Introduction

**Needing Care and Caring Needs**

All living creatures have needs. To need is to be alive. Still, we often let ableism classify some needs as socially accepted and others as not. Instead of receiving support, people [with] intellectual disabilities often lose their autonomy if they need help making decisions. Cities send police officers [with] guns if a person needs psychiatric support. People who need daily assistance are called “drains” on the state. Capitalism is most exploitative when it focuses us to ignore limitations or needs. *How can we hold need as sacred?* [emphasis added]

—Disability Justice Culture Club, “All living creatures”

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I

**Needing You**

On the late afternoon of October 28, 2012, I was needed by and simultaneously needing my friends. Texts from a number of friends from disability communities flooded my cell phone. They were all desperately looking for emergency care supports for our friends Michael and Sonia, as Superstorm Sandy was approaching New York City. Although they direct their own long-term care routines—twenty-four-hour home nursing care for Michael and several hours of care a day for Sonia—they urgently needed someone to come over and carry out care tasks that they direct during the hurricane.

The urgency was palpable as the sky got darker and the wind caught speed—all signaling that the storm was about to land on New York City. City officials had announced the closure of the subways, bridges, and tunnels that connect Manhattan with other boroughs and New Jersey. It meant that nobody—including the care worker who was supposed to take the next shift—was entering or leaving the island. I immediately hopped onto one of the last subway trains from Brooklyn to Manhattan. The subway cars as well as the streets leading to their apartment were almost desolate—occupied only by people who were experiencing housing insecurity, wearing layers of clothes, sitting with shopping carts full of their belongings to prepare for
the hurricane. Acknowledging their presence from the corner of my eyes and feeling the chill in my backbone as the city’s lack of care for certain people was more alarming than the hurricane itself, but I continued rushing to my friends, who were my priority that afternoon. Finally, I arrived at the tall residential building where they lived in lower Manhattan. Many apartments in the building seemed vacant as the occupants had left to seek safety and comfort, while building managers hurried to get ready for the hurricane.

As I walked into Sonia and Michael’s familiar and warm apartment, I was immediately embraced and competed for space with power chairs, beds, complex connections of wires, computers, and other communication and entertainment devices, as well as the tall towers filled with medical devices, including Michael’s ventilator. These devices filled the room with the rhythms of different and constant sounds signaling that they were functioning just fine. This is their living room/bedroom/community gathering space, which was covered by the decorations from the last birthday the room had witnessed. The room acts as activism strategy office, movie-watching social space, and home-away-from-home for disabled wanderers from all over the world. Michael and Sonia are, after all, a power couple and the keystones of disability communities both virtually and in real life, and they do not hold back support for anyone who comes their way. They are activists and cultural workers who are friends and crip family to me and so many others. They took care of me, as they fed me emotionally, physically, intellectually, financially and much more in this room, just as they did for anyone who comes their way.

That afternoon, the apartment was a cave, protecting its inhabitants from the anxious rush on the other side of the door. Sonia and Michael welcomed me with a smile just like any other day—Sonia from her power chair, sitting between her and Michael’s beds, and Michael from his bed. Michael’s care worker and friend, Jason, was engaging in tasks as usual, and just like any other day he was leaving after his shift in the early evening (instead of extending his stay and care shift) in order to take care of his own and his family’s needs, which meant leaving Lower Manhattan before all the transportation got shut down. There was no sign of other care workers coming to take the next shift, or any shift in the near future, because of the emergency situation—hence Michael and Sonia had reached out. They had prepared several gallon jugs of water and their fridge was filled with just the usual amount of food. After all, we were not sure how big the hurricane would actually be, and we also were facing the limits of what we could prepare as disabled people leading the life of the financially poor (but rich with community love).
Going to a shelter or hospital was not an option, they told me early on. The shelters and even hospitals were not accessible enough or ready to provide the particular care they needed. Electricity is key to providing Michael with air, nutrients, and medicine as he lies on his bed and to enable Sonia's power chair and their reclining beds to do their work. Hundreds of tiny pieces of plastic, metal, and fabric must be assembled and work together perfectly for them to live. In these circumstances, anywhere but home felt precarious. Any hiccup with hospital generators; a lack of time, energy, or will of nurses to learn specific and individualized ways to provide care to Michael (particularly his tracheostomy care); lack of wheelchair-accessible space for Sonia to be near Michael to direct his care; or even a tiny dislodge of Michael's oxygen bag, which provides him with air, while he was transferred to a hospital could end my friend/family's life. Michael had endured the trauma of institutionalization in his earlier life and was determined not to go back. Based on how disability services and programs are set up and budgets are allocated, it was easy to imagine, and pretty much guaranteed, that evacuating to a hospital would automatically lead to Michael’s being reinstitutionalized without any promise of getting out.

We lost electricity the second night after I got there, and then water, and eventually cell service. Lower Manhattan never gets dark—ever. It is home to Wall Street, city hall, and the heart of this nation's economy. And yet that night, it was weirdly dark—except for the construction site of Freedom Tower, which was intensely lighting up nothing but concrete and metal.

The sudden cutoff of electricity acutely showed why I was needed. Electricity enabled them to live. Without electricity, the battery of Michael’s ventilator would run out in a few hours and stop assisting Michael to breathe. Here my needs kicked in too—I needed my friends to survive the hurricane and continue allowing me to be embedded in their lives. I was the only one in the household—consisting of three disabled people (since Jason had left already)—mobile enough to take the stairs to go to the nearby fire station to use their generator to charge a spare ventilator battery. The game plan was this: I would go there every few hours to charge the spare battery, the ventilator would keep working, and my friend would keep breathing and living. A straightforward and simple task—except that it is not. To do so throughout a night without adequate sleep, go down and up staircases in absolute darkness for at least a dozen floors which were occasionally occupied by strangers, seemed nothing compared with the alternative—Michael wouldn’t get to breathe. And yet, it was hard in its own right—to be beyond exhausted, walking up and down staircases with a body not used to such exercise in the middle of the night, passing strangers who were way bigger than me and intoxicated, in the complete darkness, and knowing that most
of the apartments in the building were vacant, so no one could hear me or come to help. But the hardest part, which still gives me chills today, was the sense that my friend’s life literally depended on me. My head told me to stay calm and rational, yet my body and imagination exploded with anxiety and panic. Every nightmare from the past occupied my head, and all the anxiety of the future thrummed in my skin. My friend’s life depended on me, in an acute and direct way, as much as my safety also felt precarious in a different way, as a Northeast Asian disabled cis woman living in a world filled with race-based gender violence—but again, I repeated to myself, this was nothing compared with the anxiety Michael and Sonia must be feeling to put all their eggs in one basket—me.

By the third day, the sun was shining, the hurricane was gone, and we sat and lay in the sunlit room together, alive but still desperate with no water or electricity, not much food, and dying phone batteries with no cell signal. Our phones had been our lifeline connecting us with the outside world, so losing them activated another level of devastation.

It was then that an unexpected knock on the apartment door vibrated the air of the quiet apartment. Surprised, we looked at each other exhaustedly, and when I opened the door, there were two strange men. They were holding a box of food, water, and other supplies and quickly told us that our friend and local disability rights activist had sent them, and they were in the middle of delivering more supplies to other people.

Right before we lost our phone signal, I posted on Facebook: “Day 2, no power. Which means I’ve [sic] been running up and down of 10+ stories stairs every few hours to charge batteries. Which means no food. While the city offers a car to pick up nurses, no nurse since Sunday night. HELP.” What we did not know in that small New York City apartment was that the disability community had gotten together online, collecting supplies needed to keep us alive and connecting with local strangers or disability community members who were mobile enough to send supplies our way.

Using Google Docs, a virtual network was ever-expanding with friends and strangers signed up to take turns making the battery run for Michael’s ventilator, to provide ad hoc care for Michael and Sonia, and to coordinate people to collect gas and drive to pick up and drop off their home care workers. People all over the United States sent marine and car batteries so that Michael and Sonia could have electricity at their own home eventually without running to the fire station every few hours. A community-based care and support structure was established, and it lasted for months. So many connections were forged and many new friends were made. In particular, queer communities came first by bike to Manhattan to support Michael and Sonia—strangers to them.
Weeks later, still in the middle of my own recovery from what had happened, I sat down with participant observation assignments submitted by the students in my disability studies qualitative research method class at a continuing education college. The class was filled mainly with those who worked as care workers at group homes for people with intellectual and developmental disabilities. They were almost all Black and Brown migrant women. Given that the hurricane happened in the middle of the semester, many documented their experiences during the hurricane. What filled their participant observation papers was how they had to work day after day—even a week and more—nonstop during the hurricane and its aftermath. There was nobody to come and release them from shifts, as transportation, bridges, and tunnels were still shut down or operating in a very limited capacity. Some care workers were forced to go back to work while their own disabled elderly parents sat in flooded homes without electricity. Many of those care workers, in other words, had to make hard and yet familiar choices of work or family—which is ultimately about whose care needs to be prioritized.

New York City’s recovery was not done equitably. While the business district of Manhattan recovered in a blink of an eye, people living in the periphery of New York City lived without gas and electricity or among debris for months to come. A documented 106 lives were lost during this deadliest hurricane of 2012. This includes a death caused by failure of an oxygen machine due to the electricity shortage. Furthermore, countless people lost their wheelchairs and other assistive devices in floods and during the mess of evacuation.

My need to keep my friends alive was met, and I gained new friends and assurance of community support during the ad hoc care shifts; however, it took me a while to regain a calm mind, however temporary. Questions from those days still occupy me: How can government meet people’s needs and where are their limits? What are the possibilities of community-based and grassroots care and what are its limitations? What happened to other disabled people (and their needs) who did not have the kind of social capital and resources that Michael, Sonia, and I had? Whose needs are highlighted and whose are put aside? Why are we trained to prioritize people’s needs: Are the needs of disabled people in group homes more urgent than the needs of disabled elderly parents whose children who are the primary family care providers and also work as care workers for wage have no choice but to leave them behind to go back to their work to attend to other disabled people?

Are some people’s needs more sacred and urgent? How are their lives more precarious than others? How do we measure people’s needs and determine priorities regarding whose needs will be attended to first? Whose
and what needs can wait? How do we know whether needs are met or not? How do we meet the needs of those who are unaware or taught to ignore that they have needs? Who is allowed to need? Whose needs are met with care? Reflecting on the opening quote from Disability Justice Culture Club, how can we shift society and our ideologies to “hold need as sacred?” What would our daily lives be like, and how would it feel to embrace and center our needs and dependencies as our principal values?

Care often emerges from needs, while needs are not always met with care. The preceding story, at a glance, seems an extreme case of care—caring during the superstorm. And yet it is not. It is a mere extension and continuation of the precariousness and challenges of everyday care that people negotiate whether they are situated as care givers, care receivers, or both. Exploitative labor conditions for care workers and of the difficulties that disabled people and others with long-term care needs face in securing ad hoc care have been a chronic issue, as the care crisis has become a regular occurrence in the United States. How to decrease expenditures by public healthcare programs (e.g., Medicaid) while the number of people who need daily care and support only increases, and how to find care workers who will work under unjustifiably difficult conditions (i.e., low wages with meager benefits) have been the challenge politicians are tackling—but this problem also shows how poorly they understand and imagine the structure of care and people’s needs for care. On the ground, though, those who perform care work have always had to decide every day whose care needs to prioritize (e.g., their clients’, their children’s, their aging parents’, or their own). People who are situated as care recipients, including people who are disabled, have always had to improvise when care is lacking by being carers for one another, as much as they cry, complain, and advocate together to end the low-quality care (aka ableist abuse) that they are subjected to.

In Just Care, I investigate the multiplicity of care—how it is turned into a mechanism of social oppression and control while simultaneously being a tool with which marginalized communities activate, engage in, and sustain social justice fights. Care has been turned into a business opportunity for care industries, especially under the current neoliberal political economy. Care offered by the U.S. public healthcare system represents the line the nation draws to divide protected citizens (those who are cared for) from the unprotected ones (those left without care), while there is no guarantee that the care it provides is of high quality or is not used for surveillance and control of welfare beneficiaries. The structure of care is deeply embedded in and embodies the cruel social order (e.g., racism, cisheteropatriarchy, ableism, neocolonialism). All of these elements determine who is made to
survive and thrive with and through care in the current political climate and who is made to deteriorate under the name of care. However, care also consists of everyday support systems woven together by everyday people and is embedded in each breath of our lives. Care at the micro level can facilitate connecting or gluing people and thus entails the potential to foster solidarity and mobilize mass.¹³ Care is inherently collective and can activate and enable more sustainable relationships, and care is a necessary foundation for the more-just world that social justice activists fight for. Additionally, many social justice movements are undergirded by care, no matter how invisible an act of care is made to be.¹⁴ It is community-based care or care for one another that lets marginalized communities survive and thrive, when they have been deprived of structural and public care, which I call state violence.¹⁵ Care is the foundation and necessity for inclusivity, accessibility, and from-the-ground-up social transformation. It is a life-making and world-changing practice, while it is simultaneously used for money making—or worse, life sucking and sometimes life taking. Given this contradiction, I begin this book by thinking of care broadly as a site where bodymind, political economy, and historically formed social oppressions and social justice struggles intersect and interact. It is thus a way to envision and practice alternative, radically collective, and affectionate ways to live.¹⁶

In short, I examine care injustice where people—whether they are situated as care workers, care receivers, and others—deteriorate under the name of care when care is used as a mechanism to enhance political economy and neglect the well-being of those situated as care workers and care recipients. I also examine care justice, or just care, which occurs when people feel cared for affirmatively, whether they are situated as care workers, care receivers, or both, and when care is used to improve the well-being of people, the community, and the surrounding (i.e., natural and built) environment, and for more-just world building. The first half of the book looks into lives unfolding in the assemblage of Medicaid long-term-care programs taking place in people’s own homes (instead of residential facilities like group homes). We assume (and hope) that governments guarantee a safety net when we are or become disabled and lower-income (including poor and working-class people)—but do they? Who is granted U.S. public healthcare support, and how? Who is made to assume responsibility for care under such programs, and how? I examine how the circumstances of those who are situated as Medicaid enrollees and care workers are different, overlap, and are interwoven, and whether they are cared for as care recipients and as workers in the U.S. public healthcare sector. The neoliberal status quo has been intensifying the social injustices that are directed toward those who are situated as care workers and care receivers and within which their lives unfold while their everyday lives are profoundly embedded in each other’s. In this
context, what kind of resistance can they (and others) activate and nurture in the middle of care-based structural oppressions? What visions for better care practice are dreamed of, shared, and enacted by those who are situated as care workers and care receivers?

The second half of the book explores how care justice is imagined and enacted as well as how care undergirds and expands social justice activism. To do so is also to tap into various marginalized communities’ tactics to survive and thrive by caring for one another when government fails (or actively neglects) to meet people’s care needs. My particular focus is on care collectives (community-based mutual-aid groups) formed by disabled and queer people to meet each other’s care needs and to actively practice interdependence—a principle that disability justice activism advocates for. What is it like to practice such social justice vision—interdependency—in their everyday lives, when the surrounding world operates the opposite way: enforcing individualist independence? As members of the collective desire to be entangled in each other’s messy dependency, what does such desire activate and how does it enable different ways to be with each other? What are the implications of yearning to reclaim their dependencies, when dependency has been used as a key tactic to justify ableism inflicted on disability communities?

Finally, this quest to unfold the multiplying and contradicting layers of care lands on bed activism—resistance and visioning that are happening in bed space. Sick and disabled people of color (among others) have put forward crip wisdom from their bed spaces. Crip wisdom emerges from the everyday lives of disabled, neurodivergent, Deaf, Mad, sick, injured, and debilitated people. What and how do critiques of the status quo and normalization of activist works, as well as unique resistance and visions, emerge from bed space? What do moments of enduring pain, fatigue, depression, and other bodymind conditions in our beds activate and animate? What becomes dreamable as we take seriously the resistance and visions bubbling out and embodied in sick and disabled people’s beds? What possibilities, wisdoms, and even struggles does a bed space hold, offer, and teach us and the world?

Caring

Care is present throughout the opening story of Superstorm Sandy. For example, the government determined what care was offered (or was not offered) to those who were experiencing housing insecurity and/or disabled people like Michael and Sonia who rely on Medicaid and whose complex care needs are hard to meet at evacuation sites—all of which dictate their well-being, vitality, and ability to stay alive. Or what the building managers
may have thought of as care by calling 911 to send firefighters to check on us during an electricity outage can also be read as their concerns about liability, in which we are turned into their risk. It was simultaneously care from friends and strangers that enabled us to continue living under desperate circumstances. Care is transient, malleable, and subjective. Multiplying meanings, intentions, and impacts are contained in and enacted by a gesture of caring.

What care does is the focus of this book. My curiosity is about care as a modality of power dynamics. Care is used to enforce top-down dominant power as much as care is exercised at the grassroots level to enable resistance against such dominant power and enact transformative power for a more-just world and way of living. Care is structured and institutionalized in the interlocking system of racist, cisgender patriarchy (i.e., sexist, transphobic, and queer-phobic dominance), neocolonial, and disability economies. It is commodified by care industries or turned into a way for governments to manage and control people, particularly those who are involved in public healthcare programs. And yet care has also been an everyday tool of everyday people to survive, thrive, and transform the violent status quo. In short, our lives are enabled and hindered by care (and the lack thereof) as much as we enact care.

I begin this book by thinking about and understanding care as the energy and time we spend in intention to contribute to others’ well-being, vitality, and lives. Care is a way to orient ourselves and direct our energy toward something or someone. I begin with such a broad definition to avoid prescribing the notion of who can care or normalizing and hierarchizing different forms of care that are evident in the narrow way care is structured and set up in the larger society. Specifying care as a particular action (e.g., the physical care of feeding someone), for example, can obscure care by disabled people who may not be able to perform the particular action. Standardization of care offered by the care industrial complex often values physical care over emotional and spiritual care. It also dictates who can care and which people are exclusively considered as receivers of care. My understanding of care has profoundly grown from the work of disability justice activism and the writings of Patty Berne, among many others who advocate for interdependency, which illuminates that we all are capable of care, need care, and are worthy of being cared for. In other words, the act of sending positive vibes to others from one’s bed is care, just like the physical act of care (e.g., cooking for others) that is built into long-term-care support services. Additionally, care is highly subjective, and one’s intention to care may not be always met with observable outcomes such as a change in vitality and well-being, or it may not be received as care by the person the care was intended for.
Care is a name we give to our experiences—what we do, sense and feel, or think. Care is inherently relational, whether it actually ties together humans and other living and nonliving entities, or even our inner self (i.e., self-care). It can touch (physically and metaphorically) lives to various depths. Care manifests in various modes: physical, material and financial, emotional, cognitive, and spiritual care, to name a few. Care transgresses time and space—words from an elder may touch a youth decades later, for example. It is subjective as much as it is susceptible to and embedded within the forces of political economy as well as the intersecting social oppressions. This means that what one person thinks of as caring can be experienced by others as violence, control, pity, love, debt, a life saver, and so on. The practice of care is deeply cultural, sociopolitical, and historically situated—which I further explain later. My understanding of care is further shaped by how it is defined by theorists including Christina Sharpe, who describes care as “a way to feel and to feel for and with, a way to tend to the living and the dying,” or Berenice Fisher and Joan Tronto, who define care as “species activity . . . to maintain, continue, and repair our ‘world’ [which includes] our bodies, our selves, and our environment.” Additionally, the teachings of disability justice activism illuminate how care circulates among people, although it is often arranged to be given from a provider to a recipient. People are simultaneously care recipients (who, after all, can live without care?) and care providers in varying degrees, though not everyone is equally provided with care or subjected to care-providing. To address this multiplicity of care, I use the term care practice in this book to portray the expansive layers and forms of care—as provided, received, and circulated—as they are often indistinguishable and noncompartmentalizable.

Thinking of care as open-ended and circulating is my intervention on how care has been often compartmentalized in the field of care studies. Defining care often entails and prescribes dichotomization of people as either carer or cared—“Care is conventionally defined as the activities and relations involved in caring for the ill, elderly, handicapped [sic] and dependent youth.” This example definition used in labor studies of care not only restricts care solely as an action but also prescribes the subjects and objects of such actions. It also simultaneously indicates who needs care and who does not, or who is capable of caring and who is not. Different schools of care studies—including feminist, labor, and disability studies of care—have highlighted and prioritized studying circumstances of different constituencies who were embedded in the care structure. Paying attention to how the term care is scrutinized and described with different synonyms and adjectives, alone, gives us a glimpse of various approaches one can take to studying care. Burden and responsibility, for instance, are commonly used synonyms to describe care, particularly in feminist and labor studies of care.
Those words explain that the care consists of daunting yet unavoidable work often tasked to women and gender-nonconforming femme people who are situated as care providers. Another commonly used term, dirty work, illustrates that care is work that involves feces, sweat, vomit, mucus, and other bodily discharge that is considered dirty. Those terms shed light on how care is taxing labor and how people are disproportionately situated to that labor under the intersecting forces of cisgender heteropatriarchy, white supremacy, neocolonialism, and more that shape labor stratifications. Such an approach to care illuminates and problematizes the inequality bubbling on one side of the care equation—care giving. What is rarely mentioned in such analysis is the other side of equation—care receiving and the stories of those who are exclusively situated as objects and roots of such burden and responsibilities or dischargers of the “dirt.” Thus, the care needs of those who are situated as care workers are rarely acknowledged.

The term assistance, rather than care, has been advocated in U.S. disability communities and studies, particularly following the Independent Living Movement, which emerged in the 1970s in the United States and elsewhere. Disability communities and studies have problematized the ways disabled people are exclusively considered care recipients and dependent. This is true especially because their dependencies on others are constructed, amplified, and considered as a social burden, which is thus used to justify to deprive them of their agency to exercise self-determination. Care is, therefore, understood as a modality of patronizing power dynamics where disabled people are inherently made powerless. The term personal assistantship is put forward to avoid association of disability communities with the idea of care, which is thought specifically for “children, sick people, and older people, and [instead the term assistantship is believed to] highlight the empowering nature of consumer-directed models of support.” It is, in other words, a part of fight to end objectification of disabled people enacted within and through the practice of care. Here, too, what is rarely touched on is the other side of the equation—care giving—as disability communities advocate to establish employer-employee power dynamics with care workers, where disabled people are the ones with the authority of an employer. Also, it is often assumed that care workers do not have a disability.

Different approaches to studying care within these fields tease out how various oppressions are disguised and exercised through care; how cisgender heteropatriarchy shapes oppressions care providers experience, and ableism is interwoven in the experiences of care receivers. Such focused approaches in these fields enable more in-depth analysis and understanding of care-based injustices. They also provide a way not to erase different degrees and unique needs of disabled people, as well as idiosyncratic ways that care
workers experience exploitation. We can also observe how such distinct approaches and specific focuses traditionally taken in disability and feminist studies of care separately mean that the creative resistance and interventions of those who are situated as care workers and care recipients are often recognized separately, and so justice and liberation for those populations are often fought disjointly. These distinct approaches can also be interpreted as the hidden assumptions in these fields that care workers do not experience ableism, and that cisheteropatriarchy does not shape the care experiences of those who are situated as care recipients.

To bridge these discrete analyses and to approach studies of care in radically different ways, feminist disability studies scholars have been exploring ways to study care more holistically. Feminist disability studies philosopher Eve Kittay’s classic work, *Love’s Labor*, for instance, inserts dependency critiques to the theory of justice by writing about her caring relationship with her disabled daughter. Critical feminist disability theorist Nirmala Erevelles brings transnational feminist analysis into her examination of the care-based injustice disabled people are subjected to in the United States by engaging in historical material analysis. By learning from and joining (intersectional) feminist disability studies, what I am putting forward is the overlap, intersection, and interaction between the circumstances granted to those who are situated as care workers and care recipients. Such analysis shows that it is marginalized populations who are pulled into the assemblage of care structure (whether as care workers or care recipients), particularly within U.S. public healthcare programs, which further marginalizes them. In reality, those who are situated as care workers and care recipients spend most of their waking time together and co-experience each other’s day-to-day occurrences. This reality means that care workers’ and care recipients’ oppressions are experienced together and through one another, witnessed by one another, and thus entangled. Structurally, disabled people and their need for care are situated in the middle of and interwoven with the exploitation of care workers, and care workers are situated as the direct deliverers of care that many disabled people describe as ableist violence. This is to say that their daily care encounters are where macro-level care injustices trickle down and crystallize, and care justice cannot be achieved without justice for both those who are situated as care workers and care receivers.

Specifically, I analyze care by using what I call relational analysis. This analysis embodies and further expands what feminist disability studies scholars have been working on—exploring both care worker and care receiver roles and their relationships to develop a more holistic understanding of care formation. To engage in relational analysis in this book is not only to center how the circumstances and oppressions of those who are situated
as care workers and care recipients are interwoven and interactive but also to investigate and untangle the inherent dichotomization in our understanding of care. Such dichotomy can quickly trick us into thinking that care workers do not experience disabling conditions, that disabled people who are situated as care receivers are incapable of providing care, that ableism does not impact care workers, or that care recipients are immune from cis-heteropatriarchal exploitation. It also obscures the mutually implicated genealogies of how care worker and receiver populations are shaped historically. Certain populations come to be constructed and considered solely as laborers who are dispensable in the public care setup, while other populations are exclusively considered as needing care since their dependencies on one another and public services are amplified as peculiar and burdensome. The profound devaluation of care thus accelerates further marginalization of those who come to be situated as care workers and care recipients in public healthcare programs. And most importantly, I use relational analysis to illuminate and (re)activate the many times when care is used to forge solidarity to reassure and reaffirm marginalized communities’ worth and fundamental power. Dichotomized understanding of care also hinders the framework used to recognize how those who are situated as care providers and care receivers can come and are already coming together by co-engaging in nurturing care to lift one another. What kinds of dreams for care justice become imaginable with such an analysis?

Recognizing the historical development of care scholarship in feminist and disability studies as well as feminist disability studies and further inserting relational analysis, I use the term care, instead of assistance and attendant. Although these terms may not absolutely meet the demands of the disability rights community and disability studies, I am using the term to address how care is turned into a vehicle of oppression that disability and other communities face by calling it what it is (i.e., many disabled people are abused under the structure of care), in order to untangle such care-based oppressions. Similarly, I use the terms Medicaid enrollees or those who are situated as care recipients as well as care workers and those who are situated as care workers in this book. I do so, although they signal the dichotomy, in order to have the framework to articulate and make visible and denaturalize the energy and time that women and gender-nonconforming femme people devote to caring for others.33 In other words, dissolving the role of care workers contains the risk of erasing the unequal ways that people’s needs for care are made into the responsibilities of largely women and gender-nonconforming femme people. It also risks overlooking the reality that people do embody different kinds and degrees of capacities and care needs, while such capacities and needs are amplified or overlooked by ableism and other interlocking systems of oppression in this society. Also, by repeating
the unwieldy phrase *those who are situated as* care workers and care recipients, instead of automatically designating care workers as nondisabled and care receivers as disabled, I resist the widespread assumption that care workers are nondisabled or immune to pain, fatigue, and other disabling conditions, and disabled people are not agents of care giving.

### Controlling Care

Care is a racialized, gendered, trans, and queer matter, as well as entangled in power dynamics rooted in the matter of (neo)colonialism, transnationalism and migration, disability, age, and class. In other words, it is mutually structured in the racial and cisheteropatriarchal capitalism as well as the neocolonial and ableist economy. In those multiplying forces, ideas are formed about who needs or does not need care, who is suited or not suited to care, or who is worthy or unworthy of publicly funded care; these ideas simultaneously dictate and determine care worker and public healthcare enrollee (i.e., care receiver) populations. Enabling and further enforcing those notions are the dichotomous understanding of care and devaluation of care practices, particularly when it involves caring for lower-income people, which is distanced from the care that more affluent people purchase for themselves and their family members.

Unfolding care injustices helps to explain how people’s capacities and debilities or disabilities are constructed, amplified, and differently valued. It is to trace the historical roots of how mainstream society came to dictate whose needs for care supports will be recognized or unrecognized and deemed worthy or unworthy of public supports. Race, for example, has been a crucial element that is used to construct and dictate people’s capacities to take up labor and particularly physically taxing and low-paying jobs. The fundamental categorization of disability has been developed based on people’s incapacities and inabilities to enter the capitalist labor force—which is how the state legitimates and grants the status of disability and associated public supports to its people—and sets it up as if disability and labor capacity are mutually exclusive; people are either disabled or workers. A ripple effect of this categorization includes the oppressive and reductive understanding of racialized populations solely as workers, which leads to extra complexity in order for them to be recognized, legitimated, and identify as disabled and hence needing and deserving of the public services and supports. In the realm of care structure, women of color have historically and structurally been often primarily situated as care workers as their capacities to engage in domestic and care labor are amplified. This came with systemic ignorance of the reality that they have care needs too. This fundamental categorization and stereotyping of women of color as workers thus paved
more complex paths for them to claim and be legitimated with disability status and considered deserving of public supports.\(^{37}\) This setup is said to manifest in the welfare program for single mothers and families in need, for instance, that shapes today’s care worker population among other elements—which I untangle more in Chapter 1.\(^{38}\)

This is all to say that the construction of care labor capacities and incapacities and notions of being deserving or undeserving of public supports are inherently formed in intersecting social oppressions. Gender and sexuality are deeply influential to determine care giver-receiver dynamics too. Care is, for example, forged as family-based unpaid labor that is provided by mothers, daughters, and other female family members (and at a time gender-nonconforming femme members if they are not disintegrated from their families) to their biological family members.\(^{39}\) This structure has simultaneously excluded many queer people from the familiar care circle, when they are pushed out of or run away from their biological families who enforce cisheterosexual ideology. Patriarchal and cisheteronormative family ties, in this case, draw lines between those who are cared for and those who are not, as well as delineating who performs care tasks in the family sphere.\(^{40}\) I use the term *cisheteropatriarchy* to signal the intricate ways that forces of transphobia and queer-phobia, sexism, and heterosexism undergirds family-based and other care formation.

Additionally, behind each U.S. citizen who needs long-term care are often migrant women of color providing lower-wage care labor.\(^{41}\) This is the case despite the fact that these women have next to no margin to become disabled and claim disability status themselves or receive any public care supports, as their legal residency in the U.S. often hinges on their capacity to work and any sign of them needing public supports can deter them from obtaining legal status (e.g., a green card).\(^{42}\) The history of colonialism dovetails with global neoliberalism and neocolonialism to determine who will receive care and who will provide care on the global front.\(^{43}\) Additionally, feminist philosopher Uma Narayan explains how exploitation and dehumanization under colonization have often been justified by discursively flipping this violence into a discourse of care—care provided by colonizers to “civilize” the colonized: “care discourse can sometimes function ideologically, to justify or conceal relationships of power and domination . . . ‘paternalistic caring’ of the sort found in colonial discourse can also be wielded as a form of control and domination by the powerful and privileged.”\(^{44}\)

These factors also mean that not everyone who is experiencing disabling conditions (i.e., impairments and debilities) is granted disability status from the governments that determine their rights to receive public supports (e.g., Medicaid) or recognized as needing and deserving care. Even when people are bureaucratically legitimated as having a disability and successfully
enrolled in long-term-care programs funded by governments, however, this does not guarantee that they are inherently cared for. Their care needs, in particular, are woven into the fabric of ableism and interacting social injustices. What is given as care is, therefore, often experienced as paternalistic violence and abuse to control and manage disabled people situated as care recipients. Their dependency on and need for long-term care are, for example, amplified and framed as a social burden, whereas nondisabled people’s dependency on others (e.g., domestic workers to clean their houses) is naturalized. In a society where independence is enforced as a virtue, their dependencies are turned into justification for ableist violence against them and thus locate them exclusively as care recipients and incapable of care—overlooking their contributions to others’ well-being and to society.

Furthermore, this making of divisions—care giver and care receiver—in interlocking social injustices does not mean that marginalized communities and people passively experience care as a form of oppression or as care manifest only through such mechanisms of control. I tease out different structures of care that they invent and exercise in the next section. Also, this division does not reductively mean that disabled women of color who are situated as care recipients do not exist, simply because care labor is often reserved for (or forced on) women of color under the racialized, gendered, and migration-based occupational divide enforced by the care industrial complex. I will further complicate and challenge this dichotomy to assert that such a divide, if anything, indicates how the lives of disabled women of color are constantly pushed deeper into the shadows and ignored (though those women fight back—which I will examine further as well).

The ways in which care is turned into and functions as a mechanism of control and oppression is only intensified and further enforced in the climate of the neoliberal political economy: “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.” Not merely an economic structure, neoliberalism is an ideology that shapes popular beliefs, thoughts, opinions, attitudes, and behaviors as well as implementing the new social order that organizes society in an economy- and market-centered way. In political philosopher Steven Shaviro’s words, the emergence of neoliberalism is the rise of “new, flexible forms of social organization [that] have their own traps, their own mechanisms of oppression, their own devices of exploitation and subordination” through which the rich get richer and the poor get poorer. This new social order builds itself on and further intensifies already existing social injustices and social orders. Since the 1970s, this political economy and form of governing
principle have spread across the world, though its manifestation varies from region to region.\textsuperscript{51}

Neoliberalism further accelerates individualism and already existing social injustices and stratification that shape various ways that care is structured and exercised. Disability studies scholars Dan Goodley, Rebecca Lawthom, and Katherine Runswick-Cole, for example, have described neoliberalism as an incubator for ableism by addressing the reality that shrinkage of public supports and expansion of the privatized free market mean that austerity measures are constantly enforced to reduce or terminate public disability services that are lifelines to many disabled people.\textsuperscript{52} In geographer David Harvey’s words, “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.”\textsuperscript{53} Not doing well or thriving in the free market is then turned into an individual responsibility. Thus, the long-term-care needs of disabled people are increasingly pushed out of the purview of state responsibility with shrinking welfare programs, and instead made into an individual or family responsibility. Simultaneously, care industries have been flourishing by taking advantage of this responsibility as a business opportunity to develop care provision services. Public governmental responsibility is increasingly transferred to the private sphere (if these are indeed distinguishable). In such a context, inequality expands between those who can purchase care (e.g., quality healthcare insurance for medical care to keep well and thriving) and those who cannot, which leads to the gap between those who can fit the prototype of the ideal citizen and succeed in the free market and those who cannot. Discrimination between these two is not only a matter of individual financial wealth. It is also a matter of intricate social formations that determine who is deemed worthy of social supports and whose lives matter, as well as the values attached to people’s (assumed) labor capacities or lack thereof. Not only is care formation in the status quo a result of neoliberalism, but such care formation simultaneously functions to further enforce the value system put forth by the neoliberal political economy.

\textit{Resistive and Visionary Care}

As much as care is deployed as a mechanism of control and oppression, it has also been a tool for people to resist oppression and engage in alternative and collective ways of living. Such a way of living thus not only makes one’s life more sustainable, but also gives them the power to distract the flow of the status quo and enable another kind of world making. I put forth those nurturing aspects of care to show that care is the foundation of and undergirds various social change activisms and practices, a notion that is often
made invisible. Many marginalized communities have relied on care offered within them to survive and thrive, particularly when such care is needed to tend the damage of social oppressions or to counter the lack of public care supports (which is part of discriminatory state violence).

The Black Panther Party came up with a revolutionary health justice practice, for example, when white supremacist policies and climate violently prevented members of Black communities from accessing quality and comprehensive institutional medical care. They created an alternative structure of healthcare provision for communities, including supplying free meals for children, offering health education and free health checkups in the community, and accompanying elders to doctor visits. Their approach to healthcare as a basic human right and the foundation of community living was visionary and revolutionary, particularly against the backdrop of the rising industrialization (and hence commodification) of healthcare and care in general. Another example of community-based care is observable in queer communities forging chosen families to take over the care granted and limited within family of origin. Specifically, during the rise of the HIV/AIDS epidemic, such chosen families and queer kins attended to those who were ill by caring for them at every level (providing food, physical and emotional care, and more). Preceding this, the Street Transvestite Action Revolutionaries (STAR), founded by trans activists of color Marsha P. Johnson and Sylvia Rivera, created community-based care circles to provide home and nurture for trans and queer youth of color who needed them. When care has been and still is often located in the unit of family of origin and deeply shaped by cisheteropatriarchal ideologies, trans and queer communities have transgressed this foundation by engaging in peer intimate care for one another without blood-based and law-based family boundaries and restrictions. Migrant communities, particularly those who are not U.S. citizens and do not have legal documents, are also left to forge their own care structures because of the lack of healthcare supports from the state. Houston Health Action (a pseudonym), for example, is a grassroots group of undocumented uninsured migrant people who have become disabled during the physically taxing labor to which migrant populations are often subjected. In the absence of affordable health insurance and limited access to hospital medical care, they raise money on their own to buy devices such as catheters and visit one another to exchange care. Finally, disabled people too have come to forge alternative and community-based care structures, as public healthcare programs are unavailable to or underserving them or as such structure has been described as functioning as surveillance and control than nurturing care. They have followed the call from the disability justice movement, for
instance, to create alternative ways to meet one another’s care needs by transgressing the boundary that situates disabled people exclusively as care recipients. Instead, many disabled people work together collectively to provide care needed by their community members as much as they also receive care.

Although I laid out snapshots of collective care that have emerged from different communities in the preceding paragraph, they certainly overlap and influence one another, as people occupy intersecting identities and communities. The rise of care needs within a community thus indicate the manifestation of disability (i.e., impairments), signaling the impossibility of clearly drawing a line to divide those communities. Further, these examples also demonstrate how care and relationalities forged through care enabled and sustained those communities to thrive and engage in social changes.

Beyond the care structured by the state, family, or communities, care circulates, sustains, and affirms people in our everyday lives and at the micro level. Seeing #BlackLivesMatter chalked on streets, for example, to affirm the value of Black lives and existences can be crucial in a political climate that constantly gives the opposite message. When a queer youth runs away from their family, meeting a senior queer person and receiving mentorship are forms of care that can change the future trajectory of the youth. What would it mean for an undocumented migrant person to receive hundreds and thousands of signatures from strangers on a petition demanding that they be given safe and legal space in the United States? Finally, the magnitude of emotion that disabled people may feel as their care to others is recognized and appreciated—in an atmosphere that automatically turns them into social burdens—is incalculable. The magnitude of the sensations that I call care here are hard to capture, but they can entail transient moments that inherently integrate the power to affect people and activate changes in their well-being. In this book, I aim to capture these life-altering and life-affirming moments of care justice or just care that are buried under the layers of care injustices inflicted by industries and the state. When care is used to trivialize or even dispose of many people’s well-being and lives—through exploitation in the care labor force, being subjected to abuse under the name of care, or being left without care supports—people dare to continue caring for one another. They engage in care simultaneously as a way to survive and thrive, as a modality to show love, and to form a radical collectivism that interweaves people's lives beyond the individualist boundary enforced in the United States and under the neoliberal climate. Throughout Just Care, I illuminate these contradictory and multiplying realities of care to understand the life-making that is happening in disability
and other marginalized communities in the middle of a debilitating socio-political climate.

**Grounding**

So much of the care that was experienced during and after Superstorm Sandy was invisible or existed only between lines of what I could observe and articulate. I will not know the experiences of caring and being cared for that Sonia or Michael felt. Yet those invisible, inarticulable, between-the-lines feelings, senses, and actions undoubtedly add color and vitality to our lives.

In the broadest sense, how I understand care as being embedded in the larger sociopolitical forces and nurturing a vision for a more-just society was founded on the teachings of disability justice activism, affect theories, and critical feminist, race, and disability theories. Disability justice activism, in particular, illuminates different ways to engage in care in order to live in more sustainable and interdependent ways and also how care is the bedrock of marginalized communities and their social change fights. Developed and nurtured by disabled gender-nonconforming, trans, queer, Black, Indigenous, activists of color as they weave together their community and cultural wisdom, this activism centers on ten principles: intersectional analysis, leadership of those most impacted, anticapitalist politics, building cross-movement solidarity, recognizing wholeness of people, prioritizing sustainability in social justice fights, commitment to cross-disability solidarity, investing in interdependent relationships, working for collective access, and collective liberation. Although these principles emerged to reimagine or reactivate radically inclusive and accessible social justice movements, they also guide us in how to conduct our everyday lives in more-just ways, which simultaneously allows us to build and embody a different world. The care justice or justice enabled through care that I write about here, therefore, is an attempt to reflect this activism, while I write this book with a hope to further contribute to the deepening of this movement. In other words, disability justice activism teaches me how to dream collectively while it also equips me with the sharpest analysis to detangle the violence we witness and experience in the status quo under the name of care. In this way, I am thankful for leading disability justice activists such as Patty Berne, Mia Mingus, Leroy F. Moore Jr., Sebastian Margaret, and Eli Clare as well as Stacey Park Milbern, Leah Lakshmi Piepzna-Samarasinha, Lydia X. Z. Brown, and more and more people who developed and nurtured the disability justice activism since the early 2000s and who are, thus, cited heavily in this book. Disability justice—which I often describe as a mash-up of
race-based, trans-specific, queer, feminist, migrant, decolonial, and crossdisability (i.e., Deaf, neurodiverse, Mad, and anti-psychiatry) social justice work—is the prism through which I understand the status quo of care and visions of what care can be and do.

With disability justice as a foundation, I also examine care through critical theories—mainly critical disability, race, (transnational) feminist, and also queer and migration studies. Building from these frameworks, therefore, I untangle an aspect of care as an oppressive mechanism that relies on white supremacist, cis-heteropatriarchal, neocolonial, xenophobic, and ableist logics—the logics that critical theorists have articulated. Critical theories also help me uncover the overlapping yet distinct histories of how care and the needs of people have been the center of community building and resistance in the marginalized communities mentioned. Writing this book on the foundation on the teachings of disability justice activism and critical theory also involved attending the emergence and development of theory happening in the everyday life of everyday people, regardless of their affiliation with academic entities. Boricua Ashkenazi disability justice artist and activist Aurora Levins Morales uses the term homemade theory to describe the theories emerging from people’s everyday lives and to bring theory out of academic walls: “we create [homemade theories] out of our shared lives, [and it] really help[s] us to make sense of everything that we are and all that we find to love.” She transgresses the inaccessible and exclusionary ways that theory is written within academia and instead reclaims and engages in theory building, which is rooted in shared lives of people regardless of their academic training and affiliations. Learning from her and other like-minded feminists, I bring together theories primarily emerging from academic spaces with theories that emerged and developed from and during my conversations with Medicaid care workers and enrollees, members of community-based care collectives (mutual-aid groups developed by disabled people), and those who engage in bed activism together to better understand the status quo through the analysis of care and needs. The critical theories (which are mainly emerging from academia) that I unfold in this book include differential inclusion (conceptualized by Yën Lê Espiritu) in Chapter 1, necro-theories (developed and written by Achille Mbembe, Lauren Berlant, and Jasbir Puar) in Chapter 2, affective body (theorized by Audre Lorde) as well as hapticity and undercommons (written by Stephano Harney and Fred Moten) in Chapter 3, critical analysis of interdependency (woven by Baggs) and messiness (explored by Martin F. Manalansan vi) in Chapter 4, and dreaming from bed (put forward by Aurora Levins Morales, Leah Lakshmi Piepzna-Samarasinha, and Johanna Hedva) in Chapter 5—all of which I further describe throughout the book.
These ideas and thoughts are further enhanced by homemade theories of those whose lives are intimately embedded in public healthcare programs and community care collectives.

Affecting Care

I situate care directly in relation with life: shaping the vitality and well-being of people. To recognize and write the relationality, I rely on the concept of affect together with the aforementioned activist, critical, and homemade theories. I use the idea of affect to describe the invisible, inarticulable, between-the-lines feelings and senses that care activates. As much as care can be thought of as a concrete action, it can also be understood as what circulates among and through us and transforms us (for better or worse). It is the invisible force or energy that impacts us as much as we emanate it and influence others. Affect becomes feelable as we are evoked and recognizable as we attach emotion to name the affect—excited, tired, depressed, anxious, and angered, for example. Therefore, to talk about affect is also to pay attention to the transient and ever-changing energy level of our bodyminds: capacitation and debilitation. In the context of care, I explore how care becomes a site or modality of this transition. This idea put forward as affect, I argue, is familiar to disability communities. Indeed, it is an integral part of community knowledge, as people constantly communicate their fluctuating energy levels with or without the metaphor of spoons, which I bring up in the following.

Political philosopher Gilles Deleuze has described affect as follows (in his interpretation of Dutch philosopher Baruch Spinoza’s work):

> The affections (affection) are the modes themselves. The modes are the affections of substance or of its attributes. . . . These affections are necessarily active. . . . The affection refers to a state of the affected body and implies the presence of the affecting body, whereas the affectus refers to the passage from one state to another, taking into account the correlative variation of the affecting bodies. . . . “By affect I understand affections of the body by which the body’s power of acting is increased or diminished, aided or restrained.”

Affect theorists Melissa Gregg and Gregory Seigworth have described affect as a synonym for the force emanating from people and manifesting at the site of encounters by connecting us with our surroundings (i.e., other people and environments) that can draw us toward or repel us from one another. Also, affect can be a flow of energy that influences—enhances or decreases—one’s vibrancy and vitality. It escapes the comb of empirical measurement.
while moving people and shaping lives, or it is interpreted (i.e., cognitively registered) as a certain emotion. To apply affect theory is to pay attention to experiences and phenomena as being felt in the gut and sensed through the skin.

Viewing girls with muscular dystrophy on TV telethon programs, for example, moved many viewers to open their wallets and donate—this force or affect might be named as a feeling of pity or fear that is deeply rooted within ableism in society. Images of disabled people, including disabled children, abandoning their wheelchairs to crawl and drag themselves up the staircases of the Capitol to advocate for the Americans with Disabilities Act in 1990 pushed many disabled people to join the movement—such an affect can be registered as empowerment. In affect theorist Brian Massumi’s words, affect is “a prepersonal intensity” and “govern[s] a transition where a body passes from one state of capacitation to a diminished or augmented state of capacitation,” and thus “every transition is accompanied by a feeling of the change in capacity.” To encounter others, surrounding environments, and political atmospheres entails the potential to be influenced in how we feel, act, think, and dream. The encounter, therefore, activates an increase or decrease in a bodymind’s capacity and vitality.

Affect theory informs this book in multiple ways. My primary understandings of care as modality, transient encounter, or what circulates among and through us are all shaped as I conceptualize care through this theory. My use of the terms capacitation and debilitation to illustrate the fluctuations in a person’s capacity (i.e., increased or decreased vitality or energy) through care is another way. On one hand, these fluctuations are part of every bodymind’s daily and transient experiences, corresponding to the ever-changing energy level or vitality of the bodymind. I use the terms, therefore, regardless of a subject’s status as a disabled or nondisabled person. On the other hand, I also use the terms capacitation and debilitation to describe the prolonged status of a bodymind. Disability and race theorists (among others) have deployed this latter use of these terms largely to depict a more permanent status of a bodymind as debilitated—whether it is recognized or identified as disability or not—which has been caused by social injustices (e.g., armed conflict, police brutality, labor exploitation, lack of quality healthcare). Accordingly, I use the term care to entail the sense of a modality that shapes people and their well-being and vitality. To use affect as a theoretical framework for this book is, therefore, to pay attention to (1) the realm of sensual experiences, (2) people’s fluctuating energy as well as states of bodymind, and (3) what circulates between people, other (non)living entities, institutions, and surrounding environments, which is to set a unit of analysis as connections and relationships among elements rather than the element itself.
I engage with affect theory through and with the aforementioned critical and homemade theories and under the prism of disability justice teachings. This includes taking critiques against the theory seriously by making efforts to decenter who is considered as knowers of affect and by integrating its diverse developments before and since the theory’s initial popularity in the 1990s (e.g., the field’s initial overlook of Indigenous wisdom and knowledge on felt theory)\(^8^1\). In particular, many people have pointed out the field’s initial lack in recognizing how social power dynamics are present in experiences of affect.\(^8^2\) Mad studies theorist and artist Rachel da Silveira Gorman points out that “[Queer of color theorists assert] affect as a product of repetition and sedimentation of ideology, rather than of ‘preindividual bodily capacities’ in which the diversifying complexes mediating social relations vanish into the appearance of unmediated essence.”\(^8^3\) As this quote demonstrates, there have been developments of affect theory that insert or follow the tradition of critical theory. Building on this, using affect theory for my analysis and understanding of care does not mean letting go of sociopolitical and cultural power dynamics that are profoundly present in care—but bringing them together and centering them. Also, it is to recognize, for example, Audre Lorde’s writings about the erotic as seminal text theorizing about the affective capacity of bodyminds, without relying solely on those mainstream affect theorists (on which I further elaborate in Chapter 4).

Affect studies’ focus on the body, its sensation, or its capacity and debility as an area of exploration, I argue, is compatible with and useful for disability studies. Affect theory has shifted the paradigm of studying a body away from an investigation of representation or meaning attached to bodies (which was popular prior to the affective turn in the 1990s) and toward a body itself.\(^8^4\) It explores what a body can do or how a body affects or is affected by its surroundings. To refocus on bodies in affect studies terms is not equal to solely measuring bodies based on the functionality and values attached to them, a measurement that disability studies has wrestled to dismantle over decades. Although I engage in the capacity- and debility-based commodification and exploitation that people are subjected to in the current political climate, this refocusing on bodies expands on more than that. One principle of affect theory is to illuminate the vitality and capacity emanating from the existence of a living body (and bodymind) itself by paying close attention to subtle ways that a bodymind affects others—the heat it releases, the rhythm it beats, the odor it radiates, the touch sensed by others and with which it saturates others.\(^8^5\) What are the aspects of care practice that such illumination and attention make feelable and recognizable? This theory, in other words, allows us to acknowledge the power of a bodymind and the power that it emanates on a very micro and subtle
level and its shaping of care. This overlaps with disability studies’ call to understand disability as part of diversity without pathologization and criminalization.  

What does it mean to recognize and value people based on their bare existence, which emanates energy, instead of evaluating them solely on their functionality and its usefulness to the political economy? Using such an affect studies approach to bodymind is also to ask how to recognize the power of existence beyond and against the neoliberal extraction of debilitated bodyminds and oppressed status (e.g., how the toxic-waste-management business flourishes by discarding trash to marginalized neighborhoods and the Global South, and how their marginalized status itself forms the foundation of this business as it uses that status to justify this form of social oppression manifesting through environmental injustices and enacted under the political economy). It also means grasping care as being more than physical actions (and also happening emotionally and spiritually, among other ways). Cognitive function is often deployed as the foundation upon which to define, standardize, and value people, for instance.  

People’s experiences, agency, and ultimately human-ness are overwhelmingly recognized in the ways they assert themselves verbally and through exercising certain functionality, for example. Disability studies as a field has been critiquing this bias and grappling to make a shift by analyzing and problematizing the overt focus on mind (e.g., the deployment of IQ to measure, categorize, and value human beings, which simultaneously has led to discrimination against and devaluing of those with intellectual and developmental disabilities). Indeed, there has been a move within disability studies to prioritize a body or blur the division between body and mind, instead of exclusively prioritizing or privileging minds. Mad activist-scholar Margaret Price, for instance, questions the fundamental divide between mind and body by describing how both elements interactively shape our experiences and existences by putting forward the term bodymind. Focusing on how disability studies along with affect theory can further assert different understanding and valuing of bodyminds does not neglect the reality that ableism is rooted in the function-based valuing of disabled people and dictates our desires (e.g., overt emphases on enhancing one’s abilities through rehabilitation to be part of the political economy). Or this highlighting of existence (i.e., ontology) is not the same as saying that disabled people cannot function or have no function in this society. Instead, I am following the insights and knowledge of disability studies and communities as well as neurodiverse communities who fight against the pathologization of certain ways our minds work and to acknowledge and value the diverse ways people’s bodyminds operate. Further, such focus can make visible
multiple ways that we care and experience care, while physical care is considered as default and the basis for paid care labor formation.

This idea that bodyminds are dynamic as their energies fluctuate is wisdom that is always and already nurtured in disability communities. Describing and communicating such fluctuations of energy and capacity have been crucial for disabled people to articulate what kind of care and supports we need and to illustrate the state and needs of our bodyminds, which are not necessarily visible to others. In particular, those with chronic fatigue and pain have developed spoon theory to explain their energy level and how it changes across the day in a visualized and quantified way that is easily comprehensible to others. When Christine Miserandino, who lives with Lupus, wanted to explain what it is like to live with such chronic illness and fatigue and how her energy is drained or regained differently than that of her nondisabled friends, she grabbed spoons to use them as a metaphor for the energy she had for a given day. The number of spoons she has and how quickly she loses a spoon is a dynamic combination of her disabled bodymind and internal and external influences. Weather and temperature (external factors) or the amount of sleep one gets the night before (an internal factor) can cause one to lose spoons quickly, and different tasks can cost a different number of spoons as well. Community members may tell their friends, “My spoons are low this evening due to the cold weather, and I cannot go out anymore,” to explain the need for last-minute cancellation of plans. Having care or a personal assistant, in this context, allows disabled people to reserve their spoons and have more choices on where to spend their spoons (while their care worker can assist them with daily activity without losing too many spoons). Although spoon theory has been developed based on the needs of those with chronic fatigue and illness (that are often invisible) in particular, to communicate and make visible their changing stamina or bodymind conditions, affect theory illustrates such fluctuations of energy as happening to any body in various degrees. The theory offers language to discuss the dynamic nature of the degree or speed of how fast we debilitate (i.e., losing spoons), how much innate energy we embody (i.e., the number of spoons we have), how fast we can recover our energies (i.e., regaining spoons), and how care shapes or dictates these transitions. The community-born wisdom of spoon theory embodies what I am trying to put forward in this book by bringing together affect theory and critical studies and by relying on terms like debility and capacity. It illuminates and introduces language to capture the dynamic materialization of the political economy and social injustices in and through bodyminds. Now, what does it mean to recognize disability in this theoretical framework, which conceptualizes lives—vitality and well-being—as constantly evolving or becoming instead of being?