2013; U.S. Department of Labor, 2013a). Alisha explains,

\(^{35}\)Pseudonyms are used throughout the dissertation to maintain participant confidentiality.
“[Care labor] is still a big demand… When I took the class [provider training session at an agency], I didn’t have any skills. And I never attended a college, so it [care work’s lack of educational requirements] was the easiest way for me to find a job.” She continues, “You have to do what you have to do sometime…. I was single parent. I had children to provide for. I have people depend on me, so I didn’t have a choice.” In other words, abundant demand for care providers and the low requirements posited on care work matched these women’s limited educational background and U.S. work experience and their simultaneous desperate need for jobs to feed their families. This peculiar match is not a coincidence but the effect of the genderization of occupations and how care labor recruitment is carefully crafted to attract female workers despite its lower-wage status (e.g., Mohanty, 2003). This point is further discussed in the conclusion of this chapter.

**Characteristics of care labor under the assemblage**

Care labor under neoliberal Medicaid LTSS is described by these care provider participants as (1) low wage, (2) labor which takes extended hours, and (3) unnecessarily intensified due to care agency negligence. All the provider participants disclosed that they work 12 hours a day at least, because public health-care work is often a low-wage job. Extended work hours are common for them as they need to collect a decent income from their hourly wage in order to make a living in NYC. Sofia testifies, “12 hours [a day], 4 days a week [for the weekdays]. In the other case [weekends], it’s 8 hours [a day].” Tia describes,

We do a lot of 12 hours [shifts]. It’s not enough money. If you don’t [work long hours], if you work for like 9 dollars or 8 dollars an hour, you’re not making a lot of money. I can’t [even pay rent]. You’ve gotta do 12 hours to bring the money home, to pay your bills.
And these extended work are not adjusted during holidays—“I used to work holidays…. I’ll be with them [recipient and their family] … away from my kids and family”—or extreme weather situations—“We come in the snowstorm, all kinds of stuff. If there’s a storm, you get stuck; nobody is coming to relieve you. They [agencies] don’t wanna compensate for that…. It’s a lot” (Alisha). Sofia explains how she does not anticipate the long hours of working ending in the near future: “I [will] finish [doing this care labor in] 12 years … because they [Social Security] told me 65…. That’s [when] Social Security told me [I can retire and receive a pension].”

All the research participants, regardless of their role as recipient or provider, articulated that the low wages—and thus extended work hours—are caused by agencies and care industries. Isabella (provider) describes, “We just get the little scam…. We do a lot, but we don’t get paid. Doing home care is very hard and less money.” Indeed, according to Bernhardt, McGrath, and DeFilippis (2007), care agencies take 50 percent or more of the public funding they receive from Medicaid for administrative and overhead expenses; hence, those who conduct the actual care labor often receive low to minimum wage.36 A care recipient, Ty, describes that the information on the funding allocated to the LTSS he receives as well as the break-down of how it is used is available for care recipients on the NYS Department of Health website:

Agency gets around 25 or 27 dollars an hour for a person that supposed to be caring for.

And they pay the workers 7.50 an hour or 8 dollars an hour…. They get about 17, 18 dollars out of a person that doing the work or that they hire to do the work gets the lowest wage. So it was like they [care providers] work 12 hours a shift, 7.50 an hour. It’s

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36 Thus, domestic workers, including Medicaid care providers are not protected under the Fair Labor Standards Act (e.g., lack of overtime pay or sick leave) at the time of writing. Although NYS passed a Domestic Workers’ Bill of Rights to promise labor protection for this population, participants of this study tell another story.
probably a little bit over 100 dollars they are making for the day. And agency gets another 200 dollars. So they get twice as much as the workers get for not doing anything.

With the neoliberalization of public health care and the introduction of managed care (which requires its beneficiaries to have contracts with the industry in order to receive care), the majority of its funding goes to the care industry—often 200% of what providers receive—before it reaches the providers. Hence, care providers are left no choice but to extend their working hours.

The injustice of low wages becomes even more obvious when one takes into consideration what care work entails. In-home care providers provide a wide range of care. The trainings they receive at their agencies include physical, medical, physical therapeutic, emotional, and cognitive care. Tia describes her responsibilities as follows: “I’ve gotta do everything for her…. You need to do everything [including cognitive work such as remembering things for them], cause sometimes, they find remembering, [sometimes] they are not” (emphasis original). Also, besides the physical, medical, and cognitive labor, emotional care labor occupies the major part of care work. Sophia elaborates, “In this job you have to love the person [recipient]. You have to love this job. [If you] don’t feel the kind of love to help people, [then it] is better don’t come to this job.” This emotional bond often expands these workers’ sense of responsibility and urges them to compensate for the shortcomings of care agencies. They are the ones who directly work with their clients and often the only ones who are there for them on a daily basis. This can mean that, for some providers, their clients’ emergencies become their personal responsibility. Sophia shares a story of unpaid overtime work, for example:

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37 This information is brought up repeatedly by both care recipients and providers. Ty, a disabled care recipient, explains to me that he acquired the information because Medicaid long-term care recipients can download their individual funding allocation breakdown from the NYS Department of Health website.
When [it’s] 8 o’clock finish [time to leave for me] and the client, the last moment, move the bowel … What do you do in the moment? To leave the client, poop [all] over … and you leave the client like that because it’s time to go?… I can’t do it. I take off my coat, it’s time to work. When I finish, maybe 30 minutes after or 45, I feel happy. “Okay, she’s clean all night.” [Do I get paid for the overtime labor?] No, no.

Care work in general is intense and takes a lot of physical, emotional, and cognitive energy (Ehrenreich & Hochschild, 2006; Lynch, et al., 2009). Thus, the intensity can be added to or complicated by care recipients themselves and their families. As LTSS requires recipients and providers to spend most of their waking hours together, recipient participants describe that it can mean that they show aspects of themselves to their care partners that they would not show to anyone else. These aspects include moments of stress and frustration, which can at times be projected onto their care providers through their attitudes and moods. The disabilities some recipients have (e.g., dementia) can cause them to forget certain things (e.g., what they spent their money on) and wrongfully blame their providers (e.g., for stealing their money). As well, working at home of their clients can mean that providers at times have to negotiate, communicate with, or tolerate the clients’ families. While many provider participants describe how their care recipients’ families treat them well, as if they were part of the family, family members can be a cause of stress too. Tia describes, “Sometimes their family members don’t treat us good enough. Sometime they smoke weed…. They get drunk. They just argue about money…. When there’s an argument in the house, that’s the one thing I cannot take. It’s frustrating.”

38 Without silencing care recipients’ and their families’ personal agency in these circumstances, it is also important to take into consideration the larger context, particularly poverty, racial discrimination, and ableist oppression, which many disabled Medicaid beneficiaries and their families are forced to live with. To receive Medicaid, a recipient’s income cannot exceed 133% of the national poverty line (Medicaid.gov, n.a.). Living in poverty is a
Such intensity of care labor could be partially mitigated, if the providers were compensated justly for their labor and treated with more respect—such as assurance of a safe working environment—by their employer agencies. All provider participants pointed out the agencies’ neglect of their well-being as the primary cause for the physical and emotional insecurity they experience in the work-place. Such neglect manifests, for example, as the lack of information they receive from their agency regarding the working environment or what conditions their clients are living with. Tia and Isabella explain,

They [supervisors] give you the case, a piece of paper with an address, but they don’t tell you where you’re going … We’re going to somebody’s home. Somebody’s homes are very dangerous … It’s hard. You go to some project and tears coming to your eyes…. Sometimes you get robbery. You’re scared to go. [When you complain about going into unsafe neighborhood,] all they [supervisors] tell you [is], “Just try to get out early. Get out the neighborhood early.”

They attribute their unsafe work environments to agencies who do not pay attention to the safety concerns of their employees. Alisha summarizes the frustration as well as the yearning to be supported by their employers—agencies—many provider participants expressed: “How can you care for someone else if you’re not okay? Agencies need to have a little more … caring and compassionate towards the aides [care providers]…. The aide has to have a safe environment to work in.”

necessity and forced upon many disabled people in order to maintain the LTSS they need and yet cannot afford on their own. This leads to constant financial stress and unsafe residential situations.

39 It needs to be noted that the issue of “fair compensation” is repeatedly brought up in feminist labor studies on care. They argue the difficulty in measuring un-measurable care (e.g., emotional care) contributes to the low wage and exploitation of care workers (e.g., Daly, 2001; Lynch, et al, 2009).
These narratives illustrate how care providers are put under exploitative and unnecessarily intensified care labor within the neoliberal public health-care assemblage. These characteristics were somewhat true to care work even before the care crisis and rise of the neoliberal political economy. Nevertheless, the neoliberal public health-care assemblage is deepening the exploitative and intense nature of care labor.

**Consequences of laboring in the assemblage**

The consequences of such exploitative and intensified care work manifest through the psychological and physical stress care providers experience: (1) frustration about the lack of time spending with their own families, particularly their children; (2) emotional devastation about the contradiction of not receiving care for themselves, while they relentlessly provide care to others; and (3) physical deterioration. Because most of the care providers I interviewed were mothers, they expressed anger and a sense of defeat, when it came to the ways in which the extended hours of and exhaustion caused by care labor prevented them from spending time with their families and being mothers to their newborns and children. Many of them had no choice but to take extra hours of work right after they gave birth to their children, as they are single mothers and sole providers for their children. Isabella recalls, “When I had my daughter, it’s kinda rough. I worked 6 days; I took extra workday just to make extra money. But even that wasn’t much extra [money].” Tia shares her sense of defeat regarding not having a choice but to take exploitative care work for income. “It was a lot of compromise to do with my family…. The hours is long, but what’s you gonna do? It’s work.” Alisha, a provider, shares the devastating circumstances many of these provider women are put under: “The people that provide a lot of care, they don’t get the care themselves. It’s kinda like you neglect yourself. But it’s not that you purposely neglect yourself, you do without even realizing.” Her eyes filled with tears with the
devastation when she could not come up with a single name to respond my question, “Who takes care of you?” The stresses of exploitative care labor have serious consequences for the providers’ own bodyminds. Isabella describes, “You don’t have no life. You don’t have time for yourself. [Even on your day off] you have things to do, you need to run around, and by the time you’re done all of that, you’re tired.” Tia explains the physical deterioration: “Sometimes you don’t eat. I lost a lot of weight, when I started this job.” Providers’ physical deterioration is keenly observed by care recipients too, as these recipients are indirectly impacted by the contentious work treatment their providers receive. Ty (recipient) explains how agencies “are not taking care of workers…. Regular health care agency don’t offer that (benefits)… Because you see a lot of home attendants with no teeth. You be like ‘Damn, you need care more than I do.’” Amy (recipient) shares an example of the confusing moments when the line between herself and agency-provided providers gets blurred, as they share some debilitating conditions and have a hard time completing tasks.

A lot of the people that I have also had their own physical issues. They couldn’t do something that I needed because they don’t get health care…. Once she [a provider] would come sit down and talk on the phone, and every time she got up, you could tell she was in pain from standing. And I get to the point, where I was “It’s okay, you stay, I’ll manage.”

Maria (recipient) continues, “A terrible dynamic it is to have a job where you are providing health care where you are not getting your own health insurance…. Agencies are abusing these people that are coming in.”

In the neoliberal public health-care assemblage, what is valued is the labor capacity of these provider women, who take care labor with low wages, in order to increase profits for the
industry and suppress state Medicaid expenditures. In the assemblage, the well-being of those workers become secondary, and they deteriorate physically and emotionally. While such deterioration is an effect of many intricate elements, it is not an exaggeration to say the exploitative and intensified care labor is largely triggered by the care agencies that directly train and monitor the providers and are in charge of their work environments.

**Narratives of Disabled Care Recipients**

**Entering into public health care**

For disabled people, entering into the neoliberal public health-care assemblage (in terms of Medicaid LTSS) is a long and complex process compared with their care partners’. In order for disabled people to receive any social services, they need to be certified as having *legitimate* care needs. Disability Determination Services at a local Social Security Administration examines all the proof of impairment that is submitted by disabled claimants and their doctors.\(^\text{40}\) Medical and other documents are used to determine whether applicants can be classified as “disabled individuals” under the Social Security Administration’s specific disability determination criteria, which is “based on [their] inability to work”\(^\text{41}\) (Social Security Administration, n.d.). After being legitimated as certified disabled individuals, they go on to apply for publicly funded long-term care—in this case Medicaid—and often Supplemental Security Income (SSI), as SSI recipients are usually automatically eligible for Medicaid. Application for Medicaid and SSI entails submission of documents to prove citizenship, age, address, and any income information (e.g.,

\(^{40}\) “Usually, the DDS tries to obtain evidence from the claimant’s own medical sources first. If that evidence is unavailable or insufficient to make a determination, the DDS will arrange for a consultative examination (CE) to obtain the additional information needed” (Social Security Administration n.d.).

\(^{41}\) This materialism-based classification of disability is further discussed in the discussion section below.
paystub and bank account), and proof of disability status (NYS Department of Health, n.d.; Social Security Administration, n.d.).

Becoming a Medicaid (or any social service) beneficiary (or entering the public health-care assemblage) and maintaining beneficiary status are daunting. Disabled care recipient participants of this study describe the process as long, defeating, and rather ridiculous, as it involves proving their disabilities (as well as their permanence) and their need for long-term care to the authorities, which are obvious to themselves and others (as most participants’ disabilities are visible with or without assistive devices such as a wheelchair) but to the authorities. It is often a back-and-forth repetitive process between disabled people and the bureaucracy of social services to prove disability status. Keisha describes, “Social Security turned me away a bunch of times. The question was always what kind of disability you have [she has cerebral palsy and uses a wheelchair]… I had to mail a picture of me, my son in his wheelchair [to prove my and my son’s disabilities].” The focus group was at one point filled with enthusiastic conversations about how recipients share similar difficult and ridiculous experiences of social service applications. Rick begins, “I’m standing there in front [of the state employees examining disabled people for their qualification], it’s obvious that I have disability [he has visible physical disabilities, congenital arthrogryposis, and uses a scooter] … I mean, it’s obvious that I have a disability!” (emphasis original). Keisha continues while others in the focus group enthusiastically agree that what happened to her happened to them as well: “They’re [those who are examining the legitimacy of her disability] sayin’, ‘What is it [her disability]? Oh, can it [her cerebral palsy] go away tomorrow?’… Or ‘You don’t sound disabled. You don’t really look disabled…. You don’t look disabled enough.’” Rick echoes, “I’ve been told that, and I was ‘wow.’ I don’t look disabled to you now.” He continues: “My disability is a progressive disability. It’s gonna get
worse. It’s not, in million years, gonna get better!” The complexity of the service application process poses extra hurdles to many who find it difficult to fill out required documents on their own. Anton, who has learning disabilities, describes how defeating the process is to apply for Medicaid: “Medicaid application, I open it up, and they close it…. I open it up, they close it.... I can’t stand the cycle [of opening the case and having it be shut down].... Over the years, sometimes you have to memorize stuff [spellings of words to fill out the documents]. And sometimes I forget how to spell my own address, and I’ve been there [the address] twenty-something years.”

Regardless of its complexity, it is the painful truth that disabled people need to be legitimated and qualified for their incapacity and needs in order to receive services and stay in the system. Thus, receiving services and staying in the system means surrendering to surveillance and control by the government. For example, to receive SSI—which leads its recipients to receive Medicaid LTSS—applicants’ and beneficiaries’ bank accounts and every income document are scrutinized by the state to justify that they need and deserve these social services.42 Rick says, “Social Security wants to be your sole income. It’s so that they tell you [that] you can only put less than 2,000 [dollars] in a bank.” Keisha continues, “Yeah, if it’s there too long, they take it. Yes, if it goes over 2001 [dollars], they take it.” Paula adds her personal example:

SSI saw that I have too much money in my account for the whole year 2012. So they see [my bank account] for the whole year of 2012, and they automatically cut me [off of SSI]

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42 As SSI recipients are automatically eligible for Medicaid, many who receive Medicaid also receive SSI. To receive SSI, applicants need to prove that total of things they own values less than $2000 for a single person and $3000 for a married couple. Thus, they need to submit medical proof of their disabilities and incapacities (in the case of disabled applicants) (Social Security Administration, n.a.).
... and they make you *re-apply* to get the services back. But they said that I can’t re-apply until I prove what I spent the money for.... How the hell do you live on 2,000 dollars?! (emphasis original)

SSI is available only to those whose total value of possessions is under 2,000 dollar. It means that beneficiaries of Medicaid are forced to live in poverty in order to maintain services. This forced poverty many care recipients live under is recognized by providers too: “Sometimes they [recipients] have no food. They don’t get enough food stamps. It is never enough money” (Tia, care provider).

These narratives of care recipients and providers illustrate the difficulties in gaining and maintaining Medicaid beneficiary status for disabled people. Entering the public health-care (or any social service) sector means surrendering one’s financial and social conditions to the state, and thus depending on them for one’s sole income and health-care services. As much as disabled bodies and their care needs are essential in the assemblage, a number of people have care needs are increasing dramatically, and therefore entry into the assemblage is heavily policed. Thus, once someone is in the system, the objective imposed on them is not necessarily support for their financial independence but, rather, continued dependence on the state and subjugation to its surveillance and control.

**Characteristics of care reception under the assemblage**

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43 At the time of the dissertation revision, U.S. Congress had passed the Achieving a Better Life Experience (ABLE) Act at the end of 2014. This policy allows disabled people and their families to save more than $2000 under the disabled individuals’ names without losing necessary social services such as Medicaid. Though this is major progress for disability communities, as the policy is still in the process of implementation and has not had any direct effect on disabled people’s lives yet, I am including narratives on this $2000 limit in this dissertation.
Maria cynically portrays her numerous encounters with providers her agency has sent as “a comedy, it’s a tragic comedy” with a defeated laugh. This sense of hopelessness was present throughout focus groups with disabled care recipients, whenever they talked about application for Medicaid or the quality of care they receive from the agencies. The care these disabled people receive is characterized as poor quality, or at times dangerous, by participants of this study. They describe that this poor quality of care is induced by agencies’ careless hiring, lack of rigorous training for their care providers, and negligence toward both care providers and recipients. Ty summarizes agencies’ treatment of care recipients, and all the other participants vigorously agree:

A lot of times, [agencies] just hire [anyone], they just need a body, fill a spot, because they want to get the money from Medicaid…. So anybody walks in who have application, they [agency] give it to ‘em…. Agencies don’t care, as long as they send someone there [recipient’s home], and you are covered … whether they [providers] go or not. It’s horrible…. The agencies don’t care at all…. The agencies are just collecting money sitting back and whatever Medicaid need them to do in order to continue to get the money (emphasis original).

The above quote painfully illustrates that when care is commodified and the long-term care structure becomes heavily profit centered, the quality of care recipients receive becomes a secondary concern. This situation can mean the failure of care agencies to gate-keep those who are not qualified to be providers from entering care work. Provider participants of this study repeatedly mention that care work is not for everyone, but rather one needs to be caring and loving to continue working in care work, especially when it is a low-wage job. Disabled recipients are painfully aware of how agencies hire anyone who walks in their doors regardless
of these applicants’ motivations for and attitude toward care work. Focus groups were, therefore, heavily occupied by discussions of how the public health-care sector is filled with unqualified providers who cannot or do not know how to provide quality care for their clients. Maria (recipient) shares her observation based on working with a number of care providers sent by agencies, that many providers she has encountered “are there just for paycheck.” One provider told Tonya (recipient),

“I haven’t worked for many years, and I’m working now [as a care provider] only because I have to get my benefits [unemployment checks] back. [In order to get the benefits back,] I have to do this [care work], this many hours.” So [the provider] just went the week, however around, and that’s it, [they] are gone.

This neglectful hiring can facilitate devastating results such as stealing and abuse. Recipients testify that, within Medicaid long-term care, stealing is unfortunately a common practice. Paula describes, “They (her past providers) stole from me. They took things that they wasn’t supposed to take…. And it was a strain on our relationship…. It was just hard to figure out: why this happened…. It’s a very vulnerable situation.” Physical and emotional abuses were experienced by recipients and witnessed by some provider participants of this study as well. Amy (recipient) describes, “When they got angry or aggravated or having a bad day, they took it out on me … I didn’t feel safe.” One care provider, Isabella, explains what she witnessed or heard: “Some people [providers] are frustrated…. They had their own problem at home, and they come to the job, and some jobs are difficult…. They just take it out [on their clients]…. Some of the workers are very angry… don’t care about the patient.” Particularly under long-term care, disabled care recipients and their providers spend most of their waking hours together. As much as providers witness a variety of recipients’ moods, recipients also experience their care partners’
moods directly, as they manifests in the care recipients receive. While there are overwhelming accounts of interpersonal abuse, all participants attribute these incidents to the negligence of agencies: “They [agencies] just don’t seem to care, and the stories of abuse and theft are getting worse, it’s not getting better. It’s getting dangerous…. All of us are abused one [way] or the other” (Maria, recipient).

Furthermore, these recipients describe how the agencies’ negligence manifests in a lack of quality training for the care providers. Ty explains, “They [agencies] say they are train’, but they ain’t service training. Not the good.” Ty continue,

They offer service training, but they don’t have people like us [disabled care recipients] to come in and help with training … I’m like how you gonna teach somebody to take care of us, when we know what we need. We should be there also, tell them what we need, how to care for our needs; not so-called experts, because they went to a college and got a degree. Our degree come from being in this position every day. We didn’t go to school to learn how to be disabled, it was just happened to us. So we should be [training our own providers]. I offer the agency to come in there, free of charge, and help doin’ service [training]. They said okay, then, they changed their mind [and turned down my offer].

In this context, agencies are not only compromising the quality of training their employees (providers) could receive but also ignoring the wisdom these disabled care recipients have gained from their first-hand experiences of receiving care. Thus this quote shows the clear line drawn in terms of who agencies perceive to hold expertise when it comes to the training. The improvement of care provision training—and hence the quality of care recipients receive—is not set as a priority for the agencies. Additionally, care recipient participants keenly observe and attribute the low-quality care they receive to agencies’ negligence towards the providers’ well-
being. Ty describes that “[With the low wage providers receive] they are not gonna end up caring about the job the much…. If you have good workers, they are wearing off so far…. They are not gonna be able to keep the pace up too long. They get worn out just trying to make ends meet.” This quote, indeed, highlights that those whom these care recipients call “unqualified” or “uncaring” care providers may not be “unqualified” per se but instead profoundly exploited by the care agencies and left with no mental or physical energy to carry out the kind of care they desire to provide.

The care agencies’ negligence regarding hiring qualified providers, providing rigorous care providing trainings, and taking care of their employees, the care providers, caused care recipients to go through a number of providers to find ones that were capable of providing the care that they need and desire. Maria (recipient), for example, recounts, “In four or five years, I went through at least 60 [providers to find ones who care and are qualified].” This high turnover is common, according to recipients, as agencies continue to send unqualified and uncaring providers, and as the agencies exploit and wear out care providers who become incapable of providing quality care to all the recipients to whom they are assigned. It, then, becomes care recipients job to sort care providers who can provide quality care from who cannot, though it is a responsibility of care agencies. Many recipients mention how they receive different providers every day for several weeks without notice beforehand. Paula describes, “With agency, you never know who’s gonna come in your house. You have to go with the flow with that. Because if you don’t, you’re not gonna have the help for the day.” Even though agencies often send care providers who are unqualified, undertrained, or worn-out without letting recipients know who is coming to their home, those recipients have no choice but to let these stranger providers into
their home and continue to rely on agencies in order to receive the care they need to carry on with their everyday life.

Consequences of being part of the assemblage

Agencies’ neglect to hire and train qualified providers, take care of providers’ well-being, as well as failure to inform recipients about their new providers have tremendous physical and psychological consequences on recipients. Maria explains, “You don’t know who they are, and letting them into your house. I mean, [cynical laugh] think about it…. You may have everything in the room [to which you are letting strangers in].” Or Alisha, a provider, frustratingly describes,

It takes a lot for people to ask somebody to wash them up. That’s not something to get easy adjusted to do. Total stranger, somebody you don’t know, have to come in to do everything for you. People you don’t know yet! Got to see your whole entire body. Your body is a temple; it’s private. You have to use a bathroom [with them].… It’s a lot for them.

Though care practice naturally involves intimate care and embodies vulnerability for both care recipients and providers, all care recipient participants articulated how such experiences of vulnerability are amplified by the agencies—particularly the lack of information about providers these disabled recipients receive. One recipient participant described the shared opinion that “agencies are sending people sometimes three or four a week whom [they] don’t know,” and explained, “You are admitting this person to your home, you don’t know anything about the person. You are not even allowed to get their phone numbers. They know everything about you, but you don’t know anything about them which is upsetting” (Maria). And when it comes to their previous providers, “They [agencies] won’t tell you why [your previous provider is not coming
back]. They [new providers] are not allowed to tell you why. There’s no good-bye, just sending a new person next day” (Rick, recipient). The vulnerability and insecurity heightens for recipients under these circumstances, as they have no choice but to open their home and body to strangers, while such vulnerability and insecurity could be mitigated with more communication and information provided by the agencies about care providers, in addition to better gate-keeping, training, and treatment of care providers these agencies send.

The agencies’ neglect towards recipients can have life-threatening consequences. For example, a care provider, Alisha, is concerned about how agencies ignore calls from their clients, or neglect to return to their calls in a timely manner: “Clients call, and they [agencies] don’t return client’s call at all. They finally give back calls a few days after. The nursing supervisor should make sure the coordinators are more attentive … to the clients…. It doesn’t matter if aide [care provider] calls [on behalf of their clients], still they don’t pick up the call. And that is dangerous. Clients may be calling for emergency” (emphasis original). Finally, disabled recipient participants summarize the ultimate consequences of un-attentive care agencies. Maria (recipient) states,

They [providers] really don’t know what to do [in case of emergency]. If something happen to you in the house, they don’t know who to call, they don’t know how to go about it. 911 becomes a big issue. Really, it’s very dangerous. There are so many people that have died: those you never find out… I remember falling on the floor once, out of a [wheel]chair. And I told the person [her provider] to please put me on the bed. And the person began to talk to me in her native language. And I’m going “oh god.” All I know is that the person left me there. She sat on the floor with me. I was frightened, “Please take
me to the bed. Please just drag me to the bed. Try to put me on anything, on a sheet and 
drag me. Anything!” She sat on the floor with me…. She didn’t know what to do.

**Conclusion**

Narratives shared in this chapter depict how lower- (or no-) income disabled people and 
women—who are mostly women of color, immigrants, or former welfare recipients—enter the 
public health-care sector, how they are treated by care agencies, and the consequences of such 
treatment. Under today’s neoliberal public health-care assemblage, these disabled people and 
care providers are both commodified and exploited based on their care needs and labor 
capacities. They are consumed in the assemblage, and treated as disposable. The consequence of 
this treatment is slow death. In the assemblage, both care recipients and providers are slowly 
deteriorating, and fast approaching death. Neoliberal public health care is, therefore, 
necropolitical.

Psychologists offer a great deal of insight into psychological factors that contribute to the 
marginalization of certain people. Hahn (1988) and other critical psychoanalysts (e.g., 
Watermeyer, 2012), for example, theorize how anxiety is aroused in an encounter with those 
who are perceived to be different from the social norm. Hahn explains concepts of existential and 
aesthetic anxieties that disabled bodies (or any bodyminds that stigmatized as different) elicit. 
This chapter, then, extended the theory to understand how the social injustices and 
marginalization are utilized in the current context of neoliberalism. Under the circumstances, 
minority people are not only marginalized but commodified and consumed for the profit-making 
of industries and prepared for disposal, as those who take care recipient or provider roles are 
framed as excess in this globalizing world. This line of thinking adds layer to the analysis and 
theorization developed in this chapter, about the ways in which capacity- and need- based
exploitation is profoundly shaped by factors such as race, gender, immigration status, and types and degree of disabilities a person embodies. Integrating the last chapter into this one, it is the labor capacity of lower-income women of color that is capacitated; and yet, simultaneously, its productivity is devalued, as care labor entails low wages and harsh work environments. Thus, it is the care needs of those who are disabled enough, but whose needs are not too costly, whose care needs are exploited. Further, it is this set of people whose well-being is neglected as they are consumed for the industry’s profit and the state Medicaid’s budget suppression.

Another point I want to highlight in this conclusion is the similarity between the oppressive positions in which both recipients and providers are situated. On the one hand, their situations are different as they occupy different roles in the system and have different responsibilities, expectations, and rewards. A close reading of the recipient and provider participant narratives even indicates their situational antagonism (e.g., maltreatment of one another, such as stealing). Existing care studies’ exclusive attention to either the care recipients’ or providers’ situation highlights the divide between these two populations. Nonetheless, on the other hand, there is an overlap as well. Looking at their relationship with the industry and the state at a more macro level, they are both consumed and deteriorated.

Transnational feminists often juxtapose different, yet overlapping, standpoints of women across the world in order to depict both diversity within the gender category as well as similar strategies used by patriarchal society globally and the similar impacts those women experience (e.g., Mohanty, 2003). Through the juxtaposition, transnational feminists plant seeds for careful and critical transnational solidarity building. With a similar hope, this chapter juxtaposed narratives of care recipients and providers. Such juxtaposition conveys the following points:
• Neoliberal public health care creates the assemblage that involves the exploitation of care recipients and providers.

• In the assemblage, labor capacities of women and the profitable care needs of disabled people are deployed for care industry profit making and Medicaid budget suppression for the state.

• The neoliberalization of public health care turns care providers and recipients into consumable and disposable populations.

• A result of being part of the assemblage for care providers and recipients is their physical and psychological deterioration and slow death.

The previous chapter provided historical and more macro level descriptions of how care recipient and provider populations emerged in relation to the neoliberalization of public health care. This chapter introduced more micro analysis and examined how the current context—the neoliberal public health-care system—shapes the realities of these recipients and providers. The next chapter, then, goes even more into the micro level to look into the interaction between them: how affective relationality emerges from these care practices, and what the affective relationality does to the larger assemblage.
Chapter 6

Affective Relationality: Recursive practices of care and Co-Capacitation between Disabled Care Recipients and their Care Providers

Abstract

This chapter takes a close look at the relationship between disabled care recipients and their providers. Using Spinozian and Deleuzian conceptualizations of affect and the body, this chapter develops a concept of affective relationality that is interdependent, caring, and co-capacitative. I argue that the recursive encounters and practices of care co-conducted by the care providers and recipients give rise to affective relationality through their adaptation to each other’s distinct capacities, needs, desires, and rhythms. In the recursive practices, also, the vulnerability care providers and recipients individually experience, and hold against each other at their first encounter, slowly turn into shared vulnerability, which ignites sympathy and intimacy between them. This positive connection between these individuals turns their relationality into a capacitative one. In the following, I provide a theoretical description of affective relationality, which is followed by the narratives of care providers and recipients to enrich the theoretical development. Finally I explore what affective relationality does in the neoliberal public health-care assemblage by contrasting it with the psychological studies of solidarity building and by describing it as the undercommon of the neoliberal public health-care assemblage.

An attendant, which is not only an attendant, but it’s a person who you conside with in so many ways. That is the closest person, the closest relationship you really have. Because not even the husband, you share the much of your life ... They [care providers] see you when you are good and when you are bad ... There’s a lot of things you share with them that you don’t really show it to anybody else. It’s one of things where they can sense when you don’t feel good. They can sense certain things no other person can sense. Because they are with you so much, in so many circumstances, so many environments, and so many places ... [It] is the closest relationship you have in the world, really ... It’s an unbelievable relationship. I’m just, that’s alone: the love and care you feel for them. They probably would never know, but it’s really “thanks” that you don’t know how to tell them. “Thank you!” (Maria, care recipient, emphasis original)
For me it’s [care arrangement relationship] the most important [relationship]… Love for the patient [sic], compassion [for them] … It’s [the love I have for my client] so much, I can’t explain to you. (Sophia, care provider)

**Introduction**

The last two chapters investigated the macro, or molar, level of the neoliberal public health-care assemblage: its structure as well as its effects on care providers and recipients. In these chapters I described how the current public health-care sector becomes necropolitical under its neoliberalization. Under the neoliberal public health-care assemblage, care becomes a site where both care providers and recipients are exploited, consumed, and deteriorated. Additionally, the site is often turned into a point of friction in activism between domestic workers’ (which includes care providers) and disability rights activism—where care recipients’ and providers’ injustices are fought separately, as though only one justice can be achieved (e.g., the recent changes in the Fair Labor Standards Act; Darling, n.d.). This observation brings Erevelles (2011) to ask, “How do we forge a collective struggle [with women who are situated as care providers and disabled people who receive care] without destroying the people we really care for?” (p. 197).

The above question is the point of departure for this chapter. Reflecting the molar movements within the assemblage as summarized above, this chapter builds on it by focusing on the molecular level of the assemblage: namely care arrangements made between disabled people who receive long-term care from NYS Medicaid and those who are situated as these disabled people’s care providers. In this chapter, I trace the development of affective relationality as it
emerges between some\textsuperscript{44} of the care recipients and their providers as well as what the affective relationality does. Bringing Spinoza-Deleuzian affect theories to care studies, I argue that it is the recursive encounters and practices of care co-conducted by these individuals that allow them to adapt to one another’s distinct capacities, needs, desires, and rhythms and to foster interdependent and caring relationality. This affective relationality is also capacitative, as it turns the sad, passive positionalities care recipients and providers are initially situated into joyful, active positionalities (Deleuze, 1998). Finally, this affective—or interdependent, caring, co-capacitating—relationality happening on the molecular level is a way for those providers and recipients to destroy and change the flows of the public health-care assemblage from within.

These arguments are contextualized with the narratives of care providers and recipients of NYS Medicaid Long-Term Services and Supports (LTSS). I use the same set of data I used in the previous chapter, but with a different theoretical framework. More information on data analysis is found in chapter 3. Additionally, this chapter is developed to respond the last two questions of this dissertation:

- Does relationality emerge between care recipients and their providers, and if so, how?
- What does such relationality do?

A discussion on relationality or relationship is not without controversy within care studies. Indeed, discussions on relationships are often quickly absorbed by the vacuum of critique. As described in previous chapters, care is practiced within interlocking injustices and thus often seen primarily as a site of oppression: either the “service” mostly women are assigned

\textsuperscript{44} I would like to highlight that not all care arrangements and practices lead the providers and recipients to develop affective relationalities, nor does the development of affective relationality always create caring and nurturing interactions between these individuals. This point is further discussed at the end of this chapter.
(or forced) to do or the “management” disabled care recipients are put under. Therefore, the priority of care studies is generally set to reveal and challenge the oppressive context, and the discourses on the relational or restorative aspects of care are often critiqued for their romanticization of care labor, as a sign of internalized sexism, or potentially obscuring social injustices that are inherent to care arrangements (Folbre & Wright, 2013; Zelizer, 2005).

Even though the relational aspect of care is often toned down within care studies, connections between care recipients and providers (e.g., friendship) inevitably occur, and they were apparent in the focus groups and individual interviews. There is more to a care practice than total oppression and exploitation. Thus, I speculate that care studies’ resistance to recognizing the relationships formed within care arrangements is partially rooted in its deep reliance on discursive analysis—analyzing care based primarily on its significance and meaning, instead of on how it is experienced ontologically by those who are involved in it. Care practices are nuanced and complex, involving both oppressive components and mutual affection, and therefore care studies requires an analytical framework that can hold these nuances and complexities. In order to achieve a more nuanced understand of care practices, I turn to theories of affect.

Specifically, I use the Spinoza-Deleuzian conceptualizations of affect and the body, as they allow me to conceptualize the experiences of care providers and recipients without privileging the brain or cognitive connections (Henriques, 2010; Puar, 2012). Affect theories enable the conceptualization of relationship beyond cognitive and instead through proprioceptive connection—bodies’ direct connections through their senses (Venn, 2010). In terms of care practices involving disabled people, the turn to affect enables “a recognition of disabled subjects
(or any subject) as social subjects located within reciprocal relationships that bind them to other bodies, and that, in turn, bind them to communities” (Erevelles, 2011, p. 174).

**Theoretical Development**

The point of entry I use to bring affect theories to care studies is the Deleuzian conceptualization of the body. Care studies often launches its theorization based on discursive analyses of body and care—meanings and symbols attached to the concepts of body and care. Instead, Deleuze (1990) conceptualizes the body as an assemblage where macro and micro elements and temporalities come together and interdependently shape it as a whole. In this line of thinking, *body* is open-ended, composed by *bits* that constantly reconfigure their arrangement and relationship. In Bennett’s words (2010), “While the smallest or simplest body or bit may indeed express a vital impetus, conatus or *clinamen*, an actant never really acts alone. Its efficacy or agency always depends on the collaboration, cooperation, or interactive interference of many bodies and forces” (p. 23). Body is ever in formation, as its bits are constantly influenced and reshaped from both outside and within. This understanding of the body provides a different way of understand the encounters of multiple bodies.

Existing bodies do not encounter one another in the order in which their relations combine…. Relations combine *according to laws*; but existing bodies, being themselves composed of extensive parts, meet *bit by bit*. So parts of one of the bodies may be determined to take on a new relation imposed by some law while losing that relation through which they belonged to the body. (Deleuze, 1990, p. 237, emphasis original)

Encounters of disabled people and their care providers, arranged by care agencies, stir up both bodies at the molecular level, and new formations and relationships of bits are repeatedly arranged within both bodies based on the encounter. In other words, an encounter is experienced
beyond what cognitive perception and understanding as well as what the discursive meanings added by scholars contribute. Zooming out a little from the bits that make up the body, Haraway (2008) eloquently describes what is going on and how the encounter is choreographed and experienced by its participants:

All the actors become who they are in the dance of relating, not from scratch, not ex nihilo, but full of the patterns of their sometimes-joined, sometimes-separate heritages both before and lateral to this encounter…. [W]ho they are is in constant becoming in these rituals. Greeting rituals are flexible and dynamic, rearranging pace and elements within the repertoire that the partners already share or can cobble together…. [A] greeting ritual [i]s a kind of embodied communication, which takes place in entwined, semiotic, overlapping, somatic patterning over time, not as discrete, denotative signals emitted by individuals. An embodied communication is more like a dance than a word. The flow of entangled meaningful bodies in time—whether jerky and nervous or flaming and flowing, whether both partners move in harmony or painfully out of synch or something else altogether—is communication about relationship, the relationship itself, and the means of reshaping relationship and so its enacters. (p. 126)

The above quote clearly points out that the encounter is a process of becoming—the collective becoming of two bodies involving their past memories as well as constant re-making of their bits and their relationships. The encounter is becoming, inheriting both the capacitative and debilitative potentials of the encountering bodies. In this paper I am thinking about recursive encounters and practices of care. Disabled people and their care providers often spend most of their waking time together, as disabled beneficiaries of Medicaid LTSS require care for most of their waking hours, and as care providers need to work extended hours in order to earn a living
wage under Medicaid LTSS. They work together every day and repeat the same care routines assigned by the agencies. These recursive practices of care routines, I argue, bring some of the care providers and recipients closer regardless of their distinct capacities and needs. The recursive practices allow them to ontologically learn one another’s bodies and movements and to adapt to their particular capacities, needs, desires, and rhythms—at this point, affective rationality emerges. “Practices are the individual’s main way of relating, with beliefs and values secondary to, and serving the relation we have, with others” (Slife, 2004, p. 158). And in Henriques’ words (2010, p. 77), “Affect revolves round repetition. Repetition can cause affective attachment … In addition, affect can also cause repetition” (emphasis original).

Affective relationality is embodied relationality—“the interpersonal sense of connectedness written into our bodies that can characterize such care” (McCarthy & Prokhovnik, 2014, pp. 18-19). And it is a strong relationship (Slife, 2004), a connection deeper than cognitive connection and instead including a proprioceptive and ontological relation involving “the concrete, experiential forms of non-conscious and proprioceptive communication that take place through touch, smell, the gaze, movement, sound, taste occurring directly between bodies, and sensed as a tacit knowledge of oneself and the world that doubles as an embodied way of being-with others” (Venn, 2010, p. 156). It is the recursive practices of care that give a rise to affective relationality. In other words, it is the labor of both providers and recipients that lets bits of their bodies continue their reconfigurations, slowly adapting to the other body and its shape, movement, rhythms, and desires. In this collaborative dance of reconfiguration, they learn and adapt to each other’s capacities and needs, knowing proprioceptively when and how to move their body in order to be in sync with the other body to accomplish the care task.
Also as described later in the data section, care providers and recipients are initially situated antagonistically by the care agencies that arrange their care. Yet, in the repetition of care practices, the feelings that circulate between providers and recipients transform. Initially, they experience vulnerability *individually*, which is largely induced by the negligence of care agencies: vulnerability infused with defensiveness. Nonetheless, throughout the recursive care practices and as they spend most of their waking hours together, they start acknowledging each other’s vulnerable circumstances or at times co-experiencing the vulnerable moments together, which causes many to start feeling sympathy for their care partners and building a sense of solidarity together: vulnerability infused with intimacy. This transformed, more positive view of one another is a key for the last development of affective relationality I discuss here.

When a body “encounters” another body, or an idea another idea, it happens that the two relations sometimes combine to form *a more powerful whole*, and sometimes one decomposes the other, destroying the cohesion of its parts…. When we encounter an external body that does not agree with our own (i.e., whose relation does not enter into composition with ours), it is as if the power of that body opposed our power, bringing about a subtraction or a fixation; when this occurs, it may be said that our power of acting is diminished or blocked, and that the corresponding passions are those of *sadness*. In the contrary case, when we encounter a body that agrees with our nature, one whose relation compounds with ours, we may say that its power is added to ours; the passions that affect us are those of *joy*, and our power of acting is increased or enhanced. (Deleuze, 1988, pp. 19-27, emphasis original)

In these shared experiences and feelings and development of embodied relationality, two bodies are combined together and each body’s power is increased. Conducting collective, recursive care
practices, in this context, capacitates both recipients and providers, while simultaneously capacitating their relationship to become “a more powerful whole” (Deleuze, 1988, p. 27). It is communal becoming which contains the potential to transform each body’s capacity (Curti & Moreno, 2010). Or, in Ruddick’s words (2010), “The expansion of our capacity to act is at once relational, produced by mutually reinforcing collaborations, and the outcome of a complex interplay of affect and reason” (p. 26). The narratives of care providers and recipients depict that the affective relationalities that emerge from some care arrangements—as a result of continuing labor and co-capacitation by the recipient and their provider—are interdependent, mutually caring, and co-capacitating in nature.

**Contextualization of Theories with Narratives**

In the following space, I further illustrate the theory developed above by embedding it in the narratives of disabled people who receive their long-term care from NYS Medicaid and care providers of the NYS Medicaid long-term care program.

**Vulnerability at the Door and Against Each Other**

Supervisor gives you the case, but they don’t tell you where you’re going…. You go to some project, tears coming to your eyes, because you don’t know where you’re going, you’re scared to go. They [care agencies that send these providers to clients’ homes] don’t tell you nothing about patient [sic]: [if] this patient has no foot, this patient is bedridden. So when you reach their house, patient give you the attitude, and you have to calm them down saying that “you know what? I didn’t know.” (Tia, care provider)

The agency, they are sending people sometimes three or four a week who[m] [you] don’t know…. You are admitting this person to your home, [and] you don’t know anything about the person. They know everything
about you, but you don’t know anything about them which is [an] upsetting set up. (Maria, care recipient)

With agency, you never know who’s gonna come in your house. You have to go with the flow, with that. Because if you don’t, you’re not gonna have the help for the day. (Regina, care recipient)

Right before the first encounter, vulnerability heightens in the bodies of a care recipient and their provider at opposite sides of a door: a provider outside and a recipient inside. This vulnerability in anticipation of the first encounter is more than that which might naturally accumulate. Such vulnerability is induced by external factors: care industries that arrange and manage care practices, social injustices that are inherent to care arrangements and internalized by the care recipients and providers in the form of stereotypes, and previous negative care-related experiences that recipients and providers each carry with them. Their past experiences in care practices, such as the unfortunately common incidents of stealing (which happens to both recipients and providers), condition them to be cautious of their new care partners. Regina (care recipient) explains, “They stole from me…. It was a strain on our relationship…. It made it hard to look for someone [new].” Further, socially circulating stereotypes and other oppressive ideologies also shape the initial encounter and the care practice as they are internalized by recipients and providers, and thus they create subtle power dynamics within the practice. A common comment from provider participants was how disabled people are human too, just like them: “I have respect for her [her care recipient], even though she may have a disability, she’s still a person. So, I do respect her, I do care for her” (Terri, care provider, emphasis added). Such reaffirmation of disabled people as a human implicates how disabled people are generally considered to be less than human or non-human, hence undeserving of equal treatment. The fact
that almost all provider participants used this rhetoric shows that care practices do not begin on
equal ground; rather they begin as if the disabled care recipients were less human and their
providers were the liberators who discover the humanity in their clients. It is not only providers
who enter care practice with internalized assumptions. Disabled people as well enter their care
practices with internalization of the capitalist ideal of service: how care practice should be, what
they are entitled to, and how their providers should behave. Particularly, as they are not
mandated to take training on how to work with their care partners—like their providers—the
ways they work with and treat their care partners are left up to them.

Some of them [recipients] don’t think our lives, just be with them, only. Just to work,
work, work, work, and take care them … you tell them [that you] have a kid, but they
don’t even care. Just want me to be there for them only. Just to do for them, them, them.
(Isabella, care provider)

As much as past experiences and social ideologies inevitably inform care recipients and
providers prior to their encounter, it is primarily care agencies that directly shape the foundation
of care practices with their administrative authority. This point is staggeringly clear in this
section’s opening quotes on the vulnerable first encounters. Both care recipient and provider
participants attribute the main cause of their vulnerability as the agency’s withholding of
information. Both quotes address that the lack of knowledge about who they are encountering
and what kind of environment they are entering escalates their vulnerability. Indeed, care
practiced between a disabled care recipient and their provider is never without interference by
care agencies. Care agencies, for example, cannily seed and manipulate subtle power dynamics
within care practices, whether through the trainings they provide or the rules and guidelines they
enforce:
[At a training,] they just talk to you, walk you through with dos and don’ts. [They tell you] even if the client yells at you or they are little annoyed which they can be, all you have to do is just talk to them. You have to let them know … you are there to help them … Make them feel that that’s their home. Don’t make them feel like you’re coming in … You have to still give them a little independence. So they [the agency] talk to us about that. (Alisha, care provider, emphasis added)

If you tell home attendant, “Could you do me a favor? Please could you just clean that spot over there.” And they call the agency and say “She wants me to clean,” and you talk to the coordinator [who tells you whether she can clean the spot or not]. I’m always wrong and they [providers] are always right [putting her hands in the air]. (Maria, care recipient)

Alisha’s quote above, regarding the agency’s advice to its employees to give “a little independence” to their clients, highlights the acknowledgment of fundamental power differences due to the lack of ability for these disabled people to navigate their lives without care providers. Though the quote also signifies how the agency teaches its employees that they are there to serve and assist their clients, thus needing to tolerate mistreatment by them, still these providers are taught that ultimately power over their clients and the well-being of these clients is in their hands. Maria’s quote demonstrates vividly how the agency is seen as the authority that decides the infrastructure of the care practice and judges who is right and who is wrong. What stands out in Maria’s quote is that both she and her provider take the care agency’s authority unquestioningly.

Directly through training or indirectly through care plans and rules, care recipients and providers are reminded of the strict separation between them. The major rule enforced by
agencies and brought up continually by all the participants is the ban on forming any relationship (e.g., friendship) between recipients and their providers for the sake of the agencies’ liability. While these external factors influence care practices profoundly, this ban on connection highlights how agencies are eager to detach care partners from each other. Enforcement ensures that breaking the agency’s rules comes with a huge cost, according to Keisha and Rick (care recipients): “If the agency finds out [that care recipients and providers are building friendship against the agency’s rules], they [agencies] take them [provider] out [clap of hands]. All of a sudden somebody’s be at your door, and they won’t tell you why. They just say, ‘Oh, the old lady, she is gone.’” Additionally, these bodies in the beginning of care arrangements are not only detached but also put in oppositional, antagonistic positions. In other words, both recipients’ and providers’ bodies are already affected at the door with a number of predisposed expectations and assumptions. Their bodies are habituated to where “social practices and relations are materialized” (Blackman, 2013, p. 187). Key components for the development of the relationship are, then, whether and how the care recipients and providers collaboratively work to negotiate and undo the power dynamics seeded by agencies and other external factors.

**Shared Vulnerability**

While these external factors continue to haunt and shape the care arrangement, the practice begins. By care practice, I mean the daily encounters of care recipients and providers, and their co-engagement to fulfill the care plan assigned by the agency, based on the assessment it made about these recipients’ needs and capacities. It consists of Activities of Daily Living and Instrumental Activities of Daily Living such as eating, bathing, dressing, or managing finances. Under the Medicaid LTSS, most of the provider participants conduct the assigned care activities for 12 hours a day, five to six days a week. Some of recipient participants receive care 12 hours a
day, while others receive several hours in the morning almost every day of the week (if not the entire week). Many describe how this factor—the extensive amount of waking time spent together—inevitably brings them closer: “Being with them so long, you get to love them, because they are like your old family member” (Tia, care provider). Care practice is repeated on a daily basis, and recipients and providers re-encounter each other every morning. Through these practices, they learn and adapt to each other’s unique needs, capacities, desires, and rhythms.

Reflecting on one of the challenging care practice Alisha has engaged in the past, she narrates,

> Just doing what she [her client] asked of me, no matter how many times she asked. And just doing it. She said that it takes a lot, a lot of patience. This is what I dealt with every single day … Sometimes I did it a right way, but she’d say, “But I don’t feel it right, so you’ve gotta do it all over again.” [Laughing out loud]. Woof! I really, really learned.

(Alisha, care provider)

Learning and adapting to their care partner’s needs, capacities, and desires take practice and patience. As illustrated in the above quote, it is set up as a provider’s job to learn and adapt to their client’s needs and desires. Nevertheless, care recipients also learn and adapt to their providers’ capacities, needs, and desires as they manifest in the care practices: what they can and cannot do and how they conduct the care activities. According to the unique ways these providers work, recipients adjust their body movement and posture to make their care partners’ work easier.

That’s how agency want it, [do not want you to have a relationship with your aide], but it’s hard. When you’re working with a person 6 hours, 8 hours, 9 hours, 4 days a week, 5 days a week, 7 days a week, you start to know what these people are. What their habits are, you know what their
needs, you can almost anticipate what their needs are. (Rick, care recipient, emphasis added)

Care practice, on paper, seems a rigid, clear-cut list of services providers are expected to perform for their clients. In reality, though, each task comes with a number of collective decisions, communication, and co-practicing and –adaptation of each step based on ways the recipient and their provider work together. Such co-practicing and –adaptation entail, for example, how the recipient wants to be transferred to their chair, and in what ways the provider’s bodily capacities allow or prevent the transferring method.

During the conscious and sensual process of learning and adapting, the power dynamics between a recipient and their provider slowly shift as well. At the beginning of care practice—at the first encounter—the vulnerability of each recipient and provider is highly evident. Manipulated and constructed by care agencies, they individually experience the vulnerability—coming from and with defensiveness. In the repetition of care practices, though, they both start witnessing and acknowledging the vulnerability their care partners experience.

She [his current provider] was about to quit…. She was not gonna take anybody’s mends. If I had said anything wrong, it was gonna go down…. because her last client really pinched her last nerve…. I was nice, I just asked her to do my laundry on the first day (Rick, care recipient)

You know what, there are a lot of good people [care providers] that do the work, and they don’t get acknowledged. (Anton, disabled participant)

In the above quotes, Rick explains that care providers’ physical abilities do not always mean that they hold the ultimate power and immunity from emotional stress. Anton also acknowledges the exploitative labor conditions their providers are put under. Not only do they acknowledge each
other’s vulnerable experiences, but the extensive amount of time spent together means that they encounter and experience vulnerable moments together. Tia describes,

It was better for her [her client] and better for me [to leave the house]. Because if [the recipient’s] family members start arguing, that’s too much, too frustrating. And then if someone there smokes weed, it smells bad, and I can’t [stand it]; it’s hard.... So we say “Let’s go. Can we just go watch a movie?” We go, and we laugh. It’d be better for both.

(Tia, care provider)

Both Tia and her care recipient are negatively affected by the arguments of the recipient’s family members, and so they co-conduct the escape to take care of each other.

Witnessing, acknowledging, and sharing vulnerable moments also mix in with a sense of sympathy for each other as well as intimacy, and it moves both to care for one another as their care partner goes through a vulnerable moment. Sympathy and caring for those who are going through vulnerable moments is evident in Rick’s quote above, where he acknowledges the tough situation his new provider was previously in and eases the care plan for the day in order to care for her.

What they going through is not easy. It takes a lot for people to ask somebody to wash them up. That’s not something to get easy adjusted to do. That’s a total stranger, somebody you don’t know have to come into do everything from you, [though] you don’t know [the person] yet. Got to see your whole entire. Your body is a temple, it’s private…. It’s a lot for them as well. (Alisha, care provider)

It [care she received] was three days a week. And then, I asked for extra hour, because … I’m considerate of them [providers]. That’s not paying enough them. So I said you know what, let me get an extra hour. They
wouldn’t give me an extra hour, but they gave me an extra day. So, I said, you know what I’ll take the extra day (Keisha, care recipient).

The above quote by Alisha illustrates her acknowledgment of the vulnerable nature of care arrangements recipients go through as well as her sympathy toward the situation. The sympathy and care for care partners is also materialized above, where Keisha recognizes the economic injustice her provider experiences and tries to improve the situation by asking for more hours for them, thus economically capacitating her care provider.

As care recipients and providers repeat care practices, spend extensive hours together, and learn and adapt for one another, the feelings that circulate between them change too: from individual, defensive vulnerability, to collective and shared vulnerability, to sympathy and intimacy. Through recursive practices, they develop genuine care for their care partners. As the above quotes demonstrate, bodies that are initially put in an antagonistic position begin to care for one another in whatever ways their capabilities and standpoints allow; affective relationality emerges and is embodied by them.

**Development and Embodiment of Affective Relationality**

Being able to anticipate just enough, not too much. And that’s tricky, that’s growing, organic things that develops over time … [S]he [his provider] could *anticipate* just enough to be [helpful] to the point. She didn’t need to be directed or asked; but not too much so that she took away my independence. (Bill, care recipient, emphasis added)

As evident in the above quote, care recipients and providers are both adjusted to each other’s working styles—capacities, needs, desires, and rhythms—. They anticipate them pre-consciously; thus, their relationality is embodied. As their relationship grows, they co-develop their own ways to communicate and conduct care activities:
[Akemi: He gives you the wink to communicate with you?] Yeah…. He can’t move it [his body], but he can move the eyes: makes his eyes so big [she is demonstrating how he opens up his eyes to communicate]. Last Sunday, his beard grew already. I asked him: “You don’t mind if I shave again?” He said “noooh.” So, I did…. I take my time, I have a fun … to do that. He puts like that, eyes so big [saying], “Okay, Sophia okay. Thank you so much.”” (Sophia, care provider)

Sophia describes how she and her client both learned to communicate in their own way: an unconventional communication mode that involves movements of his eyes such as winking. Also the relationality that emerges out of care practices is about building and recognizing unique ways mutual care circulates between them: “I do receive care from her [her client with developmental disabilities]. She appreciates things…. She gives me hugs; she tries to do a little thing. Or sometimes she shares things…. She shares some foods sometimes” (Terri, care provider).

At the beginning, care practice is primarily shaped by external factors, including the care agency that sets the infrastructure of care practices. Throughout the repetition of care practices, though, bits of each body reconfigure in ways to adapt to the other body. Regardless of how care providers and recipients embody distinct capacities and needs and different ways of communicating or moving bodies, they adapt and learn to communicate and care for one another. Care starts circulating between them, rather than being sent from a provider to their recipient as the agency or society teaches them. Thus, they build their own care structure, transgressing care guidelines enforced by the agency:

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45 As English is a second language to both me and Sophia, the interview involved a lot of body language and our own way of communicating.
We built a pretty good relationship. Like she [her care provider] fixes me food or anything. She’ll probably take something [foods] for herself. Stuff like that. That’s how we do things. I don’t mind, as long as you don’t take it for granted. Or I’ll let her leave early, or she says “Paula, today I have to leave early, because of another cases.” And I’m like, “Okay, you can, make sure you finished [the task]. Can you come back later or can you finish that next day?” (Paula, care recipient)

In the above quote, Paula demonstrates how she and her provider developed enough trust to build their own routine of care practices suited better to them, while transgressing the guidelines from their care agency. In the circulation of care between them, they built a special and unique bond. As the opening quote of this paper illustrates, care recipients and providers become the “closest person, the closest relationship… [where] they see you when you are good and when you are bad…. It’s an unbelievable relationship…. The love and care you feel for them. They probably would never know. But it’s really um, thanks that you don’t know how to tell them.” Through the recursive encounters and practices of care disabled people and their care providers co-conduct, they adapt to each other’s distinct body, the ways the body moves, its capacities, needs, desires, and rhythms. In this relationality, they care for one another and capacitate each other.

**Further Elaboration of Affective Relationality**

Human relationships are a heavily scrutinized topic in psychology, whether in the study of solidarity building, intergroup relations, or attachment. Psychological inquiry into human relations often attributes its roots to psychoanalysis and builds on the premise that people are attracted to and form relationships with those who are similar to them (e.g., Watermayer, 2012). The perceived similarity—whether it is personal trait or similarity in belief—therefore, is considered to be a key for solidarity and other human connections (Goffman, 1963). In social
psychology, for example, social category theory is used to describe solidarity building for activism. Wiley and Bikmen (2012) theorize the necessity of an umbrella group identity (e.g., reproductive right activists, instead of abortion rights) with which all constituencies can identify. They argue that it is this umbrella identity which brings those different constituencies (some who advocate for abortion rights and some who demand the broadening of the goal, as their communities historically experienced forced sterilizations) together to share and build the goals and values (reproductive rights) and form the solidarity. Here, the similar goal and belief as well as shared identity are considered to be necessities for solidarity to flourish.

A theoretical psychologist, Slife (2004) critiques this type of solidarity (which is the dominant way solidarity is conceptualized and studied in psychology), as it is based on the “weak relationship.” He describes that the weak relationship relies primarily on cognitive connections such as shared value and goal and is not a relationship of “all the way down.” According to him, a weak relationship can be easily destroyed with the emergence of intra community differences in perspectives and beliefs, unless it is submerged or gotten rid of right away. Instead, he advocates for a “strong relationship,” where constituencies develop ontological relationships, beyond cognitive-based alliances, and where differences in opinions and values are welcomed for the further development of the relationship. Additionally, I would argue that solidarity building is in general theorized and practiced with a premise that all participants are independent and will take care of and contain their personal needs in the private sphere. Some psychologists (e.g., Wiley & Bikmen, 2012; Cole, 2008) began to write about the importance of forming solidarity, without overlooking the constituencies’ different backgrounds, in response to
the call from feminists and womanists. Nonetheless, the “difference” brought up in these writings is based on standpoint (e.g., identity and access to resources) and ignores the difference in embodied capacities and needs. Particularly, there is rarely discussion on a kind of solidarity building where the different degree of embodied needs and capacities means that some require assistance in order for them to be present and participate in solidarity building.

The notion of affective relationality that is co-capacitative, interdependent, and caring offers profound insights into solidarity building studies and practice. It is a “strong relationship,” as Slife (2004) describes, in which constituencies relate “all the way down,” and in which differences and conflicts are welcomed, as they are considered tools for the group to learn about and adapt to each other, and grow as collective. This type of relationality certainly can mean more than a friendship but also entail political implications. In Curit and Moreno (2010)’s words, it is “‘the little mo(ve)ments’—that is the embodied and shared micro-political moments as movements—that are the vital relational circuits through which negotiations, capacities for responsible and effective agency and change can most tangibly be grasped, explored, expressed and understood” (p. 414).

Elaborating on the concept of affective relationality, therefore, I advocate for solidarity that is built on a foundation of interdependent, caring, and co-capacitating relationality. It involves beyond-cognitive relationality: embodied and ontological relationality (Henriques, 2010; McCarthy & Prokhovnik, 2014; Slife, 2004). This relationality takes the time and labor of all the constituencies to grow by learning and adapting to each other’s different capacities, needs.

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46 Feminists, particularly womanists and feminists of color, raised the importance of understanding identity intersectionally and recognizing the diversity within an mono-identity-based community (see, e.g., hooks, 2004; Lorde, 1984)
desires, rhythms, and working styles. It also requires each member to acknowledge their own needs as well as capacities to contribute to the group. Thus the capacity building of a group may take nontraditional routes: acknowledging people’s contributions that may not align with mainstream ideas of contribution (based on capitalist ideas of productivity) yet are crucial to the capacitation of the collective (e.g., giving hugs or being “there” for one another). This affective relationality capacitantes those who participate in it as much as it capacitantes the collective. On the contrary, traditional weak solidarity sucks participants’ capacities toward the shared goal and management of the solidarity, including preventing intolerable differences from emerging, as such differences are considered as threats to break the solidarity (Slife, 2004). Solidarity based on affective relationality does not require its participants to be independent and self-contained; instead the collectivity nurtures the capacities of the group to meet the needs of its participants in order to avoid overburdening and burning out certain participants. Not only do its participants take into consideration each other’s differences in standpoint, this relationality addresses the different capacities and needs each of them embody as well.

Ruddrick (2010) compares Hardt and Negri’s and Deleuze’s interpretations of Spinoza and their applications of them to solidarity-building theories. Hardt and Negri’s interpretation relies on what Ruddrick calls “patchwork activism,” where different constituencies come together based on a shared goal (similar to the weak relationship brought up above). Ruddick critiques it as “frustrating in that it leaves unasked, and consequently unanswered, questions regarding difficult divisions, conflicts or divergent agendas in this process” (p. 40). Deleuze’s

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47 This, of course, requires constant practices and adjustment in order to keep the balance. Here, I am not trying to simplify the challenges and hardships of practicing interdependence. Instead I am promoting its potential and highlighting that many grassroots organizations and groups of people are already and always living in this way (see e.g., Mingus, 2010.)
interpretation, instead, underscores the process of solidarity building that is much messier, and it speaks to the development of affective relationality discussed in the chapter. According to Ruddick (2010), Deleuze and Guattari suggest that the ungrounding [of social fields] can only occur in a cramped space, a literal and figurative space where discourses collide, or broach their limits, where one is forced to think … in which everything becomes political and the individual is connected immediately to politics, to a social field … a terrain in which one is forced to invent or create new possibilities out of necessity … [I]t suggests we need to reflect on all that limits and bounds our politics, that we need to leave the comfort zones of our traditional arenas of operation and venture onto less stable terrain, where a new thought, new practices and a new world become possible. (Ruddick, 2010, pp. 40–41)

It is only through dire needs and collisions of impossibilities that possibility is born. Solidarity building, as well, needs to engage in deeper relationality where anyone can be a contributor. Only through the involvement of those who were formerly excluded from the solidarity terrain can imagine and enter new modes of thought and practice, and ultimately a new world.

**Conclusion: Affective Relationality as Undercommon of the Neoliberal Public Health-Care Assemblage**

People’s capacities are exploited by the neoliberal health-care assemblage, on one hand. On the other hand, capacity as discussed in relation to affective relationality is conceptualized more closely to the capacity to restore care recipients and providers as well as their care practices and relationships. “Spinoza distinguishes forms of power between *potentia*, an indwelling capacity to act, and *potestas*, a form of domination or alienation, which exploits and separates things from what they can do” (Ruddick, 2010, p. 25). I echo Spinoza and explore possible
classification of capacities: a capacity to “exploit and separates things,” as the care industry exercises (capacity to dominate), from the “indwelling capacity to act,” which has a restorative element as demonstrated in care relationships. This differentiation of capacities may seem meaningless, as neoliberalism appropriates all capacities indiscriminately; and indeed, it is the restorative capacity which keeps bringing care providers back to care work day after day. Nonetheless, this capacity also allows them to build relationality instead of subscribing to the individualization promoted by neoliberal ideology; and this making of a collective destroys neoliberalism itself.

The argument I developed in this paper is not to romanticize relationships emerging from care arrangements. It is also not to state that every care arrangement will turn into a relationship, nor claim that the relationship cancels out the injustices done within the neoliberal public health-care assemblage toward these people. On the contrary, my focus on relationship building is to suggest that solidarity and interdependent, caring, and co-capacitating relationships can emerge in the middle of interlocking injustices. As much as the assemblage contains the force to recode and reterritorialize the molecular to the molar (e.g., re-disciplining its participants based on the larger social norms and rules), there is always a line of flight, or a force breaking through the territorializing forces (e.g., a revolutionary force destroying and breaking through social norms and disciplinary power).

The theorizing of relationships within the care arrangement has been interpreted as a manifestation of sexist gender roles or internalized ableism, as described at the beginning of the paper (Erevelles, 2011; Folbre & Wright, 2013; Zelizer, 2005). Some scholars, such as Shildrick and Prise (2006) and Negri and Hardt (2004), have theorized this relationality as a form of resistance. Similarly to these thinkers, yet slightly distinctly, I understand the care arrangement-
based relationship or affective relationality as a form of the undercommon. Harney and Moten (2013) describe the undercommon as “underground, the downlow low down … where the work gets done, where the work gets subverted, where the revolution is still black, still strong” (p. 26). This concept acknowledges the inevitable existence of nonconformists underneath any institution, where the vital and constant interactions are manifesting and destroying the institutional order. Though all these thinkers identify Spinoza or Deleuze as part of their philosophical lineage, my turning specifically to the concept of the undercommon is due to its acknowledgment that relationality is happening, while its actors are deeply embedded in violent institutions. The acknowledgment that relationality is always and already happening everywhere highlights the unstoppable potential for people to relate, connect, and transgress institutional boundaries. People build relationships that make sense to their needs, capacities, desires, and rhythms. On one level, the care industry exploits the good intentions of those who enter care work or forces many to enter care labor; it also controls, manages, and debilitates those who require long-term care. One another level, some care recipients and providers are always and already engaging in collective caring, healing, resisting, and destroying of the neoliberal public health-care assemblage, which created the very care arrangement itself. They are happening simultaneously, and neither can be underestimated.
Chapter 7

Conclusion: My Manifesto and Embodiment of Our Resistance

Abstract

This final chapter is a reflection upon this dissertation. Provided herein are summary responses to the research questions I pose at the beginning of this dissertation. Then, I lay out limitations of this dissertation: one, which is methodological and the other, which is theoretical. My assessments of what constitutes “care justice” is documented next. In this section I explore both macro and micro ways of actualizing and practicing care justice. Finally, I end this chapter and dissertation by describing how the actual writing and editing of this dissertation is an embodiment of affective relationality. By applying what I have developed in this dissertation to the practice of academic writing, I describe ways in which my friends and I share the task of editing this dissertation for English grammar and usage (particularly when needs, such as English editing, are not institutionally supported in the university). Based on my experiences asking for English editing and negotiating ways to barter this necessary labor, I list questions of differently embodied capacities and needs as well as power and privilege to re-consider ways bartering of a labor is discussed and practiced.

I want to restate that the main purpose of this dissertation is to honor the axiom:

Care is fundamental to all life.

Put another way, everybody is dependent, and our lives and bodyminds are deeply interwoven with other lives and bodyminds.

Only through love, connection, and care, can we break the oppressive structures under which we live while imagining and practicing mutually co-capacitative, interdependent ways of living.

While this statement holds verity, this dissertation’s findings came to assert that various meanings, intentions, and motivations are attached to care practices, and it is not as straightforward as the statements about love and care indicate. Indeed, the virtue embedded in the above statements (held by many to be true) is used manipulatively to continue the legacy of gendered, racial, and class-based divisions within caring labor, which correlates with overall undervaluing
of care labor. Thus, this ideology is often infused among and confused with ableistic and sanistic understandings of disabled people’s agencies. These misrepresentations and misunderstandings can result in disrespecting of the rights of disabled people to practice self-determination, and/or the overprotection of disabled people.

One of the challenges I faced in developing this dissertation was this point exactly: how can stories that embody the tension within the kinds of labor that is both universal, restorative, and indispensable to life at the same time that this kind of labor is considered the purview and sole responsibility of certain populations’ and that the exploitation of certain populations is constitutive of the care industry. These conflicting realities are reflected in the title of a leading care studies book published recently: “For Love and Money: Care Work in the United States” (Folbre, 2013). The book shares care workers’ stories, stressing that it is both money and love that motivate their continual involvement in the care labor. Such tension is a main topic of this dissertation and has been interwoven into the following sections in as nuanced a way as possible, with the goal of avoiding binary perspectives and reflecting the complex reality of these two distinct yet inseparable perspectives.

The following section summarizes this dissertation’s findings in the form of responses to the research questions that are brought up in the introduction chapter. After that, I share two of this dissertation’s limitations: one methodological and the other theoretical. Then, I explore possible ways to conceptualize or explore what care justice entails. Finally, in the closing section, I reflect upon the process of writing this dissertation by directly applying what has been investigated: the process of neoliberalization as well as examples of collective and micro resistance.

**Summary of Research Findings**
• How has today’s public health care been shifted and shaped by the neoliberal political economy and its austere policy reforms?

The neoliberalization of the public health-care sector has manifested in a minimizing of governmental responsibility through the deregulation, privatization, and maximization of an individual’s (and their family’s) responsibility. In reviewing Medicaid and its related policies, it is clear that the privatization and deregulation of Medicaid began to accelerate in 1993. 1993 marks the year when the government started to grant of Social Security Act 1115 waiver to a number of states. With the use of this waiver, managed care took over major parts of the Medicaid care provision, handing much of the care administrative authority from the public sphere (state governments) over to the private care industry. As the industry simultaneously receives a major part of its revenue from Medicaid funding amassed by federal and state governments (as well as county in case of New York State; NYS), it was able to proliferate in the 19902, gaining power to significantly shape Medicaid care provisions. As the private care industry continued to take over the public health-care sector, the purpose of public health care shifted to become the accumulation of profits for the industry and suppression of governments’ public health-care expenses. A shift such as this one manifests itself interconnected ways: changes in the eligibility criteria for receiving care and changes in wages and working conditions if one is providing care. This slow but steady transition means that both care recipients and providers have come to experience exploitation and overall neglect and precarity.

• In what ways are the existing social injustices further deployed under the neoliberalization of public health care (e.g., sexism, racism, classism, ableism, sanism, and xenophobia that are inherent to care labors and practices)?
Care work is historically built on the bedrock of sexist, racist, classist, heterosexist, ableist and sanist, and xenophobic ideologies. Disability studies scholars explain how under widespread ableism and sanism disabled people’s agencies are overlooked, while, at the same time, their care needs and forms of dependency are overemphasized. Thus, care is often understood as a method used to confine and manage the lives of disabled people. Feminist scholars have similarly describe how women (specifically lower-income women of color and immigrant women, in the case of paid care works) are made responsible for both paid and unpaid caring labor. The feminization of caring labor thus contributes to the undervaluing and attribution of low wages to that labor. Queer studies scholars have shown how such a feminization of care labor relies on heteronormative constructions of care responsibilities. Social injustices and the marginalization of minority people within the sphere of care are further deployed as part of the process of neoliberalization.

Under the neoliberalization of public health care, many disabled people came to be measured based on the degree of their care needs. Some individuals are capacitated or considered “not disabled enough” to receive services, and are then pushed out of Medicaid, while others are considered “too disabled” to receive in-home care, debilitated, and are sent back to institutions. Their profound care needs are considered cheaper to attend to within mass-scale institutions. The rest of the American population needing care—those who are disabled enough, yet not too disabled—are kept under the Medicaid home-based long-term services and supports (LTSS). Those populations are kept under the home-cased long-term care, as their legitimate care needs brings public health-care funding from the governments to the industry, yet actual costs of providing care do not sum up too much: the perfect structure to maximize industry’s revenue. Welfare programs for single mothers also faced a neoliberal turn with the development of
Temporary Assistance for Needy Families (TANF). TANF imposed a five year limit on receiving benefits, thereby pushing the program’s beneficiaries into the labor force. Implemented three years after the neoliberal turn of Medicaid, TANF produced a mass number of lower- (or no) income single mothers—mothers who are disproportionately women of color—and who are forced to take any job. With the privatization of Medicaid and an increasing demand for people who will take on low-wage care work, many former welfare recipients were pushed into care labor jobs under the Medicaid. In addition, the emerging issue of the care crisis within a framework of globalization among nations of the Global North created transnational care industries that educate, train, and immigrate among mostly female workers from the Global South to put them into the abundant low-wage care jobs in the Global North. The neoliberalization of welfare in America—which some describe as a turn from welfare to workfare—capacitates lower- (or no) income single mothers and immigrant women from the Global South as low-wage laborers. Such workers are measured and valued based on their labor capacity and exploited based on the capacity.

In lieu of the reconfiguration of Medicaid beneficiaries and under the larger neoliberal public health-care assemblage, a transition within welfare programs and a rise in the transnational care industry related to immigration worked to further oppress those who are already marginalized in society based on race, class, gender, immigration-status, and disability. In other words, measuring and valuing labor capacity and care needs based on capacitation and debilitation of bodies is deeply shaped in relation to race, class, gender, nationality, and degree of disability.
What are the psychological and physical effects of the neoliberalization of public health care on those who are involved in it—particularly disabled people who receive their long-term care through New York State (NYS) Medicaid and their care providers?

While lower- (or no) income disabled people and women of color are measured based on their care needs and labor capacities and debilitated and capacitated accordingly, their care needs and labor are simultaneously commodified. In this process of commodification, their wellbeing becomes secondary to the industry and the state’s functioning. Through their roles as care recipient and provider, disabled people and women of color become consumable populations. Thus, the excessiveness of people who require long-term care, or the excessiveness of people who work low-wage care jobs in the U.S. turns all individuals further into disposable populations (Grioux, 2006). In the neoliberal public health-care assemblage, both care recipients and providers are exploited, often deteriorating physically and psychologically. Participants of this study who identify as care providers described physical consequences of taking on extensive hours and intensified care labor. Additionally, what occupied our conversations more were the psychological effects of engaging in care labor. As most of the laborers are also single mothers, they share the stress of not being able to spend time taking care of their own children. Their psychological stress accelerated through an unnecessarily intensified work environment induced by a lack of safety provisions on the job by the care agencies. Disabled care recipients simultaneously articulated a deterioration in the quality of care they receive from care agencies. These agencies are responsible for neglectful hiring, a lack of quality training for care providers, and a failure to attend to both providers’ and recipients’ needs. Many of the participants who are disabled care recipient comment on how one of the frightening consequences of low quality care is in fact death. Depicting actual experiences where their lives are threatened due to the lack of
trained care providers, care recipients explain how low quality care contains life-threatening risk even though care is often considered an enhancement of life. Both care providers and care recipients are put onto paths of slow death (Berlant, 2007). The public health-care sector under neoliberalism is not necessarily about assisting care beneficiaries achieve better qualities of life. In its current form the public health-care sector is also not able to support its workers in striving for better working conditions. On the contrary, the care sector’s focus on profit making has left workers and beneficiaries without the care and wage security they need; the neoliberal public health care has turned necropolitical.

- Does relationality emerge between care recipients and their providers, and if so, how?

As much as narratives of Medicaid care recipients and providers are filled with stories of the unjust treatment they receive amid the care assemblage, both populations also assert that there is more to care practices than total mistreatment and exploitation. According to this research’s care recipient and provider, care practices often begin with a clear divide between care recipients and providers. Such divides are induced by care agencies through guidelines, rules, and trainings, in addition to internalized social stereotypes and negative experiences providing and receiving care. Yet, recursive, co-engaged care practices bring the bodies of care providers and care recipients closer in mutual adaptation of each other’s distinct capacities, needs, desires, and rhythms. For sure, not all care practices blossom into caring relationships between care providers and recipients. When insufficient hiring practices become mundane among care agencies, un-supported and over-worked care providers occupy the majority of the care sector, care recipients must go through a number of potential care partners in order to find those who are qualified and caring, for example. Nonetheless, care recipients and providers repeatedly encounter and conduct care practices assigned to them and mediated by an outside care agency.
As they learn about one another, relationality emerges. While care practices are made to be binary, each movement and decision that constitutes a care relationship must be negotiated and synchronized between two bodies. By repeating these movements and actions, not only cognitive but proprioceptive connections between care providers and recipients emerges as both parties modify and shift their bodies in order to ease care practices. In addition to bodily connection, emotions begin to circulate between both parties. The beginning of care relationships present antagonistic power dynamics due to factors such as the inherent austerity measures of care agencies, the effects of pre-assumed stereotypes, as well as each person’s previous experiences of care. Yet within recursive care practices, care recipients and providers come to acknowledge the vulnerable experiences and situation their care partners undergo in their day-to-day lives or begin to share the vulnerable moments together as they spend most of their awake time together, side by side. Sympathetic feelings, thus, stem from this acknowledgement between care providers and recipients. This transformation of circulating feelings happens as care recipients and their providers adapt to each other’s distinct capacities, needs, desires, and rhythms.

- What does such relationality do?

Affective relationality which emerges from some of care recipients and providers is embodied relationality, a connection deeper than cognitive connection, and a proprioceptive and ontological relation. Centering both parties’ distinct capacities and needs, it is the recursive practices of care that give rise to affective relationality. It is the labor of both providers and recipients that allows them to slowly adapt to each other’s bodies, the ways they move, their rhythms and desires. Their bodies know proprioceptively when and how to move themselves in order to be in sync with each other when accomplishing the necessary task. They capacitiate each other. Such affective relationality is undercommon of the assemblage. The relationality is always
and already emerging amid the interlocking injustice within the care industry resisting and
destructing its structure. People within care relate to one another in ways that make sense to their
needs, capacities, desires, and rhythms. As such they transgress guidelines enforced by care
agencies. This affective relationality is an example of micro resistance: disabled people and their
care providers work to resist injustices circulating in the neoliberal public health-care
assemblage, slowly transforming the flow within the assemblage.

The kinds of insight provided by the concept of relationality is also applicable to theories
and practices of solidarity-building. Psychological theorizations of solidarity-building are
traditionally thought to be based on cognitive connections: solidarity made manifest through
shared belief, values, and goals. This type of solidarity is often built on an unspoken rubric:
contain oneself and keep personal needs in the private sphere in order to maximize the time and
energy needed for solidarity-building and the social justice goals of the public sphere. As
practical as it sounds, this type of solidarity is also susceptible to inter-group conflict; it is
limited to only those who are capable of containing their needs. Instead, solidarity-building
involving relationality develops much deeper levels of emotional, cognitive, and ontological
connection achieved only through repeat encounters and slow mutual learning that co-creates
unique ways of working collaboratively. This involves building group capacity in support of the
embodied needs of the group’s participants. Such affirmative and caring groups capacitate group
members inasmuch as they capacitate the collective. As much as it may be a more time
consuming and messy process, solidarity-building which entails affective relationality is a
‘strong relationship’ (Slife, 2004) allowing people with diverse capacities and needs to
fundamentally re-conceptualize possibilities for collective living among people of different
backgrounds, capacities, and needs.
Limitations of this Dissertation

I elaborate upon two of this dissertation’s limitations here. One is on its methodological limitation, and the other is on its theoretical limitation. In terms of the methodological limitation, or more specifically, in terms of limitations of data drawn from participants, this dissertation built its argument primarily on the narratives of people with physical disabilities. While it included a few participants who identify primarily with intellectual and developmental disabilities, this study is certainly not representative of larger disability communities inclusive of many different types of disabilities. As explained by Stainton and Boyce (2004) and others, the quality of care that disabled people receive largely relies on their ability to articulate and effectively communicate their needs, and, I must add, also the ability to negotiate forcefully with care agencies. Without these abilities or without the proximity to someone who can advocate on behalf of a disabled person’s care needs, exercising one’s agency and self-determination becomes a challenge. The focus groups were filled with stories of disabled participants’ challenges in receiving the care they desire and deserve. Nonetheless, still missing in the data was another layer of difficulty many with “severe” intellectual and developmental disabilities may experience without someone to advocate for them and without efficient methods of communication around their care needs and desires.⁴⁸ Other limitations of this dissertation include the lack of direct accounts from those who work at care agencies and a lack of official documents to back-up the information participants provided. It is no doubt that including the narratives and perspectives of care agencies to this dissertation would have enriched this

⁴⁸ A participant, Anton, described how his learning disability prevents him from applying for the social services he needs. Nonetheless, as he was only person who shares the experience and this type of account was a small part of the data, barriers experienced by intellectually and developmentally disabled people in the care system did not become to be the focus of this dissertation.
dissertation greatly. Yet, the primary focus of this dissertation is to understand the neoliberal
effect on public health-care assemblage from the perspectives of those who are most negatively influenced
by it. As this dissertation is the first step in understanding this assemblage, the next steps will
include connecting the data gathered with works already done in political science or sociology
(e.g., dissertation by Polson, 2013) that untangle care structures from the perspective of care
agencies. With regards to the needs of official documents to back up participants’ testimonies,
the need for this documentation has been pointed out throughout the development of this
dissertation. In particular I was asked to provide a copy of guidelines and rules enforced by
agencies as well as official documents that specify the breakdown of Medicaid funding
distribution among care agencies and providers. These requests were initially brought up in
relation to participants’ dismissal of guidelines and rules enforced by care agencies as well as
their complaints on ways the majority Medicaid fund is taken by the agencies before it reaching
to care providers. I attempted to obtain a copy of the guidelines used by the care agencies; yet
many participants told me that these documents are strictly for use by employees and not allowed
to be passed to outsiders. I, therefore, attempted to support participants’ testimonies by providing
information on the funding distribution among care industries’ revenues (e.g., how much revenue
is directly funded by the Medicaid). One of the disabled participants told me that recipients of
Medicaid LTSS can access information on the funding sources of their care services through the
NYS Department of Health’s website. One way for me to obtain official documents outlining
funding breakdown is, therefore, to ask care recipient participants to download their records for
this research. I felt, however, that asking for this information is too personal and invasive a
request. Because my research topic (everyday care practices) is already a very personal one,
asking for more information felt inappropriate. Therefore, I decided to use these participants’
testimonies as the primary source of this research, particularly since this dissertation focuses on the perceptions and understandings of the neoliberal care structure on the part of care providers and recipients in equal measure to an analysis of the care economy.

In terms of theoretical limitations, I am concerned as to whether my dissertation theorizes its findings within an overtly binary framework. The binary-formatting of narratives has been critiqued in social science and elsewhere for its over-simplification of narratives (e.g., a juxtaposition of the critiques of bad institutions with the simultaneous glorification and romanticization of the lives of resilient minorities); thus, more nuanced and complex forms of data analysis and theorization are sought. Reflecting on this critique in light of other critiques of the possible romanticization of theorizing care relationships, I wonder whether chapter 6, in particular, provides enough nuance. Such worries become heightened when reading the following narrative about an author’s autistic sister and her relationship to her care providers (Marcus, Kasnitz, & Block, In print, emphasis added).

I was thinking … how my sister [who is “autistic and does not speak”] vocalizes selectively and privately and how this is also matched with stimming movement. She does not do this in public with strangers or acquaintances. It is with her intimates and loved ones where she will relax and hum her feelings. Happy, excited, pissed off, frustrated, angry... Actually her staff probably do hear the pissed off, angry, frustrated ones, but I doubt they interpret it as music and calming movements—some staff see it as a sign of escalating behaviors that need to be managed, redirected and controlled.

This quote reminds me how adaptation and learning among distinct capacities, needs, and ways of communication can be used for the surveillance of individuals, potentially leading to unnecessary interventions. As I emphasized at the end of the chapter 6, the interdependent,
caring, and capacitating relational dynamic among care providers and recipients does not always emerge from recursive care practices. When it does, every interaction between a care provider and their recipient may not always be caring and capacitating. One way I think of recursive care practices and affective relationality is through Henrique’s (2010) work. Making a connection between affect and recursiveness, he describes: “[T]here is no repetition without variation. Repetition, like the Heraclitean river, is never the same twice” (p. 77). Similarly, just because a care recipient and their provider reaches a place where they regularly practice interdependent care does not mean that each daily care moments result in the same quality of care. Upon closer inspection, daily care routines are dependent upon care recipients and providers’ wellbeing that very day (e.g., whether they slept well or not). One reason for devoting an entire chapter to the discussion of the formation of affective relationality is because it is a major part of the participants’ narratives that cannot be overlooked. The importance of describing the significance of such relationality and its potential to root and strengthen any collective organizing (e.g., activist solidarity) is clear. My intention in theorizing the emergence of capacitating relationality is to underscore such relation-building as an unstoppable human force, even as these forces remain embedded in care-based structural injustices.

The Question of What Care Justice Entails

One question which arose continuously in the process of this dissertation writing was what “care justice” entails. The concept of “care justice” is used as an antonym to “care-based injustice,” and care-based injustices are composed of various factors. These injustices are multilayered. The public health-care sector exists as an assemblage and it includes both molar and molecular flows, each embodying different temporalities. The number of interventions that can be made are equivalent to the number of components in the assemblage. I use the term “care-
based injustice”, for example, to describe sexist, racist, classist, heterosexist, ageist, ableist, sanist, and xenophobic aspects that are inherent to care practices, and to highlight neoliberal elements such as an intensified exploitation of caring labor and a deterioration in the quality of care. Similarly, “care justice” has been conceptualized in many diverse ways by different scholars and activist organizations. Scholars such as Lynch et al. (2009) and Daly and Standing (2001), for example, approach care justice from a human rights perspective. Approaching care justice from the field of international labor studies, Daly and Standing (2001) state that there should be

[A] human right to receive care, which means that there should be a right to provide care

… [T]here must be adequate income, both for those providing care and for those in need of it. There must be … real freedom for caregivers and care receivers, which means having access to the mechanisms of defending and enhancing the same rights as those enjoyed by all other groups of workers and citizens in society. (p. 1)

Their conceptualization of care justice demands lifting care recipients and providers’ social statuses to the levels of others through mechanisms of free choice and individual rights. A similar right-based model is utilized in sphere of activism as well. Working directly with domestic workers communities and some disability rights and senior citizens’ rights communities, the Caring Across Generations49 movement states five goals50 for achieving their version of care justice (Shilley & Buchanan, 2013). These goals entail:

- responding to the future need for two million new home care workers

49 A national campaign to change the face of care by building solidarity between domestic worker, disability right, and senior citizen communities. More descriptions are shared in chapter 1.

50 There are different versions of the five goals, and I am using the latest one I found for this chapter.
- providing a living wage for current and future home care workers
- providing quality training programs for long term care workers
- providing a pathway to citizenship for these workers
- creating social insurance programs that provide financial support to individuals and families that need long term care services.

In contrast to the quote by Day and Standing, Caring Across Generations’ five goals advocate for more specific and practical rights, primarily for care workers. These conceptualizations of care justice reflect how justice for care providers and recipients take place at multiple levels: from the need to resist and deconstruct the larger global economic inequality, to ensuring the wellbeing of those who labor in care and those who require long-term care. In the remaining part of this chapter, I briefly explore ways to actualize care justice by reflecting on the findings of this dissertation. First I address care justice on the macro level by contemplating ways to disrupt and transform the neoliberal public health-care assemblage. Then, I explore care justice on the micro level by providing equally powerful examples of everyday resistance that work to mitigate the intensity of care labor and improve the quality of care provided.

When I think about macro level intervention, on one hand, I dream of building the caring structure beyond the confines of the state without having to rely on the state. My dream is a self-governing collective, for example, where members accumulate the collective capacities needed to cover all of its members’ care needs; and where everyone’s contribution to the collective is valued regardless of the degree and the type of contribution each participant makes; and where the development of one’s own system of care is interdependent with others’ care. Simultaneously, though, I feel the urge to think about care justice in very realistic and grounded approaches: what changes, for example, are achievable in the next one, five, or ten years? While
there are cases where a small number of people coming together to build a caring collective group (e.g., the care collective I participate in shared in chapter 1), the majority of disabled people lack resources to organize and access such collectives.

Taking this reality into consideration, I first make suggestion for interventions to the existing system. A direct, and yet tricky, response to the pursuit of care justice is an increase to the Medicaid budget, which would safeguard and ensure that a certain percentage of Medicaid funding is allocated solely for care providers. As superficial as it may sound, this recommendation is one way to increase the value attached to care work. Whether it is achieved by cutting some of the country’s largest, military and defense budget or by raising taxes on the wealthiest of Americans, raising the wage of care labor allows care providers to work shorter (and more standard) amounts of time than the current extended work hours that exploit them. It thus allows care providers to spend more time with their family members and to take care of their own wellbeing. Additionally, raising care providers’ wages is one way to re-value care labor. Such a raise can encourage more people to take on and share the responsibility of care and can begin to undo the gender-, race-, class- and immigration-based division of care labor. As a long-shot as it is, improving the quality of the working conditions and the wellbeing of care providers can lead to an increase in the quality of care received and exchanged. An increase of the Medicaid budget would allow agencies to hire only those who are dedicated to care which would facilitate the implementation of more rigorous training for care providers.

To achieve a fundamental transformation within care, other social policies deeply entangled with the care sector require change and improvement. The related policies include the welfare program for single mothers and immigration policies, both populations make up the majority of care labor as care providers. Policies related to social services for disabled people
(e.g., supplemental security income) must also be improved. Change to all three areas of U.S. policy is necessity for paving the way for the wellbeing of these populations constitutive of the care labor industry. Improving politics that intersect with policies currently shaping the care industry means these constituencies will have more agency over where they work and what kind of labor they engage. As this dissertation has repeated stressed, care work is not for everyone. Improvements made to these policies will allow those who do not desire to work in the care sector to resist being forced into care jobs. Allowing those who do not wish to work in care jobs to work elsewhere will therefore lead to a higher level of service that those needing long-term care receive. As this dissertation is completed, the U.S. disability community celebrates the passage of Achieving a Better Life Experience Act of 2014 (as known as ABLE act) which eliminates the $2,000 limitation placed on the total savings by SSI and Medicaid beneficiaries. The ABLE act allows disabled people and their families to save funds greater than $2,000 without penalizing or taking away social services (e.g., SSI and Medicaid) that supplement disability-related expenses. This act is designed to encourage disabled people to practice financial independence, allowing to work and save the earnings without losing their medical care. These types of interventions to policies affecting both care providers and care recipients must continue in order to achieve care justice.

In addition to intervening at policy level, the ways in which the care industry manages care arrangements must be changed. Though I will not go in-depth here, there have been interesting interventions made to the structure of care agencies. As minor and/or experimental as some of these examples are, I briefly review two non-traditional care agencies. One include the rise of consumer-directed care due to two reasons: one, the disability rights movement’s advocating of community living and deinstitutionalization, and two, the government’s move to
suppress Medicaid’s funding of institutional care expenses. Under the consumer-directed care program, a greater amount of administrative authority is given to care recipients as they hire and train care providers on their own (a more detailed historical description of the consumer-directed care program is given in chapter 2 under the literature review section). Some of the research participants of this dissertation who have utilized this consumer-directed program shared that there are benefits to using the program: including direct negotiations with potential care providers as well as an absence of heavy restriction or surveillance when it comes to their own care. Also, many participants explain that this program pays care providers higher wages, with more benefits (including 401Ks) due to the lessening of care agencies’ responsibilities, administrative and otherwise.

Another intervention made to the long-term improvement of care agencies is the creation of a non-profit care agency focused on a “community–based” approach that has “at its core a community of people—our members, providers of care, staff and friends—who share a common vision and beliefs: that senior adults and people with disabilities or chronic conditions can often take the lead in planning and managing their own health care and social supports” (Independence Care System, n.d.). Based in Brooklyn, NY, Independence Care System was founded by former care providers and is an organization inclusive of rights activists as well as other elderly and disabled people who receive long-term care. All of these represented constituencies serve as part of the organizational board; senior staff members also aim to reflect the voices of the communities they are part of (even if, they find themselves to be in the minority in number). Additionally, this agency hosts a number of community events that are planned and organized by consumers of the agency (disabled care recipients), and that function as a community building space primarily for disabled people, in collaborations with their care providers as well as other
Independence Care System staff members. Such events allow care recipients, providers, and staff members to build relationships with one another. In other words, this organization is more than just a care agency, and many individuals whose care is coordinated by Independence Care System describe it as a big family.

As much as the two examples used in this section have great potential for making real positive differences in the way that long-term care is arranged, they are also like any initiative, not without critique. These critiques include, for example, that in consumer-directed care, some care providers are made vulnerable due to a lack of outside support or accountability in the event of mistreatments (e.g., sexual harassment in the workplace). As much as consumer-directed programs minimize the involvement of care agencies in the relationship of care, it also means that care recipients and providers must communicate and negotiate with one another without guidance of industry standard. Another critique of consumer-directed programs is the amount of added responsibility that disabled care recipients must endure by way of completing administrative work that was formerly the purview of the governments or the care industry itself. While acknowledging the shortcomings and the need for continuous revision and reflection, I bring these two examples to light in order to provide examples of alternative systems of care. While fundamental changes to public health care are still needed, there are ways for agencies to practice care justice at a greater scope and scale. The reconfiguration of the ways agencies operate requires the day-to-day wisdom of both care providers and recipients.

In addition to calling for direct and achievable systemic transformations within care agencies, this dissertation also seeks to highlight examples of micro resistance. Consistent and persistent acts of micro resistance maintain the humanity within us and slowly destruct the systemic oppression all around us. As Curti and Moreno (2010) describes as: “the little
mo(ve)ments’—that is the embodied and shared micro-political moments as movements—that are the vital relational circuits through which negotiations, capacities for responsible and effective agency and change can most tangibly be grasped, explored, expressed and understood” (Curti & Moreno, 2010). In particular, this dissertation spotlights the importance of affective relationality as micro resistance. Concepts and practices of dependency, interdependency, or collectivity are frequently mentioned in scholarship as solutions or alternatives to structures of neoliberalism and generalized oppression. Butler (2004), for example, centers interdependence in order to imagine an alternate and more peaceful world: “[T]he dislocation from First World privilege … offers a chance to start to imagine a world in which that violence might be minimized, in which an inevitable independency becomes acknowledged as the basis for global political community” (p. VII). Butler continues by stating that "I confess to not knowing how to theorize that interdependency” (p. VIII). As Bultler shows, a general awareness of the importance of interdependency exists in academia without much in-depth conceptualization or theorization as to how it might work. Here, understandings of collectivity’s ontological nature can be overlooked when human connection is imagined based solely on cognitive connectivity (e.g., correlation among shared values, goals, and beliefs), ignoring differences of bodily capacity and need. As chapter 6 describes in depth, such cognitive collectivity is considered superficial or weak relationality, thereby excluding individuals who might be incapable of independently participating in such collectivity, and thus vulnerable to the inter-group conflicts (Slife, 2004). Instead, this dissertation suggests that care justice entails strong relationships or ontological connectivity, among those involved in care practices (beyond care recipients and providers, to include family members and friends in addition to those individuals employed by care agencies). Micro bonding is fundamental to larger strategies of resistance necessary to
collective living that is both more humanistic and more ethical. In Dupree’s words (2015, In print), people’s spirits and souls are inherent components to this form of affective relationality:

We need a Medicaid system that understands that there's a human spirit. Failing that, we need communities, religious and otherwise, that understand that there's a human spirit. Failing that, or preferably, in addition to that, we need small groups of dedicated people who understand that there's a human spirit, groups that can form the foundation of a new movement. I propose a new, deeply human movement, that is built around the human dignity inherent in the disabled person and all mankind … [L]eading empathic actions on the ground and in person, communicating and connecting with the most marginalized and disconnected, taking their stories “viral.” We must strike the empathic chords within the human spirit, remind people of their humanity. In speeches, Chris Hedges often references the violinist that appeared in the subway during the worst ethnic cleansing of the Bosnian conflict in the '90s, playing beautiful classical pieces, reminding everyone that there are other things to listen to besides Slobodan Milošević's warmongering state TV and hate radio, and that we can still be human. These small acts of resistance should be the main aim of our new movement.

We must continue the practice of care in order to learn and adapt to one another’s distinct needs, capacities, desires, and rhythms. This adaptation will lead to a deep ontological and embodied forms of relationality that recognize interdependence as the way to live collectively and which capacitate all bodies. Such relationality is undercommon: fundamental to the destruction of neoliberal structures deeply rooted in our spirits and souls.

Closing
Affective relationality was present in the process of writing this dissertation. It is this collectivized relationality that enabled my thoughts and ideas to be communicated to others. As neoliberal forces continue to pressure academia to adopt an overestimation of individualized responsibility, I was solely responsible for the editing of my written work (Nishida, 2015). There was no institutional support from my university. It was, therefore, the support and assistance of my friends who provided the editing services that allowed me to complete this dissertation in addition to other graduate-level work. As much as this form of assistance can be understood as warm and loving support, another way to read it as sharing an individualized responsibility and reclaiming deeply individualized academic labor as collective labor. Indeed, as my friends and I discussed ways for me to give back to them, many friends reminded me that “it is a collective task” and that “it takes a whole village to raise a dissertation.” This recursive process of asking friends for help and conversing together ways to complete the bartering exchanges provided me deep insights into this dissertation and evoked many emotions in me. These emotions included vulnerability felt under the conditions of asking for help; internalized feelings of inferiority due to the continual need for English editing; feelings of regret for taking up so much of my friends’ time; and, finally, frustration and anger toward the exclusionary nature of English-centered academic knowledge production. To this day I continue to ask myself what it means for me to internalize these emotions within the context of English-speaking academy. When one is granted the privilege of English language fluency and others are deprived of such privilege, what does it mean for the recipients of such care (in this case English editing) to give back to those who provide the care? And simultaneously, as much as the service of English editing can be understood as a way for English-speakers to share their privilege, it is nonetheless labor that takes up time and energy. These questions of embodied capacities and needs, of privilege and
power, and of the complexity of negotiating labor at the seam of intersecting structural injustices are deep and complex questions for future work and through.

While I do not have a clear answer to those questions, one thing I know is that this dissertation would not be completed without the English editing services provided by Park McArthur, Michelle Billies, Joe Martello, Rachel Liebert, and Amalle Dublon. Also, by naming these individuals, I do not mean to take for granted the love and support given to me by those without time, energy, or skills needed for English editing, and have nonetheless offered various kinds of support. As much as this dissertation is about the documentation of the neoliberal public health care and relationality building between disabled people and their care providers, the production of this dissertation is also an example of our collective response to the neoliberal, individualized turn within academia. This dissertation is my manifest and embodiment of our resistance to collectivize academia.
### Appendix A: Focus Group and Individual Interview Questions

Focus group with disabled care recipients

<table>
<thead>
<tr>
<th>Settling in and care art activity</th>
<th>Please use all the art supplies in front of you as you like to express your answer to the question: “What does care mean to you?”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introductions and description of care</td>
<td>Please introduce yourself and tell us about your art. How often do you receive care? What kind of care? How long have you been receiving care? (Sharing of the art) From whom do you often receive care?</td>
</tr>
<tr>
<td>Worst and best care practices and relationships</td>
<td>Can you share stories of challenging care relationships you have had with your care providers? What makes some care relationship more challenging? What is the best care relationships you have had with your care providers? What makes some care relationships better? In what ways do you show your care to your care providers?</td>
</tr>
<tr>
<td>Critique of system</td>
<td>How does your agency treat you and other consumers? How does it treat its employees? Do you think the agency cares about you, other consumers, and its employees? If yes, please tell me how agencies care about you and others. People say that the system is profit centered and not people-centered, and do you agree with this statement? Why?</td>
</tr>
<tr>
<td>Practicing of just care</td>
<td>What is ideal care for you? What is “just care”? How do you want to be treated by your care provider? How do you want to treat your care provider? Is there anything you are doing now with or for your care provider to practice just care? If yes, can you share some examples?</td>
</tr>
</tbody>
</table>

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51 Follow-up questions used are omitted here for the purpose of clarity, as they were often spontaneous and unique to each conversation.
### Individual interview with care providers

| Settling in          | How often do you give care to disabled people?  
|---------------------|-------------------------------------------------  
|                     | What kind of care?                              
|                     | How long have you been doing care work?         
|                     | Can you tell me what care means to you?         
|                     | Who do you often give care to?                  
|                     | Who do you often receive care from?             

| Becoming a care provider | Can you tell me how did you come to be a care provider?  
|-------------------------|----------------------------------------------------------  
|                         | How and why did you choose this career?                  
|                         | Can you tell me what types of training have you received at your agency?  

| Critique of system | How does your agency treat its employees?  
|-------------------|------------------------------------------  
|                   | Do you receive any benefits?             
|                   | Some people have told me actual examples of how care providers are treated horribly by their employers. Do you have any example?  
|                   | Do you think that agencies care about their employees?  
|                   | If yes, please tell me how agencies care about you or other employees.  
|                   | How do your care recipients treat you and other care providers?  

| Worst and best care relationships | Can you tell me stories of challenging care relationships you have had with your care recipients?  
|-----------------------------------|----------------------------------------------------------  
|                                   | What makes some care relationships challenging?           
|                                   | Do you have any body pain or discomfort caused by this work?  
|                                   | What is the best care relationship you have had with a care recipient?  
|                                   | What makes some care relationships better?                
|                                   | In what ways do you think your care recipients care about you?  
|                                   | In what ways do you show to your care recipients that you care about them?  

| Practicing of just care | What is ideal care for you?  
|------------------------|-----------------------------  
|                        | • How do you want to be treated in your care work?        
|                        | • How do you want to treat your clients in your care work?  
|                        | Is there anything you are doing now with or for your care recipients to practice it?  

Appendix B: Participant Descriptions

Care Providers (10)

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age</th>
<th>Gender</th>
<th>Race</th>
<th>Immigration status</th>
<th>Recipient of social services (other than Medicaid)</th>
<th>Years working as care provider</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alisha</td>
<td>43</td>
<td>F</td>
<td>Black</td>
<td>Not immigrant, nor a child of immigrant</td>
<td>N</td>
<td>14 years</td>
</tr>
<tr>
<td>Isabella</td>
<td>36</td>
<td>F</td>
<td>Black</td>
<td>A child of immigrant</td>
<td>N</td>
<td>7 years</td>
</tr>
<tr>
<td>Tia</td>
<td>40</td>
<td>F</td>
<td>Black</td>
<td>Immigrant</td>
<td>N</td>
<td>14 years</td>
</tr>
<tr>
<td>Sophia</td>
<td>55</td>
<td>F</td>
<td>Hispanic</td>
<td>Immigrant</td>
<td>N</td>
<td>14 years</td>
</tr>
<tr>
<td>Jessica</td>
<td>--</td>
<td>F</td>
<td>Black</td>
<td>Immigrant</td>
<td>N</td>
<td>More than 10 years</td>
</tr>
<tr>
<td>Patricia</td>
<td>--</td>
<td>F</td>
<td>Latina</td>
<td>Immigrant</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>David</td>
<td>--</td>
<td>M</td>
<td>Caucasian</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Stephanie</td>
<td>--</td>
<td>F</td>
<td>Black</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Terrie</td>
<td>--</td>
<td>F</td>
<td>Black</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Olivia</td>
<td>--</td>
<td>F</td>
<td>Black</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
</tbody>
</table>

52 Age and years of care receiving/providing are at the time of interview: 2013. Disability and Race are stated based on what the participant wrote down on the demographic questionnaire.
<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age</th>
<th>Disability</th>
<th>Gender</th>
<th>Race</th>
<th>Years receiving LTSS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paula</td>
<td>44</td>
<td>Cerebral Palsy</td>
<td>F</td>
<td>Black American</td>
<td>15 years (since 2000)</td>
</tr>
<tr>
<td>Maria</td>
<td>66</td>
<td>Rheumatoid Arthritis</td>
<td>F</td>
<td>Spanish</td>
<td>10 years (since 2005)</td>
</tr>
<tr>
<td>Amy</td>
<td>32</td>
<td>Physical</td>
<td>F</td>
<td>White</td>
<td>15 years (since 2000)</td>
</tr>
<tr>
<td>Tonya</td>
<td>61</td>
<td>Spinal Cord Injury</td>
<td>F</td>
<td>African American</td>
<td>19 years (since 1996)</td>
</tr>
<tr>
<td>Ty</td>
<td>45</td>
<td>Quadriplegic</td>
<td>M</td>
<td>African American</td>
<td>23 years (since 1992)</td>
</tr>
<tr>
<td>Keisha</td>
<td>45</td>
<td>Cerebral Palsy</td>
<td>F</td>
<td>Black</td>
<td>22 years (since 1993)</td>
</tr>
<tr>
<td>Anton</td>
<td>52</td>
<td>Dyslexia, Reading and Writing</td>
<td>M</td>
<td>American Bilingual</td>
<td>N/A</td>
</tr>
<tr>
<td>Rick</td>
<td>54</td>
<td>Congenital Arthrogryposis</td>
<td>M</td>
<td>Black</td>
<td>8 years (since 2007)</td>
</tr>
<tr>
<td>Joanne</td>
<td>24</td>
<td>--</td>
<td>F</td>
<td>Hispanic</td>
<td>--</td>
</tr>
<tr>
<td>Shantel</td>
<td>63</td>
<td>Cerebral Palsy</td>
<td>F</td>
<td>Black</td>
<td>40 years (since 1975)</td>
</tr>
<tr>
<td>Joshua</td>
<td>59</td>
<td>Pervasive Developmental Disorder</td>
<td>M</td>
<td>Caucasian</td>
<td>8 years (since 2007)</td>
</tr>
<tr>
<td>Bill</td>
<td>41</td>
<td>Cerebral Palsy</td>
<td>M</td>
<td>Caucasian/ White</td>
<td>N/A</td>
</tr>
</tbody>
</table>


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