How
Disabled People
Improvise
More Habitable
Worlds

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Cover art: An activist affordance for cooking. Photo by author.

Babanneme . . .

To my grandmother, Lütfiye Dokumacı, whom I deeply miss every single day

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INTRODUCTION

Arseli's Story

One morning, I was in the bathroom. I stood up from the toilet and pulled my jeans up in the slowest of motions. My hands, elbows, and shoulders were inflamed, tender, and painful (as they often are). Then came the hardest part: my fingers were swollen to the size of mini-bananas. I could not bend them even to the slightest degree needed to grasp the zipper. How the hell was I going to zip up?

Everyday life is full of such negotiations for me because, since my early teenage years, I have been living with chronic diseases that damage my joints, causing pain and gradual disablement. None of this is immediately apparent to an observer.[1] Because the diseases in question affect joints, and because joints mean movement, my everyday life turns into a stage for what I would describe as *choreographing the dance of avoiding pain*—a dance that is sometimes done solo and at other times with another, or others. In this solo "dance," in order to zip up, I kneeled down a bit, put my right knee on top of the left one, positioning my legs in the shape of a crooked X. I bent slightly forward, and exhaled a big breath. The distance between the two sides of the zipper was now almost erased. The button on top and its buttonhole were now almost overlapping. All that was left to do was to slide the zipper up. I did so not by grasping the zipper but by pushing it up from the base with the nail of my thumb that I rested on my other fingers. This is a routine choreography that I rehearse whenever I have to wear trousers. I now also minimize the need for this dance by maximizing my time at home, where I can wear loose clothing like PJs or, indeed, anything without zippers.

Henri's Story

Henri has lived most of his adult life with rheumatoid polyarthritis, which has ended up damaging the joints in his hands, arms, and feet, among others. On a languid Sunday morning in Montreal, Henri and I were sitting around his kitchen table while my life partner, François, filmed us. Beautiful sunrays and a light breeze were coming through Henri's kitchen window, filling it up with all the distinctive smells and senses of the fall. As Henri slowly sipped his coffee, we got into a deep conversation about lives lived with a chronic painful disease, what this living does to us, what we do with it. As Henri slowly but skilfully stood up for a refill (figure 1.1), he suddenly turned back to me and said, "Do you want to see how I put a full mug on the table?" After explaining that he has a very limited range of motion in his wrists, which affects their flexion and extension, Henri described with almost mathematical precision how he puts a full mug on the table without spillage.

Henri: [When] I put a cup on the table, if I don't bring that elbow to the same level as the table [figure 1.2]. You know, it's gonna, see, it's gonna drop, it's gonna go like this [figure 1.3]. So gotta bring down the elbow to put the cup on the table [figure 1.4].

The dance of zipping your trousers in crooked limb angles. The dance of putting a full mug on a table in bent bodily curves. The dance that lets you avoid pain and relieves your impaired body parts of their presumed functions by making the rest of your body move with ordinary objects, together in extraordinary union. In and through the dance (see chapter 5), the fixed, rigid, and obdurate materiality of the environment becomes something else, as if it were alterable and bendable, as if it were alive, sensing, reciprocating and caring for your sick, impaired body in pain.

This book is a visual ethnography of such largely unnoticed choreographies performed in the most fleeting of movements, the most ordinary of everyday actions. It traces how chronically ill, "oddly" formed, and debilitated bodies carve out niches for themselves—though the material world bears no record of their pains and vulnerabilities, remains impervious to the

FIGURE I.1 IN THIS AND THE FOLLOWING THREE IMAGES, HENRI, WHO HAS RHEUMATOID POLYARTHRITIS, DEMONSTRATES HOW HE STANDS AND SITS WHILE HOLDING HIS COFFEE MUG SECURELY. HERE, HE IS CLUTCHING THE MUG WITH HIS RIGHT HAND WHILE LEVERAGING HIS WEIGHT AGAINST THE TABLE AS HE STANDS.

FIGURE I.2 AS HE STANDS AT THE TABLE, HENRI'S LEFT HAND MOVES ACROSS HIS BODY TO SUPPORT HIS RIGHT ELBOW AT THE SIDE OF HIS RIBS.

FIGURE I.3 AS HENRI BEGINS TO SIT, HIS RIGHT ELBOW HAS STRAIGHTENED AND HE TILTS THE COFFEE MUG ONTO THE TABLE AND AWAY FROM HIS BODY; HE PLACES THE THREE MIDDLE FINGERS OF HIS LEFT HAND ON THE TABLE TO BALANCE.

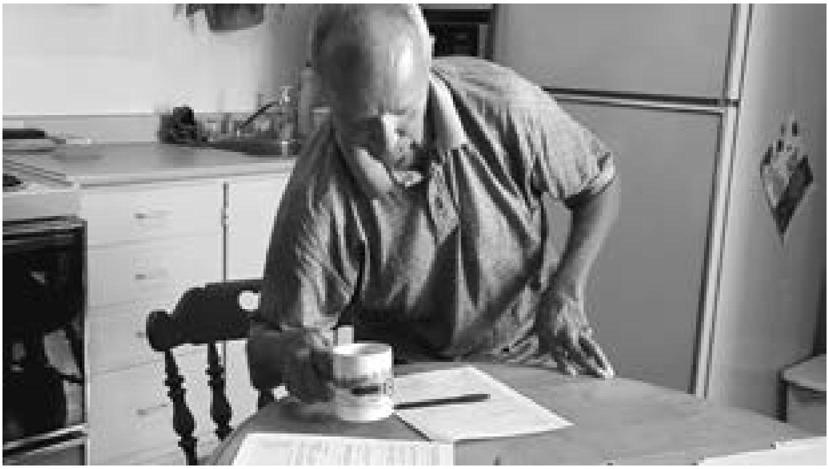

FIGURE I.4 LEANING TO THE RIGHT WITH HIS RIGHT SHOULDER ANGLED DOWNWARD, HENRI LOWERS HIS BODY BY BENDING AT THE KNEES AND PLACES THE MUG FLAT ON THE TABLE.

diseases they live with, and offers no gesture of recognition for the unusual shapes, scales, and abilities that their bodies and minds come with. This book is an account of how disabled people build accessible worlds in and through the unspectacular choreographies of the everyday that I call "activist affordances."[2] I mobilize the terms "activism" and "affordance" in specific ways: "affordance" means an action possibility shaped by the reciprocal properties of the organism and the environment,[3] and "activism" means world-making. I consider performances like mine and Henri's as kinds of actions that are inseparable from creation. These affordances are performative: they say and do, do and make at the same time. Activist affordances are performative microacts/-arts through which disabled people *enact* and *bring into being* the worlds that are not already available to them, the worlds they need and wish to dwell in.

The mode of activism in these performative acts is less about opposing or disrupting existing worlds than about "being the change you want to see."[4] To pun on J. L. Austin's famous phrasing "how to do things with words,"[5] activist affordances are about *how to build worlds with acts* (rather than with words and slogans). It is not the persons who change the world, but their actions. Their activism does not entail the intermediary action of asking for change but involves making the change itself. These affordances may be neither hailed as activism in the traditional sense, nor celebrated as art or recognized as design. In fact, they may go entirely unnoticed. But they are acts of world-building nonetheless. This is precisely the point of my intervention. These performative affordances *can* and *do* transform the world. These are acts that we, as disability studies scholars as well as scholars and practitioners of design, need to name, trace, and theorize.

In theorizing activist affordances, I build upon and expand the emergent literature on disability maker-cultures, their histories, and the resourcefulness, ingenuity, and expertise that contribute to a broader recent emphasis on design and making across the humanities and social sciences.[6] This conceptualization involves a transdisciplinary blending. The term "affordance" originates from a subfield of psychology founded on the mutuality of organism and environment, or organism-environment relations. Disability, performance, and activism have not been a concern among those who use the term. Disability studies has not paid much attention to affordances either, apart from a few cursory mentions that do not take up its rich ecological grounding.[7] This is where I intervene: What happens when we think of disability, affordances, and performance together, as related terms? What can this conceptual work allow us to do? What new openings can it provide us with when it comes to the intersection of disability and design? And how does this intersectional attention turn us toward a further intersection with environmental (ecological) justice?

Activist Affordances

In the words of its coiner, James J. Gibson, affordance refers "to both the environment and the animal in a way no existing term does."[8] It describes how the animal's (organism's) action and perception are shaped through the dynamics of its relation to the environment. Affordances are possibilities of action that emerge from the reciprocity between the properties of the organism and those of the environment. A round, stiff object fits the shape of my palm, just as my palm fits the shape of the object, and with the strength of my fingers added to them, this environment-organism interaction offers grasping.

My term "activist affordances" differs from Gibson's "affordances" in that it describes possibilities of action that are almost too remote and therefore unlikely to be perceived, and yet are perceived and actualized through great ingenuity and effort to ensure survival. To perceive an affordance that exists in the actual and to perceive an affordance that is too distant a potential to even be perceived are not one and the same. When the two are treated as equals by being lumped under the rubric of "affordances," then we lose track of the tremendous labor, struggle, and creativity that it takes to discover and actualize the latter. I propose the theory of activist affordances in order to name and recognize the tiny, everyday artful battles of disabled people for more livable worlds that otherwise remain unaccounted for. I propose the concept of "activist affordances" as a way to understand how disabled people literally *make up* whatever affordances fail to readily materialize in their environments (or otherwise be immediately available for perception) and at the same time must *make up for* that failure.

The Question of Necessity

In a sense, this book focuses not so much on the possibilities for action as on the *constraints on* action, and what follows from those constraints. No doubt the material world offers possibilities and constraints to any living being, disabled or not. No doubt we all create affordances that contravene normative directives. One might then wonder: What about any of this is specific to disability? Given that affordances are so variant, is an affordance created by a disabled person any different from a daily trick invented by a nondisabled person, like Henri's "different" way of putting a mug on the table? If the idea of activist affordances always implies that affordances take different forms depending on the particularities of the perceiver in question, then what specificity, if any, is there to the affordances emerging from the experiencing of disability? By extension, do we actually need a new vocabulary and theory of activist affordances?

I argue that we do. We do because activist affordances are like no other affordance in the sense that their generation is necessitated by "shrinkage" (a term that I will discuss in full later on). It is not that Henri has a choice among multiple affordances that would allow him to deal with the mug's design limitations. Henri can manage the full cup and the liquid only through a particular affordance; and herein lies the very urgency and indispensability of the world-making acts that I call activist affordances. Impaired, sick, painful bodies, mad selves, debilitated populations, vulnerable beings—and threatened organisms, as I shall discuss later on—live in environments that for them are shrunken and shrinking. The activist affordances that they create from within this shrinkage are not a question of choice or preference, but of necessity. It is exactly this *necessity* that I want the concept of activist affordances to articulate.

Let me say this loud and clear: I am not attempting to reject restrictions, lack, negativity, and loss in the experiencing of disability; I acknowledge and take them quite seriously. My proposed theory of activist affordances is a response to Alison Kafer's yearning for "stories that not only admit limitation, frustration, even failure, but that recognize such failure as ground for theory itself."[9] In fact, activist affordances can emerge only in the face of constraints, failures, and losses that I broadly conceptualize as "shrinkage." As I will demonstrate throughout the book, when the environment's offerings narrow, and when its materiality turns into a set of constraints rather than opportunities, the improvisatory space of performance opens up and lets us imagine that same materiality otherwise. The emergence of activist affordances in an improvisatory space of performance is the subject of this book.

Performance

Performance, Diana Taylor writes, is what "moves between the AS IF and the AS IS, between pretend and new constructions of the 'real.'"[10] Performance has to do with what Victor Turner described as the "subjunctive mood."[11] That is, while "the indicative" concerns "normatively structured social reality" (the

AS IS), the subjunctive concerns the world of "'if it *were* so,' [AS IF] not 'it *is* so.'"[12] Performance enacts a world of counterfactual wishes and possibilities. In this book, I mobilize performance precisely in this subjunctive sense. I argue that whether it takes place on stage or in everyday life, performance allows us to perceive the environment AS IF it were a someplace else that already provides the affordances that we need, desire, and wish for. This is especially so, I argue, when material constraints stifle our actions—when we find no world-counterparts for our bodies, needs, vulnerabilities, and wishes in the current ordering of the world. In this book, I develop a theory of activist affordances by mobilizing this concept of performance together with disability: the imaginary space and subjunctive mood of performance opens up for the creation of affordances exactly when the normative order in which the environment has been occupied suppresses and pushes these affordances beyond the boundaries of the plausible.

Think of actors on stage. The actors have to operate within the constraints that the materiality of the stage or site (AS IS) puts on their actions. In fact, it is within these constraints that the work of imagination (AS IF) unfolds. As actors relate to the stage and its props within the imaginative layer of performance, they transform this materiality into an elsewhere and else-when through their actions. I argue that the same transformation takes place in everyday lives of disabled people, which are lived within a shrinking world of possibilities. When the existing ordering of affordances leaves no room for their nonnormative bodies and minds; when the world's surfaces become most unresponsive to the impairments, diseases, and pains they live with; when the world's offerings become unreachable in states of extreme deprivation and debilitation, it is exactly the imaginary space of performance that opens up. In this space, disabled people *make up* and *make real* action possibilities AS IF those missing world-counterparts were present. Like actors or dancers on stage, they may bring into being affordances that the environment's form, layout, and materiality did not initially seem to allow. They come up with highly inventive choreographies such as putting a mug on a table without spillage, and putting on pants, as well as combing without combs and leaving shirts partly buttoned in order to take them off later as though they were pullovers. They stand up from sofas by minimizing the use of their knees, turn light switches on and off with their heads, and improvise many more micro, ephemeral affordance-creations that this book extensively documents. Activist affordances bend the seemingly fixed forms, sand the hard edges, and give movement to the rigid layering of the world AS IF it were habitable, in as yet unimagined and undreamed-of ways.

Nonexploitative Designing

The "What if?" framework of critical design, speculative design, and other related approaches is similar to the subjunctive (AS IF) mood of performance.[13] If, as Charles Eames suggests, "design depends largely on constraints,"[14] then we can think of activist affordances as *a mode of designing* that emerges from the constraints of the AS IS and moves toward "What if?," bringing possible futures to life. The difference between a critical design framework and my framework is that activist affordances are not created in design studios or makers' labs with specialized tools and materials. Instead, they are choreographed in our everyday lives, in and through our bodies, and with whatever we find around us. In fact, let me revise my definition: activist affordances are about *making up* and *making real* worlds that we were not readily given by *making do with* what we have. The worlds that we build with our activist affordances do not require blueprints, pillars, or concrete to exist. They come into being through our bodies and imagination as we engage with the material world. In contrast to normative design and making, we design without having to possess, produce, or consume things. Our designing involves speculating about the kinds of worlds we want to live in through *making up* and *making real* within the limits of the spaces and situations we have found ourselves in and the bodies that we have to live with. While we may create a material object in this process, this is less likely rather than more likely, and in any case the creation of objects is not an important question here. Instead, the focus is on the provisional, the feat of creating something out of nothing, and the necessity of finding a way through, under constrained circumstances. Accordingly, the three defining phrases of activist affordances are *make up*, *make real*, and *make do with*.

To claim that disabled people *make do* does not, however, mean that accessibility features and services, assistive tools, adaptive equipment, and devices are redundant. Absolutely not. (This would be a serious misreading of activist affordances that would eventually lead to their co-optation within a neoliberal logic of austerity.) As I discuss extensively in chapter 10, this claim means only that the modesty of improvisatory performance can enable survival in the least likely of circumstances by allowing their creators to *make up*, *make real*, and *make do with* what they have, which at times can be only their bodies and whatever happens to be in their surroundings.

My theory of activist affordance concerns disabled lives, but it is not simply "about" or "for" disabled people. At a time when colonialist, capitalist, extractivist depletion of the world's offerings has brought life on earth to the brink of catastrophe, we desperately need nonexploitative ways of designing and making, and in particular ways that respect limits on available resources of all kinds.[15] Understood as the *art* of economizing our bodily and environmental resources, activist affordances provide one such kind of making. Activist affordances are ways of acknowledging the limits of our bodies and the environment, and of bearing “response-ability” for those limits.[16] They are matters of how to make things work within constraints. They are ways of building liveable worlds against all odds. In short, a theory of activist affordances turns disabled experiences of surviving under conditions of shrinkage and constraint into ways of living for us all. The seeming narrowness of that experience, as I will show throughout the book, can become a mode of our very survival.

Research-Creation, and Disability as Method

This book is the product of a continuous twelve-year ethnographic engagement with disability. It starts with my own experiences of living with nonapparent disability, and it continues into my engagement with disabled people and activists. It spans the different geographic locations of my everyday life across time, including Denizli, a (then) small city in southwestern Turkey; İstanbul; Florida; North Wales; Montreal; Copenhagen; London; and Montreal again. The different geographies and living conditions I have encountered in my macro/migratory movements across these sites affected my own micro/everyday movements as a disabled and (in the past) precariously employed researcher. Crucially, in each of these locations, I encountered varying meanings and valuations of disability and engaged with local disability communities (or came to realize their absence). Each site, each encounter, and each dwelling have gone into the experiential groundwork for the arguments I make. Each one was also formative for my networks, affinities, and so also for my field sites. The book’s ethnographic fieldwork sites are located in Western Turkey, where I was born, raised, and spent most of my life as a disabled person; and in Quebec, where I immigrated, built a life, and became part of a growing disability community.

The theory, methods, and modes of analysis that I propose in the book have evolved both from these ethnographic encounters and from my ongoing experimentations with “research-creation.” Research-creation, which also goes by the names of arts-based or practice-led research, refers to a diverse set of academic practices whose research questions “could not be addressed without engaging in some form of creative practice."[17] In my case, the challenge at the beginning of my research journey was: How do you study nonapparent disability and render perceivable the almost imperceptible choreographies of world-building to which they may give rise? I turned to visual ethnography and practiced it as a form of research-creation by deploying what I called "disability as method."[18] Disability as method names a creative approach through which research methods are informed by, modeled after, and tailored to the situated knowledges of disabled people. It involves attuning and sculpting research methods and modes of analysis to the particular ways of relating to the world that disabled living entails.

Photography and the camera in general have the notorious history, precisely in the history of anthropology, of being utilized as tools for othering and for control and containment with respect to people with disabilities and many other groups. In response, disability artists and activists have mobilized visual media to subvert and upend that tradition of representation, to "stare back" and perform, what Rosemarie Garland-Thomson calls "visual activism."[19] The design of my visual ethnographies builds on this genre and extends it to disability research through "disability as method."

In my visual ethnographic work, disability as method involved harnessing photographic and video editing technologies to seize what otherwise disappears in the ephemerality of performance, providing images of moments viewers may otherwise miss. I zoomed in on and magnified movements and gestures that might have remained too microscopic to be noticed. Whatever choreographies of survival got buried in the everyday, I sought to unveil and map through creative deployments of visual media. I used these methods to forge a form of what disability justice activist Mia Mingus calls "access intimacy," or "that elusive, hard to describe feeling when someone else 'gets' your access needs."[20] While Mingus's concept relies on direct access, putting media affordances to creative uses during fieldwork, analysis, and dissemination allowed for what I would call "mediated access intimacy." The photographs that I offer in the book provide images of my participants' "access needs" in the sense that they document and describe how they "make do" by creating activist affordances. To render perceptible the often almost imperceptible and largely ignored creations of disabled people and to bring them close to others was a process not just of theorizing activist affordances, but also of initiating access intimacy. It was a means of doing activist research, turning the camera into a "care device," as it were, a technology for "making kin."[21]

Nonparadigmatic People with Disability

In this book I am focusing on the stories of "noncrips," so to speak, in the sense that my participants do not fit the description of "the paradigmatic person with disability."[22] Their stories do not necessarily belong to the bodies with which disability is typically associated, or the identities through which disability has traditionally been reclaimed. I have chosen them because their world is my world as well, and there is no reason *not* to start with this group. My ethnographic work primarily concerns people living with inflammatory types of arthritis that are marked by chronic pain. I also bring in the stories and everyday lives of people living with a variety of impairments, including other forms of chronic pain, depression, cancer, thyroid disease, and blindness. Many of these people appear quite able-bodied. Only a handful would call themselves disabled. A majority of them may not even be familiar with politically informed terms of identity like "crip," and I doubt that the people I visited in remote suburbs of İstanbul would even have heard of disability (*engelli* in Turkish) as a specific identity category, let alone had the choice to identify with it or not. I say have "the choice" because to identify with certain categories or not (or to consider them as fluid or reject them altogether) still requires a degree of exposure to and familiarity with identity-based discourses. And we need to take into account the fact that this exposure and familiarity may not be available to subjects whose subjection occurs outside of North American discourses, geographies, and histories from which identity politics (and its subsequent critiques) have emerged. Given these variations in the level of exposure to and fluency in politicized discourses, which can be indicative of the privilege of English-speaking, educated, networked, urban classed people and of the different local, cultural understandings and valuations of disability, I have difficulty calling my participants "crip," although the term's fluidity might grant it the capacity for such designation. I am more interested, along with Kafer, in "making room for those who do *not* or *cannot* recognize themselves in crip,"[23] and crucially, for those who are not even part of such a system of recognition. It is exactly these "nots" that I am interested in. What kind of a disability story emerges from these experiences that do *not* fit the normative narratives around disability? What do these stories tell us about disability itself? How do they complicate and "disorient" the category,[24] and multiply its becomings?

As an ecological concept, activist affordances can be used to understand the acts/arts of survival of any being who is made to live in an inherently shrunken and shrinking world. The creation of activist affordances requires neither group identification nor belonging to a category (nor even to a certain species for that matter). Activist affordances can be undertaken by any disabled organism at any place and time. I am not suggesting, therefore, that my participants' activist affordances can arise only from their particular cultural and geographic location or from some kind of "not" identity. In fact, my ecological approach does not—and cannot—take disability as "a category inherent in certain minds and bodies"[25] but instead considers it as a particular *mode of inhabiting* a constrained or "shrunken" world of possibilities. In taking this approach, I seek to join Kafer, Julie Avril Minich, and others in thinking of disability relationally, as a way of forging collective affinity. Locating disability *somewhere* would always require us to identify where that somewhere is, creating boundaries that would inevitably need to be policed. Taking up critical disability studies "as a methodology," I seek to align with Kafer's political/relational model of disability "as a site of questions rather than firm definitions."[26] Are people with rheumatoid arthritis (RA) disabled? If so, how and under which conditions? What sort of shared affinities can be found among, say, people living with chronic pain, people in wheelchairs facing a flight of stairs, people undergoing severe mental suffering, and people whose lives are debilitated by "slow violence"?[27] Can a tree, the air, or the environment itself be disabled? If so, what does it mean to talk about the disability of the animate and the inanimate? Crucially, how can the concept of affordances allow us to navigate this messy territory?

An Ethnographic Journey

Let me rewind the process of my ethnographic journey and research-creation experiments through which I came to question and trouble the traditional theory of affordances, moving toward the theory of "activist affordances"—a term that I use only in retrospect. This journey started from my engagements with autoethnography, in which I visually documented and analyzed my own daily movements. During this pilot project, I encountered specificities in my everyday movements as a person living with rheumatoid arthritis. At the time, I was fascinated with the theory of affordances for what it could offer as a theory of movement and perception. Still, it did not fit well with the movement-related specificities of the disability I live with. This incongruence led me to ask: What possible affordance could there be for me in my "ecology," when living in constant pain from joint inflammation is often so profoundly limiting? But then I also wondered: If to be disabled is to "realize that . . . the world is not [your] dance floor," as Vivian Sobchack puts it,[28] what if disabled people imagined new floors to be danced on? What would these disabled reimaginings of the world do to the theory of affordances? What if I started with my experience and adapted the theory of affordance to it?

To find answers to these questions, I engaged in a visual ethnography. Fine-tuning the methods I had previously developed, I conducted fieldwork in İstanbul and Quebec (2009–2010), tracing the (potential) appearances of nonapparent disabilities related to rheumatoid arthritis. I worked with twenty-three participants, whom I recruited through two local hospitals, community organizations, and my own networks.[29] I visited them at their homes and explored how they went about their everyday lives. During these visits, I filmed my participants as they undertook a series of "simple" daily tasks that I chose beforehand (such as dressing or cooking) plus any other tasks for which they had developed special "tricks." During the same visits I interviewed my participants, along with any family members and friends who were present. When we met in person, my participants and I, right from the beginning, knew that we had a shared experiential knowledge base that we could move past to more in-depth issues. I was by no means a "distanced" ethnographer, "objectively" observing the field. Our meetings were less semi- or unstructured interviews than the conversations of two longtime friends who had so much to share. But it was not only the shared experiential knowledge; the recognition that we supported each other—a recognition that we could hardly have in our routine lives, and a recognition that we have long desired and hoped for—created this space of relating, belonging, and sharing. For a group that is used to being perceived and treated as not disabled, as not disabled enough, and as too disabled, there was indeed a delight in finding that you and your group are none of these things that you are said to be in an ableist world and its rigid categories. As soon as I asked my participants about their everyday "tricks," as they often called them, or what I am calling "activist affordances," their eyes often sparkled with joy as if this was the moment they had long waited for. Of course, not everything we talked about was joyful; there were many moments of frustration, anger, and sadness and the acknowledgment of loss. Nonetheless, a process of elated exchange unfolded during which my participants shared their art/acts of getting by in the everyday with someone who finally understood these acts and who appreciated their value to their everyday survival. During the interviews our positionalities became rather fluid; at times, I was the one being asked questions rather than the one doing the asking. This means that as much as I talk about my participants' stories in the following pages, I also talk about mine. Hence the interchangeable uses of the pronouns "they" and "we" when speaking of my participants.

During fieldwork, I used the following research-creation methods. I positioned the camera to try to capture whichever affordances escaped the public gaze not sensitized to recognize them. During editing and analysis I replayed the footage, slowing it down to allow me to pay attention to the details that I may otherwise have missed (some of which I was able to spot in the moment, some only during editing). I selected clips frame by frame in order to identify where and how exactly activist affordances occurred. I then captured the images of these critical moments and juxtaposed them with what my participants said about their own movements in the moment of undertaking them, or with descriptions of the creativity that I came to notice about them later on. In my writing, I use these image/text collages as a multimodal documentation of an activist affordance that once was, of a performance that once took place. This, again, is what I mean by disability as a method of creative practice: to reappropriate the affordances of any medium for our own subversive purposes, which in this case was to capture and freeze the fleeting and micromoments of everyday survival of disabled people, and render them recognizable, archivable, and shareable.

At the end of my first fieldwork period there were questions left unanswered, and more to explore. Did the affordance-creations that I encountered in the field result from the specificities of the mobility-related disability that I focused on? Would I have found something else had I explored the lived experience of another kind of disability? What if I moved beyond the sphere of homes to public places? What activist affordances would there be, if any? To seek answers, I pushed my critical interrogation of affordances further in a second visual ethnography, using the creative methods I developed in the first one. In 2013 and 2014 I conducted fieldwork in Montreal, Canada, a city that is known to be highly inaccessible because of its harsh winters, uneven geography, and strict architectural codes for historical buildings.[30] Using participatory approaches, I collaborated with differently disabled individuals living in the greater Montreal area, filming their everyday practices at home and following their daily mobilities through public places over the course of a year. In this book I reflect on my collaborations with two of these individuals: Jérôme and Anna. Jérôme is blind from birth, and Anna has a mobility-related disability (unrelated to rheumatoid arthritis). I contacted Jérôme through the association for students with disabilities at a local university. We met as participants of the Megafone.net project at Concordia University—the Montreal leg of a worldwide digital mapping project by marginalized communities.[31] I met Anna at a conference aimed at raising awareness of disability in Montreal, where she was one of the co-organizers. Given our shared commitment to disability and access issues and the highly personalized nature of the research, we decided I would not anonymize their names. At our initial meeting, I explained to Jérôme and Anna the purpose of the project, and in line with participatory methodologies, they chose the time and place of filming. Our meetings depended on which locations, events, and time periods mattered to Jérôme's and Anna's everyday lives and movements in public places. At times we were in the metro taking the train; other times we were at home baking muffins. As I expected, activist affordances were still present, but they were not always in the places that I was used to finding them. This time, an activist affordance was not an ingenious way of putting a full mug on the table but lay in placing the tips of one's fingers on its brim in a "blind style of perception."[32] Further, I accounted for how multiple variables, including technologies and the mobilities of other humans and nonhumans, have factored into affordance-creation.

Redefining Affordances

Psychologist James Gibson proposed the theory of affordances in the 1970s as part of his broader project of framing action and perception in ecological terms, and in so doing he questioned psychology's binary thinking. "The dualistic separation of a physical and mental environment," as Edward Reed writes, "has always been one of the basic philosophical tenets of psychologists, from experimental psychologists to phenomenologists."[33] "Knowledge of the world," the field's scholars assumed, "must come from somewhere; the debate is over whether it comes from stored knowledge, from innate knowledge or from reason."[34] But what if, Gibson asked, no such source is necessary?[35] What if what we perceive is not a stimulus that needs to be processed but an always already meaningful environment? Knowledge of this environment "surely . . . develops as perception develops . . . gets finer as [the observers] learn to scrutinize . . . gets richer as they notice more affordances." But "knowledge of this sort does not 'come from' anywhere; it is got by looking, along with listening, feeling, smelling and tasting."[36]

As this brief review suggests, Gibson's ecological approach attempted to bring the body and its agency back into psychology. Organisms, Gibson argued, do not perceive their environments indirectly, through the mediation of some mental system (be it memory or input-processing), but *directly* by way of their engagements with it. Crucially, they are able to do so because *self-perception and environment perception are complementary processes*. That is, we cannot perceive the world without coperceiving ourselves at the same time. It is exactly this relation that led Gibson to the idea of affordances. If we can perceive the environment *directly* as such, he wondered, then why should not we also perceive which action possibilities it affords to us? Upon seeing a flat, rigid, and knee-high surface, for instance, I see not only the surface but also the possibility of sitting, which is embodied in its materiality. But the possibility I see at the same time depends on my embodiment: I am bipedal, sighted, of a certain body weight and scale, and possibly in need of rest at that moment. Affordances describe how actions are shaped by such emergent correlations between our bodies and the environment.

Affordances are material, relational, and emergent. But they are also objective and invariant in the sense that they are "always there to be perceived," independently of whether we actually perceive them or not.[37] This is how Gibson distinguishes his ecological approach from a phenomenological one: affordances are not the sole products of our subjectivity. They reside neither "in the world of matter" nor "in the world of mind," such that "the theory of two worlds is rejected."[38]

Finally, we do not just go about doing anything with anything in our daily lives. Things have social and "canonical affordances" that have been chosen long before us[39] and that are sustained within a habitus into which we have already been enculturated. Ultimately, affordances are historicized. Some have already been taken advantage of, others not. Gibson's use of the concept of "niche," which he mobilized to refer to a set of affordances, implicates this historical transformation of the world, setting those environmental affordances that societies have already made use of apart from those that they have not yet occupied.[40]

My theory of activist affordances begins with Gibson but takes a different path. No doubt any action of the organism is shaped by its reciprocal relations to its environment, and if the organism has survived it is because that reciprocity exists. And that reciprocity is always there, as Gibson correctly surmised. But do we all find those reciprocal relations the same way, with the same amount of effort, and thereby ensure our survival? Or do some take more labor, energy, and, in fact, some creativity to discover? What does it take to actualize an affordance? What happens on the way to this discovery and actualization? What takes place in the space between the here/the actual and there/the potential; between the niches already occupied and those that are yet to be found? These are the questions that drive my theory of activist affordances.

Describing Disability Ecologically: A Shrinking Environment

In this book, I propose that disability can be described as the shrinking of the environment and its existing set of affordances for a given body or bodies, regardless of the cause of shrinkage. I use the concept of "shrinkage" to refer to the process in which possible affordances are reduced in a given body-environment relation.[41] Shrinkage makes the field of possible affordances *smaller*. Smaller than what? In the case of a congenital disability, the field is smaller than for the normate. In the case of the onset of an illness, pain, or disablement, the field is smaller than it used to be. Shrinkage is a lessening or diminishing in relation to the scope or range that was available before for the person in pain, the person who falls ill, the person who becomes disabled. Irrespective of the differences in the starting points of shrinkage, all cases share the common denominator of having *fewer* options. The environment does not afford as many possibilities as it once did, or as it currently does to privileged coinhabitants. It is exactly this scarcity of opportunities and the exigencies that it creates that I want to capture with the idea of shrinkage.

I admit that shrinkage is a risky concept. Read too quickly, it might sound like another iteration of the social model of disability, and the first thing it brings to mind can be barriers to access. Indeed, "the cripple before the stairs," "the amputee before the typewriter," and "the dwarf before the counter" all strikingly illustrate how the barriers of the built environment shut disabled people out by design.[42] The concept of shrinkage surely involves such situations of "misfitting,"[43] but it is not limited to those, and this is the nuance I want to introduce. Differing from the social model, rights-based frameworks, and demands for access—the staples of early disability studies and movements—the idea of a shrinking world goes beyond environmental barriers and encounters of misfitting to a range of other situations, processes, and experiences in which the environment and its sphere of possible actions narrow down. The world's shrinkage can arise from bodily experiences of pain and illness that cannot be alleviated by environmental changes; lack of access despite the (seeming) presence of accessibility; regimes of debilitation; and finally, the ongoing disablement of the environment itself. Let me begin with chronic pain and disease—two areas that disability studies have been slow, if not reluctant, to analyze and theorize.[44] I then move on to discussing what I call, after Pierre Bourdieu, the "habitus of ableism," and how it reduces the world's opportunities for action in unnoticeable ways.

Shrinkage: Chronic Pain and Chronic Disease

Of all our bodily states, Elaine Scarry writes, pain is the only one without a world-counterpart. While fear, desire, and thirst can have corresponding objects, there is no *thing* in the world outside that can match this unique bodily urgency. Pain, she writes, is utter "objectlessness."[45] But I would argue that pain still involves a relation to the world, albeit one that is negative. Upon touching a hot surface, for instance, a person feels what is called "acute pain," and—contra Scarry—that acute pain still takes, and in fact (given its essentiality to biological survival) *must* take, an object (in this case, the hot surface). Acute pain still offers an affordance, consequently, the affordance of avoiding what could bring harm. We can think of its affordance as avoidance, an "ill" or negative affordance.[46] When pain becomes chronic, such negative affordances inundate the person's space for action, making it shrink in direct correlation to the amount of pain the person experiences. The more pain you are in, the more the parameters of the environment narrow down, even (at its extreme) to the confines of a bed. From an ecological approach, chronic pain can be thus defined as the shrinking of the environment and its existing set of affordances. To experience chronic pain, I contend, is to experience the scaling down of the environment and the ever-widening distance between the body in pain and its previously available affordances.

Chronic pain's neighboring condition, chronic disease, may as well be described in similar ecological terms. Disease, Georges Canguilhem writes, "is characterized by the fact that it is a reduction in the margin of tolerance for the environment's inconstancies."[47] A sick person does not have a plenitude of *opportunities* at her disposal with which she can easily respond to and handle the fluctuations in her environment. Her already compromised immune system has reduced the biological resources her body has available to deal with an invading virus. A person with chronic kidney disease cannot *just* drink more. A person with osteoarthritic knees calculates every step needed to reach the next bus stop. The sick person does not want to "spoon out."[48] She does not want to take any chances, because her body can at any moment let her down. At any moment it can *fail*. Living in a state of precarity, the person begins to inhabit an environment that is more and more protected, more and more narrowed, so that no surprises will occur in the environment that the person is not ready to tackle. An immunocompromised person refrains from occasions of contact with the outside world (as made so much more evident in the current COVID-19 pandemic). Likewise, a person with osteoarthritis tries to minimize the walkable paths in her daily life. This is how the parameters of the existing environment diminish when living with a chronic disease.

The *constraining of the space of affordance from which an action can arise* is evident in the following, where Drew Leder reflects on a depiction by Herbert Plügge of the “reduced sense of time and space” experienced by cardiac patients:

> A landscape is viewed not as a field of possibility but of difficulties to negotiate. The ordinary sense of free and spontaneous movement is now replaced by calculated effort: one does not want to take chances. Etymologically, “ease” comes from the French word *aise*, originally meaning “elbow room” or “opportunity.” This experience of world-as-opportunity is precisely what dis-ease calls into question.[49]

Amending Leder’s description, I argue that chronic disease calls the existing affordances of the world into question. To experience chronic disease is to experience a shrinkage of otherwise readily utilized ecological affordances.

Shrinkage: The Habitus of Ableism

Of course, there are many other ways in which the environment contracts and becomes less reachable. A major one is related to how ableism functions as a form of habitus, that is, an “embodied history, internalized as a second nature and so forgotten as history.”[50] The idea of the habitus of ableism does not focus on the social creation of disability by barriers and discrimination (as does the social model) but on how a collective system of beliefs, habits, and dispositions that are deeply ingrained in our ways of acting, perceiving, and behaving can automatically make the affordances of the world more available to some bodies/minds than to others. By the term “the habitus of ableism,” I refer to an unknowingly incorporated set of bodily dispositions and skills and, necessarily, their affordances that have become established as *the* way of moving, sensing, and behaving in the world, negating all other alternatives. Take walking. Walking, anthropologist Tim Ingold writes, is a “skill” that humans get to incorporate during their development “within an environment that includes skilled caregivers, along with a variety of supporting objects and a certain terrain.”[51] Walking is one possibility among many (including crawling and wheeling) in which the environment can be traversed by humans. But because the affordances that complement walking have been carved into landscapes by those that came long before us (with roads, stairs, and so on), and because walking has been endlessly repeated, normalized, and naturalized, walking comes to appear as an innate “ability” that we are all supposed to have rather than a skill into which bipedals have been "enskilled."[52] Walking, in other words, becomes normative, and so turns into walk*ism*.[53] I propose the "habitus of ableism" concept in order to capture precisely this "performative magic of the social," which renders the environment only *singularly* habitable, erasing other possibilities of habitation as those "'not for the likes of us.'"[54] Those "unlikely" habitations may be called "issues of access" (which may or may not be noticed, which may or may not be provided) or "assistive" this, "adaptive" that. But those other possibilities may only ever be add-ons in relation to the hegemony that the habitus of ableism holds over the world's affordances. Here is how we are brought to the situations of shrinking, which I explore in chapter 3, where accessibility features may exist but not properly function, where accessible spaces may be thoughtlessly occupied by those who do not need them, and where lack of access may be excused away or not given attention in the first place.[55]

A Shrinking Planet

The environment shrinks and becomes less and less available for action to certain populations because its affordances have been denied them historically and systematically and weaponized against them. As histories of colonial occupation, neocolonialism, imperialism, militarization, nuclearization, capitalist expansion, extractivist operations, environmental racism, and many other atrocities tell, the colonizer, the state, disaster capitalism, and other systems of oppression wield their power over the world's affordances—seizing, exploiting, and ultimately exhausting them. Through the control they hold over the land and its affordances, they can produce and perpetuate impairment and death through direct and explicit forms of violence, as in slavery and police brutality; and through less direct and apparent forms of "slow violence,"[56] whose attritional effects manifest only over time. We can recognize the former in how the US police, in putting Black and Brown people in chokeholds, deprive them of the most fundamental of all affordances, the air. We can trace the latter in how racial segregation and the deliberate placement of polluting industries, landfills, and other toxic sites in Indigenous, Black/Brown, and other racialized, low-income neighborhoods contaminate the air, land, and water and expose these communities to prolonged intoxication. During such attritional violence, not only are colonized, racialized, classed, and gendered subjects injured physically and psychically, as Jasbir Puar unveils in her analysis of "debilitation" in Palestine; they are left without the affordances of the land, air, water, and infrastructure and state sustenance that they desperately need to recover, survive, and thrive.[57] Debilitation can be understood as the deliberate withholding of the affordances of a land, and at times weaponizing them against its inhabitants, to the degree of making the land uninhabitable and life as unlivable as possible for them. Globalized forms of power materialize themselves as domination over the world's affordances, rapaciously utilizing, usurping, and depleting them until they produce conditions of utter uninhabitability. This takes me to my final point: the shrinking of the planet and its livability.

In this age of the Anthropocene, Capitalocene, and Plantationocene,[58] we cannot decouple the disablement of humans from the disablement of other species and their lifeworlds. All lives are entangled. All livelihoods are interdependent, as the COVID-19 pandemic has most recently proved. What many Indigenous peoples, environmental justice activists, feminist scholars of science, and climate scientists have long recognized was instantiated in a matter of months in disastrous ways. The ongoing destruction of forests, lands, and natural habitats of various species has (once more) enabled the transmission of deadly pathogens from wildlife to humans and ended up disproportionately affecting already disenfranchised minorities and impoverished regions.[59] In a pandemic world, where the direct and indirect effects of human-induced environmental degradation will only increase, we need a disability theory that goes beyond human exceptionalism and addresses the environment in all its complexity, as a matter of multispecies habitation. We need a disability scholarship that moves beyond the question of how the built environment disables people, as the mantra of the social model goes, to how humans themselves injure and disable the environment through their crippling and destructive activities of *building* and *unbuilding*—activities that exacerbate the precarity of already disabled and debilitated lives. This alternative approach, I argue, requires an *ecological understanding of disability*.

The Communality of a Shrunken Environment

I have now drawn a scratchy map of a variety of situations in which the environment shrinks and becomes less and less habitable. The culprit may or may not be an explicit form of discrimination. There may or may not be a barrier, a disease, or even an actual impairment. The disabled may or may not be human. The ecological understanding of disability that I am after is not concerned with a place to locate disability, whether it is the body or the environment or one's identity (as the binary social/medical and minority models, respectively, suggest).[60] Rather, it is concerned with the commonality of environmental shrinkage with its correspondingly contracted affordances. And it is exactly this shared shrinkage, I argue, that can offer us a way to build coalitions and to approach critical disability studies "as methodology."[61] For sure it matters where, how, for whom, and under which conditions the shrinking occurs; each occurrence of disability is geographically, culturally, historically, and materially specific, and as such requires a discussion of specificities rather than "a tendency to talk of universals."[62] Nevertheless, from the perspective of an ecological understanding of disability, disability occurs as the contraction of the environment and its existing affordances, whether or not those who are affected are categorized as disabled.

An ecological understanding of disability raises the question: At what point will the environment become so shrunken that it disables all action, all life, and how can we prevent this?

Accessible Futures

Recall that the opening of the imaginative space of performance in the face of a shrunken and shrinking world is a core argument of this book. When the environment shrinks and constrains the actions of sick, impaired, nonstandard, and debilitated bodies, it is exactly this imaginative layer of performance that falls on the "actual" world and allows us to make it afford otherwise or more precisely, as Sara Ahmed puts it, "slantwise": a generative disorientation to the "right" angles and "right" order of things.[63] Let me show you what I mean in an example. When the design of a zipper asks my fingers to perform actions that they cannot accomplish, I then bend my knees inward, exhale a big breath, and push the zipper up with the nail of my thumb, making use of only a distant potential in the form and materiality of the zipper (AS IS). In so doing, I create an activist affordance that minimizes my joint pains; that somewhat counteracts the shrinking and intolerance that the diseases I live with bring about; and that correspondingly transforms what previously was a hostile object (the zipper) into a welcoming and even an accessible one, however momentarily, ephemerally, and counterfactually.

If the odd body-object pairing that makes my pants zip-up-able were to be given a material form, perhaps it would result in self-zipping trousers or garments with magnets that are yet to be thought of.[64] If the slanted positions that Henri uses to put his mug on the table were to be contoured, perhaps it would concretize in an arthritic mug that is yet to be designed. But these future objects were already actualized, and their affordances were already foreseen in and through our improvisatory affordances. The creation in and through our bodily performances of such potential "assistive" devices *in* their absence, and the making of "inhabitable worlds" whatever their unlikelihood,[65] are exactly what *Activist Affordances* describes.

Activist affordances arise from the remoteness of ecological complementarities—affordances—between bodies and their environments: the activist affordances that disabled people enact make a given environment into a livable and habitable elsewhere. These affordances, no matter how small or modest, open up room to move, create, and live onward in the absence and distance of a more readily workable affordance. Activist affordances are inherently the products of a shrunken world that multiply its conditions of livability against all odds.

Let me bring in the story of Ahmet. Ahmet fell ill when he was about ten years old, with his feet and arms completely inflamed and swollen. He could not walk without support or do much on his own. Ahmet and his family lived in a small Turkish village in the early 1990s, where his primary school was far from his home, with only a rough country road (a *patika*—literally, "a path to be walked upon") connecting the two. I asked Ahmet if he was able to attend the school regularly. He replied: "Of course. But my dad helped me. He carried me in his arms." Ahmet's father did this every single school day, back and forth, for three years, until Ahmet had to take a five-year break from his education due to intense flare-ups.

Let me put Ahmet's and his father's story in its historical and local context. Rural 1990s Turkey lacked basic infrastructure and services, and in their absence, Ahmet's father lent his arms to be carried within, and his feet to be walked with, becoming the very affordance of what would have, in ideal circumstances, been a wheelchair, together with an adaptive public transportation system or a smooth-surfaced road on which the wheelchair could easily travel. The way that Ahmet's father met the incontrovertible need to move Ahmet's impaired body from his house to the school in the absence of an adequate and accessible transport system exemplifies exactly what I mean by the *exigency* of activist affordances.

In the current shaping of the environment we may not live in accessible spaces or have "adaptive" tools, "assistive" devices, and technologies at our disposal; we may not be readily provided with infrastructures or services that would sustain our movements and activities; we may not live in an accessible world, and perhaps we never will. (Even assistive devices cannot meet the needs of every body that might otherwise make use of them. It also seems unlikely that assistive devices for every body's needs could be made generally available, given that in the current economy, custom-made productions are prohibitively expensive.) But when an activist affordance is choreographed, it is as if "inhabitable worlds" were already built, as if such "accessible futures" already existed, except that they exist in our actions, performances, and unfinished makings, not in some concretized object or infrastructure that may or may not be available in the locations that we happen to inhabit.

In *Cruising Utopia*, José Esteban Muñoz writes, "Queerness is that thing that lets us feel that this world is not enough, that indeed something is missing." Muñoz suggests that we consider embodied queer performances as actualizations of that thing missing, as "a future in the present," as "outposts of actually existing queer worlds."[66] Following Muñoz, I propose that we consider activist affordances as the outposts of already existing accessible futures. Whichever accessible presents we have not found ourselves in, whichever opportunities we have been denied, whichever inhabitable worlds a stultifying present has failed to provide for us we make up and make real in and through our ephemeral acts of world-making that I term "activist affordances." Activist affordances are "a future in the present"—a future in which the very same environment becomes habitable otherwise. Activist affordances bring "accessible futures" into life, AS IF those futures were of the here and now, AS IF they had already arrived.

For sure, an already existing accessible world might save us from having to continually and laboriously rehearse a "danced" version of it.[67] But a fully accessible world, as I have noted, is a sheer impossibility. Access is not a competition with a finish line, which, once crossed, would complete the mission. As long as life goes on, we will keep bringing accessible worlds into life in and through our activist affordances. Crucially, as we do so, we might not have all the resources at our disposal. This is exactly why I want to elevate our acts of making to the level of performance. Because when all other means of making become unavailable, when all other possibilities of articulating our sick, impaired, and atypical bodies slip away, the improvisatory space of *performance* is always there, requiring nothing more than our bodies and our imagination. And sometimes—particularly in times of deprivation, as in the case of Ahmet and his father, and in the current state of ecological devastation that threatens all living beings—our bodies are, indeed, all we have.

The Structure of the Book

The book is divided into two parts. In part I, I go back to the original theory of affordance and then trouble it by bringing in disability and proposing the concept of shrinkage. In part II, I turn to performance and gradually elaborate the theory of activist affordances.

I begin chapter 1 by tracing the lineage of the ecological theory of action and perception and the conditions of intellectual history under which it emerged. Drawing on Gibson's theorization of affordances and subsequent commentaries, I introduce the concept of affordance, foregrounding the potential it holds for disability scholarship, disability justice, and environmental justice. Then I turn to my ethnographies to bring in a series of situations in which existing affordances of the world fail, and the environment AS IS becomes a set of constraints. Each chapter in this part addresses the varying ways in which the existing environment and its affordances may shrink. Chapter 2 focuses on chronic pain and disease. In chapter 3, I consider situations in which accessible spaces and services exist but are not actually available to particular bodies, or where such spaces and services simply do not exist because the normative environment goes unquestioned. Drawing on these encounters, I introduce the "habitus of ableism" as a concept that accounts for how the absence of accessibility *and* its existence arise from a normalized environment that privileges some affordances over others. In chapter 4, I discuss the shrinking of the environment as a corollary of colonial, extractivist, and capitalist power. Through these four interwoven chapters, part I maps out disability in the ecological terms of shrinkage as the overall consequence of the failures, denials, deprivation, and diminishing of the environment's socialized/materialized affordances.

Part II asks: What happens in the face of shrinkage? This part's six chapters bring in a range of ethnographic materials to demonstrate how the shrinking of the environment, when not a complete blockade, becomes an opportunity to inhabit that environment otherwise through the improvisation of activist affordances. In chapter 5, I build upon Scarry's theory of "making" to conceptualize activist affordances as a form of creation emerging in and through the ephemerality of performance.[68] Chapters 6 and 7 present a detailed inventory of activist affordances that become evident as participants enact and explain why, how, and under which conditions they came up with improvised solutions to the shrinkage they encounter in their everyday lives.

Activist affordances can take different forms. At times we may imagine and actualize a more hospitable world in and through our ingenious movements. At other times, when our bodies reach a limit and can no longer do things on their own, other people may enable, facilitate, or directly become our affordances (as in the case of Ahmet's father), creating a subset of activist affordances that I term "people as affordances." I introduce this concept in chapter 8 and bring in various ethnographic situations where "people as affordances" materialize (or fail to do so, for that matter). In chapter 9, I think about the cumulative effects of activist affordances over time and discuss how performance and activist affordances may persist through *transformations* in the places we inhabit, including their furniture, wardrobes, kitchens, social relations, and so on. Drawing on Diana Taylor's concept of "repertoire,"[69] I refer to this persisting power of activist affordances as "disability repertoires." Disability repertoires describe the set of everyday survival techniques that disabled people create within the very constraints and normative environments that are imposed on them. Put differently, disability repertoires can be thought of as a collection of activist affordances, like a recipe book of how to go about reinventing the everyday in the face of restraints, failures, and losses. In the final chapter, I emphasize why the creation of activist affordances is an *urgent need* and speculate about the possibilities that this form of creation and way of living may offer for saving a shrinking planet.

The Affordances of This Book

This book is not an academic exercise in creating yet another theory. Instead, it emerges from the *ethical responsibility* to understand how accessible futures can be imagined and actualized in the face of enduring constraints and how livable lives can be dreamt and brought into being against all odds. Disabled people's imaginative everyday acts are acts of *activism* that need to be acknowledged, named, articulated, and theorized in themselves because they provide an important resource for living into our future as inhabitants of this shared planet. The theorization, analysis, and investigation of activist affordances are not high-minded academic tasks but pressing social responsibilities.

Like all things, this book has its own affordances. Nancy Mairs wrote a book because she wanted to offer other chronically ill and disabled people a place in which they could recognize themselves.[70] Alison Kafer wrote a book because she desired "crip futures," that is, "futures that embrace [not erase] disabled people."[71] I wrote this book because I do not want our activist affordances—the *making up*, *making real*, and *making do*—to go unrecognized anymore. I offer activist affordances as a critical vocabulary, a theory, and a method we can use to identify, trace, and appreciate the ways in which our radical affordances—no matter how ephemeral, discrete, or momentary—*can* and *do* bring livable worlds into being. This book affords a companion to those *worlds-in-the-making*, to those accessible futures, by whomever or whatever they are being made and wherever and whenever they are being inhabited.

NOTES

INTRODUCTION

1 Along with disability communities and scholarship, I have moved from naming disabilities “visible” and “invisible” to “apparent” and “nonapparent.” “The concept of visibility itself,” Carrie Sandahl notes, “relies on a metaphor that assumes able-bodiedness” and therefore bolsters ocularcentrism (Sandahl, “Queering the Crip,” 54). Appearance, in contrast, is a multisensorial phenomenon. Moreover, the idea of apparency, as Schalk writes, “shifts the onus for noticing or not-noticing disability onto the perceiving person rather than onto the visibility of disability via a person’s bodymind, accoutrements, or behaviors” (Schalk, *Bodyminds Reimagined*, 124).

2 Throughout the book, I will be using both “disabled people” and “people with disabilities” as a way to acknowledge the situated and nonstatic nature of language. The former phrase, which, after the social model, highlights the disablement of the people by the society and its barriers, and the latter phrase, which is known as people-first language, are valuable in their own right as their effectiveness varies, depending on who uses them, in which context, and how.

3 Gibson, *The Ecological Approach*, 127.

4 Activism is traditionally associated with collective and intentionally engaged activities (such as sit-ins, protests, rallies, occupations) that have a disruptive potential, are explicitly visible, and often involve confrontation and demands for change. As disability scholars and activists have already noted, there is a certain ableism and normativity to this understanding (Wendell, “Unhealthy Disabled”; Wong, “Valuing Activism of All Kinds.”; Genest, “The Body as Resistance Art/ifact”). Who else can do the work of such activism but an able-bodied/minded subject capable of acting, of moving around, and of having intentions and determinations? In bringing in the idea of performance *as* activism, I want to challenge these ableist presumptions and demonstrate that activism can take many other forms, such as activist affordances, that may fall through the cracks of recognition. I discuss activism in more detail in chapter 5.

5 Austin, *How to Do Things with Words*. Judith Butler and Jacques Derrida have used Austin's speech act theory as a foundation for their theorizations of performativity.

6 Performer and author Neil Marcus has famously described disability as "an art" and "an ingenious way to live" (Marcus, *Storm Reading*). Siebers talks of the "artfulness" of disability (Levin and Siebers, "The Art of Disability"). Belser conceptualizes the relationality between wheelers and their wheelchairs as "vibrant artistry of life with disability" (Belser, "Vital Wheels," 7). Various scholars and activists argue that disability can be considered as a "gain" rather than a loss (Bauman and Murray, *Deaf Gain*); as "benefits rather than deficits" (Garland-Thomson, "The Case for Conserving Disability," 339); and as the equivalent of biodiversity rather than abnormality (Bauman and Murray, *Deaf Gain*, xviii; Clare, "Notes on Natural Worlds," 258). Some claim that disability generates its own standpoint knowledge and "cripistemologies" (McRuer and Johnson, "Proliferating Cripistemologies"). Scully, for instance, writes about "the epistemology of the disabled experience" (Scully, *Disability Bioethics*, 13). Wendell argues that the sphere of experiences that disabled people have access to generates a particular form of knowledge, and were it to be taken seriously (rather than being silenced or dismissed), "an explosion of knowledge of the human body and psyche would take place" (Wendell, "Toward a Feminist Theory of Disability," 120). Garland-Thomson considers disability as a generative, narrative, ethical, and "epistemic resource" (Garland-Thomson, "The Case for Conserving Disability," 349). With respect to design and disability, various concepts and approaches have been proposed, such as "DEAFSPACE" (Bauman), "starting with dis/ability" (Boys, *Doing Disability Differently*), "crip technoscience" (Hamraie, *Building Access*), and "crip design" (Williamson, *Accessible America*), in order to foreground how disability embodiments and standpoint knowledges can be at the center (rather than at the margins) of design practices. In this emergent body of work, the traditional deficit perspective of disability has been turned upside down: disabled people not only have been compared to artists and scientists alike (Saerberg, "The Sensorification of the Invisible") but have also been called "original life hackers," self-taught experts, and "unrecognized" and "unlikely engineers" (Jackson, "We Are the Original Lifehackers"; Williamson, *Accessible America*; Hartblay, "Disability Expertise"; Hamraie and Fritsch, "Crip Technoscience Manifesto"; Hendren and Lynch, "This Counts Too"; Hamraie, *Building Access,* 106, 113).

For a broader emphasis on design and making, see Gunn, Otto, and Smith, *Design Anthropology*; Murphy, "Design and Anthropology"; Escobar*, Designs for a Pluriverse*; Costanza-Chock, *Design Justice*. See also Hartblay, Hankins, and Caldwell, "Keywords for Ethnography and Design."

7 Within recent literature, a few works have looked at disability and affordances, but their engagement with the terms has been rather preliminary in that either disability or affordances appear in passing. Disability, in particular autism, has attracted the attention of some ecological psychologists (see Loveland,

"Social Affordances and Interaction II"), but their work has largely been less ecological and more psychological, or rather infused with psychologizing overtones. In "Bodies, Technologies and Action Possibilities," Bloomfield et al. present one of the most interesting studies to date on disability and affordances. Drawing on research designed to "combat social isolation among housebound disabled individuals," the authors examine how objects, people, and situations interact in the creation of affordances (422). While their study is well-informed on affordances, it lacks a critical disability perspective and the experiences and viewpoints of disabled people themselves. Burns et al. ("An Inclusive Outdoors?") and Clapham ("The Embodied Use of the Material Home"), on the other hand, integrate a critical disability perspective into the deployment of affordances, but their mention of affordances remains rather cursory, without any substantial exploration of the term or any engagement with Gibson's ecological approach.

8 Gibson, *The Ecological Approach*, 127.

9 Kafer, *Feminist, Queer, Crip*, 141.

10 D. Taylor, *Performance*, 6.

11 Turner, *From Ritual to Theatre*, 84.

12 Turner, *From Ritual to Theatre*, 83. Following Taylor's style in her definition of performance, and in order to further emphasize the difference between the indicative "as is" and the subjunctive "as if," I will use AS IS and AS IF in their capitalized forms throughout the rest of the book.

13 These approaches shift the traditional consumerist, market-centered, and industry-centered focus of design to "the realm of the unreal, the fictional." They are concerned not with finding solutions to the needs of the industry but with posing questions, prompting debates, and proposing speculation about alternative futures, possibilities, and how things *could be* (Dunne and Raby, *Speculative Everything*, 11).

14 Charles Eames cited in Pullin, *Design Meets Disability*, xiii. Pullin's research shows that "it was the particular constraints of the U.S. Navy brief that led the Eameses to develop their own technology" with plywood curves and create a leg splint for injured personnel in the Navy—the plywood technology which then became "an iconic mainstream furniture" (xiii).

15 Throughout the book, I will be using the word "resource" in order to refer to bodily and environmental resources (understood as capabilities) while keeping in mind that "resource" is far from being an innocent word. As feminist environmental scientist and activist Max Liboiron writes, resource is "a colonial, settler, and imperial concept" (Liboiron, *Pollution Is Colonialism*, 63); "resources refer to unidirectional relations where aspects of land are useful to particular (here, settler and colonial) ends" (62). Further, it is not only the land that is a resource in the colonial mindset; as Indigenous scholar and activist Leanne Betasamosake Simpson points out: "My culture and knowledge is a resource. My body is a resource and my children are a resource because they are the potential to grow, maintain, and uphold the extraction-assimilation

system" (Simpson, "Dancing the World into Being"). I use the word "resource" partly because of its noninnocent genealogy rooted in colonialism and capitalist voraciousness.

16 Haraway, *Staying with the Trouble*, 2.

17 Chapman and Sawchuk, "Research-Creation," 6. See also Nelson, *Practice as Research in the Arts*; Loveless, *How to Make Art at the End of the World*.

18 Dokumacı, "Disability as Method."

19 Garland-Thomson, *Staring*, 193.

20 Mingus, "Access Intimacy."

21 Clarke and Haraway, *Making Kin*.

22 Susan Wendell writes that in the public conception, "the paradigmatic person with a disability is healthy disabled and permanently and predictably impaired" ("Unhealthy Disabled," 21).

23 Kafer, *Feminist, Queer, Crip*, 16; emphasis added.

24 Friedner and Weingarten, "Introduction."

25 Kafer, *Feminist, Queer, Crip*, 11.

26 Minich, "Enabling Whom?"; Kafer, *Feminist, Queer, Crip*, 11.

27 Nixon, *Slow Violence and the Environmentalism of the Poor.*

28 Sobchack, "Choreography for One, Two, and Three Legs," 62.

29 Names of participants from my first fieldwork have been anonymized. Translations from interviews in Turkish are my own.

30 For further projects on inaccessibility in Montreal, please consult Montreal in/accessible Collective (m.i.a.) Collective, 2013. https://cjds.uwaterloo.ca/index.php/cjds/article/view/113.

31 Megafone is a project initiated by media artist Antoni Abad in collaboration with local marginalized communities worldwide. For further details, visit https://megafone.net/site/index.

32 Saerberg, "'Just Go Straight Ahead,'" 9.

33 Reed, *James J. Gibson and the Psychology of Perception*, 54.

34 Gibson, *The Ecological Approach*, 253.

35 "Let us consider the possibility," Gibson writes, "that the stimulus input contains within it everything that the percept has. What if the flux of stimulation at receptors does yield all the info anyone needs about the environment?" (Gibson, *Reasons for Realism*, 319).

36 Gibson, *The Ecological Approach*, 253.

37 Gibson, *The Ecological Approach*, 139.

38 Gibson, *The Ecological Approach*, 138.

39 Costall, "The Meaning of Things," 79.

40 Gibson, *The Ecological Approach*, 129.

41 I use "shrinkage" to signify the contraction of space for action. This contraction may be caused by an increase in environmental stimulants, as well. For example, when a person living with multiple chemical sensitivity passes through a busy street with shops and is bombarded with fragrances of all sorts, that body's space for action collapses on itself. That is, actual increases in density

or size can *also* lead to shrinkage or contraction in the freedom to move, act, and sense. I would like to thank Jonathan Sterne for bringing this important point to my attention.

42 Garland-Thompson, *Extraordinary Bodies*, 24.

43 Garland-Thomson, "Misfits."

44 Siebers, "Disability in Theory," 177; Siebers, *Disability Theory*, 25; Kafer, *Feminist, Queer, Crip*, 12; Puar, *The Right to Maim*, xix.

45 Scarry, *The Body in Pain*, 162.

46 Gibson writes that the affordances can be "of injury or benefit" (Gibson, *Reasons for Realism*, 405).

47 Canguilhem, *The Normal and the Pathological*, 199.

48 The idea of "spooning out" comes from disability justice communities. The spoon theory was first developed by writer and patient advocate Christine Miserandino in order to illustrate the immense effort it takes to strategize one's energy when living with a debilitating chronic disease like lupus (Miserandino, "The Spoon Theory").

49 Leder, *The Absent Body*, 81.

50 Bourdieu, *Logic of Practice*, 56.

51 Ingold, *Perception of the Environment*, 375.

52 Ingold, *Perception of the Environment*, 36.

53 Laurence Parent defines "walkism" as "the normative expectation that someone can walk and climb stairs" (Parent, "Je Me Souviens," 211). For earlier uses of the term and its conceptual underpinnings see Michael Oliver, *Understanding Disability*, 108–9; Freund, "Bodies, Disability and Spaces," 695.

54 Bourdieu, *Logic of Practice*, 57, 56.

55 Titchkosky, *Question of Access*, 77.

56 Nixon, *Slow Violence and the Environmentalism of the Poor.*

57 In occupied Palestine, for instance, checkpoints, in Puar's vivid description, function as "choke points," and the space is shrunken further and further by the Israeli state with the exact aim of producing "an entire population with mobility disabilities" (Puar, *The Right to Maim*, 135–36).

58 Popularized by chemist Paul Crutzen, the term "Anthropocene" refers to the proposed geologic epoch in which human activity has become the central and most profound force shaping the earth (Crutzen, "Geology of Mankind"). The Anthropocene is a contested term widely criticized for a variety of reasons, including its underlying assumptions of a homogeneous Anthropos/human; its dismissal of the unequal ways in which different populations contribute to planetary damage, and the disproportionate ways in which they bear the burden of its consequences; and finally, its centering of the Anthropos/Man-the-maker and perpetuation of human exceptionalism (see Malm and Hornborg, "Geology of Mankind?"; Haraway, *Staying with the Trouble*; Haraway et al., "Anthropologists Are Talking"; Moore, "Capitalocene"). Since then, other critical terms (e.g., the "Capitalocene," "Plantationocene," "Chthulucene") have been proposed to enrich the debate and to foreground the omissions of the

term “Anthropocene.” In this book, I use the term “Anthropocene” but also bring in other terms, such as “Capitalocene,” in order to acknowledge the contested nature of the term and to recognize the critical work done by feminist, postcolonial, and STS scholars on the issue of naming the current epoch.

59 Vidal, “Tip of the Iceberg.”

60 The social and the medical/individual models of disability are two binary models that have been conceptualized by British disability grassroots activists and scholars (see UPIAS, “Fundamental Principles of Disability,” and Michael Oliver, *Social Work with Disabled People*). According to this conceptualization, the medical model locates disability in the individual’s body, its abnormalities, and its pathologies, whereas the social model locates disability in the society and the environment, and their barriers. I address the model and its subsequent criticisms further in chapter 1.

61 Minich, “Enabling Whom?”

62 Meekosha, “Decolonising Disability,” 670.

63 Sara Ahmed uses the notion “slantwise” in reference to Maurice Merleau-Ponty’s phenomenology, where he describes the effect of seeing a room not straight but obliquely and as “queer” (Ahmed, *Queer Phenomenology*, 65).

64 In fact, the “Design for All Showcase” held by the White House in 2016 featured a series of garments and devices modeled by disabled people, including “shirts with magnet closures to avoid the use of buttons,” as well as alternative lacing systems and jeans with side closures for wheelchair users (Williamson, *Accessible America*, 211).

65 Friedner and Cohen, “Inhabitable Worlds.”

66 Muñoz, *Cruising Utopia*, 49.

67 See Scarry, *The Body in Pain*, 291.

68 Scarry, *The Body in Pain*.

69 D. Taylor, *Archive and the Repertoire*.

70 Mairs, *Waist-High in the World*.

71 Kafer, *Feminist, Queer, Crip*, 45.

CHAPTER 1. AFFORDANCE ENCOUNTERS DISABILITY

1 Garland-Thomson, “Misfits,” 593.

2 In their “Fundamental Principles,” the UK-based grassroots organization the Union of the Physically Impaired Against Segregation (UPIAS), whose work was instrumental to the formulation of the model, famously wrote: “In our view, it is society which disables physically impaired people.” Therefore, they added, “it is necessary to grasp the distinction between the physical impairment and the social situation, called ‘disability,’ of people with such impairment. Thus, we define impairment as lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body; and disability as the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical