Encountering Disability: Orientation, Disorientation, and Ethics

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THESIS

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This dissertation is dedicated to my grandmother, for her kindness.

Also, it is dedicated to Carlos, for her friendship.

Finally, this dissertation is dedicated to my wife, Kelly, for sharing and shaping my path, and for her patience.
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This is not the dissertation I expected to write. Although a line of inquiry can be traced from this project to various seminar papers, my Master’s thesis, even my undergraduate thesis, this topic was a surprise. It was not until about halfway through my preliminary exam defense that the question of disorientation unfolded and fiercely lodged itself in my mind. For this, I must thank the members of my exam committee: Lennard Davis, Carol Gill, Judith Gardner, Rod Michalko, and Diane Perpich; it was their curiosity that sparked my own.

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SUMMARY

This project is concerned with analyzing and describing disorienting encounters with disability, their epistemic and ontological status, and their ethical implications. Specifically, I demonstrate that disorienting encounters with disability reveal the multiplicity of bodily and embodied orientations—ways of knowing, being, and relating—that inform how disabled and nondisabled people understand the world and our place in it. Being disoriented, I argue, means being uncertain of, or in uncertain relation with, (our) bodies and the world around us.

In Chapter I, I demonstrate that questions about disability are dangerous precisely because they are about disability. Such questions gather, gesture towards, and play upon a constellation of already established meanings. In doing so, these questions presuppose not only something about disability but posit disability as some-thing that is, or can be, entirely knowable and known (by the person asking and by the person being asked). At the same time these questions suggest, at least implicitly, that established meanings could be otherwise. Questioning experiences and meanings of impairment/disability means that what we know, or think we know, about what it means and, by extension, what it means to be disabled, is not simply all there is. I also demonstrate that disability can, and should, be thought of as an orientation, locating disabled bodies as sources and sites of meaning.

Building on this idea in Chapter II, I address lived experiences of impairment and disability in relation to the phenomenological notion of orientation. I put Ahmed’s (2006) articulation of orientation in conversation with Eli Clare’s (2007) sense of disabled embodiment as taking place “at a crossroads” (9). From here, I examine the relational nature of impairment and disability, arguing that each, both as concept and corporeal reality, shape and are shaped by bodily and embodied relations in space. In this way, I try to articulate an open space within which
impairment and disability may be understood as a conclusion one reaches and, simultaneously (or at least potentially), the start of new paths (ways of knowing and being). Locating impairment/disability “at a crossroads” demands that we give (and take) account of how bodies are made meaningful but also how they, all of them, make meanings. This is, in part, a response to Puar’s (2011) attempt to replace non-disability/disability with a continuum of capacity that moves between ability and debility. Her construction, I contend, leaves little space from which to appreciate the lived experience of disabled embodiment as anything more than an externally shaped subjectivity. From here, I pursue the argument that impairment/disability is itself generative of meaning through a discussion of the body as a place of home.

Chapter III takes Ahmed’s (2006) articulation of orientation as being “about facing objects that help us find our way home” (2) as a starting point for an analysis of the ontological status of disorientation and, particularly, of disorienting encounters with disability. Rather than understanding disorientation as simply a lack of orientation, this chapter seeks to articulate disorientation as a rich and varied lived experience. I begin by looking at a number of ways in which meanings of impairment/disability emerge in proximity to notions of disorientation. Then, building on Kumari Campbell’s (2009) description of disorientation associated with disabled embodiment as “the lived experience of facing two directions” (194), I distinguish between ontic disruption and ontological disorientation to emphasize the lasting effect of disorienting encounters and to emphasize their ontological status. Then, through an analysis of Harilyn Rousso’s Don’t Call Me Inspirational (2013) I address the body as a place of home that moves beyond, or out of, traditional notions of home as a stable location defined by certain relations. This, I suggest, lends itself to a reading of disorienting encounters as moments that not only
SUMMARY (continued)

reveal meanings and experiences of impairment/disability but which are also generative of new meanings and ways of relating. From here I apply Drew Leder’s (1990) conceptualization of bodily and embodied absence and dysappearance to issues of impairment/disability, focusing particularly on how appreciating disability in terms of orientation and disorientation calls for a critique of the social model of disability. Finally, I explore the lived experience of disorientation as an openness and exposure to our being with others or being-in-the-world. Being disoriented, I demonstrate, entails the uneasy slippage of bodies and world from the background of experience to the foreground. This, I conclude, is strange. Instead of regarding this strangeness as simply a momentary interruption of orientations, I demonstrate, along with Nancy (2008), that strangeness characterizes our being-in-relation in general. Disorientation thus implies an awareness that, and how, we know bodies but also how, and that, we do not know them. In this chapter not knowing is presented as a way of relating that is characterized by openness and the experience of being open. Ultimately, I suggest that some modes of disorientation constitute meaningful lived experiences of bodies that are understood as disabled.

Rather than achieving a definitive answer to questions about disability in these chapters, the question and question-ability of impairment/disability remains open. This openness reflects the unfolding of experiences and meanings of impairment/disability in disorienting encounters. This is also an effort to take seriously the ethical implications of such encounters. In the fourth chapter I explore the ethical implications of these encounters or, more accurately, I explore these encounters as ethical moments. Building on formulations of ethics as a sense of touching and being in touch (Schildrick and Mykitiuk 2005, Diprose 2002), of involvement in and with the world (Ahmed 2000, Leder 1990), and as hospitality (Levinas 1991; Derrida 2000, 2005) I
SUMMARY (continued)

demonstrate that disorienting encounters with disability are moments to open spaces in which impairment/disability can mean otherwise. Further, I argue that taking openness seriously as the ethical demand of disorienting encounters means that dangerous questions, along with the meanings and experiences that they challenge and generate, must never stop, at least not completely. Disorienting encounters with disability are not where "the story" of disability ends but rather where multiple competing stories finally appear, sometimes dysappear, and inevitably begin. In this project I contend that being exposed to these multiple stories is being disoriented and, further, this disorientation is both ontologically descriptive and ethically demanding.
I. QUESTIONING DISABILITY

A. Chapter Summary

This chapter introduces the overall topic, disciplinary foundations and trajectory of this dissertation. First, I contextualize my primary research topic—disorienting encounters with disability—through personal narrative and reflection on the importance of questions and stories for moments of disorientation. Then, I lay out my specific research questions. Next, I outline the theoretical frameworks that my project is located within and to which it responds. This work is primarily informed by, and in conversation with, disability studies, phenomenology and “postconventional” (Schildrick and Mykitiuk 10) ethics. Finally, I present an overview of the chapters that make up this project.

B. Dangerous Questions

Some months ago, a store manager and I raced through the aisles, along shelves filled with electronics and past shoppers hunting for holiday bargains. We dodged cardboard displays and swerved around abandoned carts. Our steps were as close to in unison as I could manage without bumping into something. We moved as though there was not a moment to lose. Our speed was motivated by multiple and overlapping certainties: I knew exactly what I wanted to buy, and the manager was sure he knew where to find it. As manager, he knew his way around the store, and as a sighted person he moved with certainty around the things and people in our way. It soon became clear, however, that this was where the certainty ended for both of us. As we walked quickly side-by-side he casually asked, “What’s the story?” At the moment I was focused on our fast pace and ever-changing direction rather than what he said, and so I simply repeated what I wanted and why I wanted it. After a pause he repeated resolutely, as though he
was entitled to know: “What’s the story?” It was only then that I turned to see him looking at and pointing to my white cane. I paused and wondered how to respond.

What exactly did this man have in mind when asking for “the story?” There are at least three possible answers to this question. Perhaps he wanted a personal or medical narrative of why I use a cane. Maybe he wondered why I, an ostensibly blind person, was buying a television. Or it could be that he wanted a way to reconcile my use of a cane with my ability to keep up with him and my desire for a TV. When he asked his question I had already been in the store, and with him, long enough that my presence could not be accidental, especially since I named the brand and model of television I wanted and gave a (fairly typical) reason for my purchase. Surely this story was sufficient for our interaction. Nevertheless, somewhere in the midst of our walking together he was compelled to ask for, and then demand, the story because he could not understand why I had a white cane and wanted a television.

This is the story I tell myself of his question because this is how our encounter makes sense to me. As a legally blind person who uses a white cane but also has some “usable” vision, I am accustomed to being asked, in one way or another, for “the story” of my own impairment and of disability in general. What is interesting about this particular incident is that not only am I uncertain what “the story” means, but, potentially, what the manager meant as well.

Although I cannot know what exactly this man had in mind when asking for “the story,” it is not surprising that he expects (there to be) a story. Stories make up the meaning(s) that define us—all of us—including people with disabilities. In Enforcing Normalcy, Lennard Davis writes that “when one speaks of disability, one always associates it with a story, places it in a narrative…the disability immediately becomes part of a chronotope, a time sequenced narrative embedded in a story” (3). These stories are present long before people with disabilities enter a
public space or interpersonal interaction, and they linger after we leave. Davis cautions that storying disability in this way encourages us to ignore the social construction of disability and the marginalized social locations of disabled people, and we relate to it and them instead through familiar narratives of individual tragedy or overcoming. Addressing disability from a normative cultural standpoint disallows its becoming anything other than Other, and while understanding how normalcy operates can help dismantle it, disability is not just something we speak of. Rather, it is something that people with disabilities do and something that all of us, disabled or not, encounter. Emphasizing this point, Thomas King asserts that “the truth about stories is that that is all we are” (2). This is not only an epistemic claim but an ontological one as well. This is also why it is important for disabled people, who are made to mean so many things by stories told about us, to tell our own stories. Disability stories are heard, told, retold, interpreted, and believed in unexpected—and perhaps unwanted—ways. Crafting our own narratives is important, even while recognizing that when we do this, we sometimes repeat other stories without knowing it. Previously untold stories can parallel and undermine even the most entrenched narratives. The truth about the story of disability is that it is always being told by all of us, together, even in our silences.

In the unpublished manuscript Dangerous Times, disability studies scholar Rod Michalko (N.d.) writes that “responses to disability, whether those of non-disabled people or of disabled people, are dangerous insofar as these responses are typically, if not always, framed by a normative sense of the social order.” If it is true, as Michalko claims, that what makes responses to disability dangerous is their tendency to reinforce the ableist logics (normative sense of the social order) from which they emerge, then questions about disability must present an equal, if not greater, hazard. Questions like “what’s wrong with you?” or “why do you walk/talk/move
like that?” suggest that there is a somatic norm that disabled people do not resemble. Failure to correspond to that norm is then seen as an indication of a personal failing that reflects the tragic circumstances of all disabled people. Pathologizing these differences results in people labeled disabled being universally undervalued and dehumanized by a largely non-disabled world. But questions about disability are dangerous for another reason. In addition to bolstering the notion that disability is intrinsically negative, these questions also threaten the hegemony of this belief. By admitting to a disruption of our expectations by someone that is not immediately explained by or accounted for in a (normative) sense of the world, such questions necessarily imply that things can be, because in this very moment they are, different. In doing so, they demonstrate the mutability of any social ordering.

Whether asking for “the story” or asking “what’s wrong with you?,” one wants an account of disability—in this case an account of blindness—in order to make sense of what (and who) is being encountered. Importantly, as the above example indicates, we want an account that makes sense and, specifically, that makes sense to us. We ask for a story when “the story” is not self-evident, when it does not present itself to us in a way that follows or fits in with our understanding of how the world works. The manager, for instance, asked for “the story” because in the midst of our walking together on the way to pick out a TV my blindness was evident (I use a cane), and yet the elements of its story did not add up to his story of blindness (I wanted a TV and walked with him competently). What is it about disability that permits our questioning it in the first place? For one thing, disability as a category—a way of talking about people—includes a wide variety of bodies, capacities and perspectives. Further, disability as a lived experience entails an array of embodiments, knowledges and ways of being. Disability, as an interlocking process of oppressions, involves multiple strategies resulting in varied
interpretations and experiences. Finally, it is difficult (if not impossible) and, as I will argue later, unacceptable to separate these ways of conceptualizing disability. We ask questions when someone or something does not make sense; that is, when it does not fit, or fit in with, our understanding or expectation. It is no surprise, then, that we ask questions about disability. Seeking an account of disability that makes sense does not mean that we do not already have one in mind. In the above example, for instance, we see a moment of disjunction between two competing stories of blindness. It is not, as many scholars would have it, an encounter between disability and non-disability but rather an encounter between one blindness and another. Each story of blindness, my own and the manager’s, makes sense. That is, each provides a way of understanding and then relating to disability and disabled people and does so unambiguously.

The dangerous character of questions about disability lies precisely in their being about disability. This is a tricky preposition, about. It allows us to emphasize the relationship between the various elements that make up the meaning of disability in a given moment without explicitly mentioning them. Questions that are “about” disability are those that regard it as a relatively open question and thus are free to circulate between disability and non-disability, between disability and impairment, and between the multiple meanings that disability takes on and takes up. For example, we speak of spending a morning milling about the house, an afternoon wandering about town or an evening “out and about” with friends, and in speaking this way, we pass over the specific activities, places and people that shape what is happening. Similarly, the “about” of questions about disability describes an arc of movement through space and time, a variety of people and an array of meanings, social locations and cultural positions that go unspoken in their, and our, relation to disability. The uncertainty implicit in questions about disability makes them dangerous but also powerful. It is this uncertainty that allows us to subvert
the oppressiveness of “what’s wrong with you?” with a well-timed “what do you mean? This is how I walk.” Ultimately, questions about disability are dangerous because they have the potential to change how we understand disability as a concept and how we value people with disabilities.

I begin this dissertation with a discussion of questions and stories, and with the story of a particular question, not because they are rare or even out of the ordinary but rather because they are all too common. I begin here precisely because “what’s the story” describes a particular kind of response to disability—the dangerous kind—for which disability is an open question and in which our relation to it is question-able. Most importantly, I start with this example because disorienting encounters and the transformative potential they bring are far too often squandered. The encounter described above illustrates that in this moment, and those like it, there are (at least) two different stories of blindness and disability at play or two distinct ways in which disability makes sense, and yet even here this realization does not lead to change in the moment.

My inspiration for this project comes from a humanities-based course I have taught first-year medical students for several years entitled “Disability, Ethics, and the Medical Encounter,” as well as from my own experiences as a person with a disability. This class introduces the notion of disability as a social construction and challenges students to engage with ethical issues surrounding disability. The students have enjoyed delving into controversial topics and philosophical questions, yet their anxieties about how to interact with people with disabilities preoccupy our discussions. The students ask questions to obtain protocols and procedures, almost an etiquette, for managing their uncertain encounters with disability. They ask, for example, whether they should touch a wheelchair user’s chair or whether they can ask a blind person if they have “seen any good movies lately.”
These sorts of encounters are common for people with disabilities. For instance, I imagine that my visual impairment is obvious to those I ask for directions while using a white cane; however, the most typical reply is that what I am looking for is "over there." When I ask where exactly “over there” is, the person seems to finally notice my cane—and then there is a pause. In my class and in this dissertation, I contend that fully appreciating what is at stake in these moments requires moving beyond simple questions of etiquette to more philosophical questions regarding the ontological status and the ethical implications of these questions.

Posing questions about disability is one way of responding to it, but questioning is implicated in many different responses as well. “In a first encounter with another person,” writes Rosemarie Garland-Thomson, “each participant probes the explicit for the implicit” (*Extraordinary Bodies* 12). Similarly, sociologist Fred Davis characterizes these encounters as a moment of novelty, uncertainty and curiosity on the part of non-disabled people, and cautions us that it can be dehumanizing when it becomes “a focal point of [the] interaction” (165). While Davis provides an outline of these encounters, Garland-Thomson explains them as sense-making devices; together their work contributes to my characterization of disorienting encounters as not merely the time it takes to make sense of who or what we encounter but rather as a moment of sense-making prior to the inscription of meaning. Disorienting encounters are not empty spaces bookended by uncertainty and resolution but instead are significant moments for the meaning and value of disability as a concept and of disabled people. Disorientation is an important part of life for people with non-visible disabilities; however, I focus primarily on the experience and meaning of disability and disorientation in the lives of people with visible and often visual impairments.
C. **Research Questions**

As it appears in the title of this dissertation, “disorientation” is intended in more than one sense. Taken together, these senses can be represented as disorientation, dys-orientation, and dis-orientation. In the first and most conventional sense, disorientation describes an ontic disruption in the flow of our day-to-day expectations. The second sense of disorientation is ontological, a way of being-in and experiencing the world in which one is uncertain of his or her relation to it. These two ways of conceptualizing disorientation are crucial for exploring the meaning and experience of disability. This second sense of disorientation is related to the first but is more unsettling; its articulation requires self-reflection and an awareness that *something* is disorienting *me*, and ultimately this sense makes explicit that we live in a world with others and that we always already exist in relation to them. The third sense of disorientation, which I will develop more fully through repeated discussions of the body as home, depends on the second and describes ways of knowing and being in the world that shape, and are shaped by, the perspective of living in, with or through a body-mind that is traditionally marginal(ized).

This dissertation is an exploration of moments in which disability appears as, and in relation to, orientation and disorientation. It focuses on dis-orienting encounters with disability—moments in which a legible narrative either of disability or of the world remains elusive. It is an exposure that dwells in and with questions of what it means for disability and disabled people to *be* questioned and question-able. Specifically, I explore the ontological status and ethical implications of disorienting encounters with disability. What does it mean *to be* disoriented by disability? If anything, it means having our orientations towards disability disrupted. If this is so, how do orientations towards disability shape our encounters with it, and does it matter if one is oriented by, rather than merely towards, disability? If this does make a difference, what sort of
difference? What does it say about the world we live in that the multiple meanings of disability that seemingly coexist all the time are only brought to light in particular moments? Finally, what does it say about these moments that they have the power to reveal and even transform what disability means as well as what it means to be disabled?

If we regard disorienting encounters with disability as a disruption in the flow of everyday experience that reveals as well as makes meaning, it becomes necessary to delimit and blend current theories and methods. This dissertation is interdisciplinary, bringing into productive proximity a variety of disciplinary traditions and techniques: phenomenological and post-structuralist thought, disability studies, and critical and feminist theory. In doing so, it offers a bricolage of theory and method with which to analyze and critique how multiple meanings of disability are enacted and how they coexist. Specifically, this project uses these positions as tools for analyzing a collection of “scenes of disorientation.” Rather than drawing from or building towards a single unified perspective, I hope to open up a space for new possibilities of imagining, relating to and doing disability—as well as disability theory and research—differently.

D. **Starting Points: Theoretical Frameworks and Methodology**

Theorists and activists have struggled for decades to transform, counter and re-count the meaning of disability by shifting its meaning from a personal tragedy to a social and political phenomenon. This work has led to, and been led by, the collective political action of disabled people as well as by critical scholarly engagements with social, cultural and embodied meanings of disability. Despite these efforts—but also because of them—everyday encounters with disability, as both a conceptual and an embodied phenomenon, remain disorienting. Lay persons, disabled or not, appear uncertain how to make sense of disability as anything more than an
individual medical problem in need of solution. Likewise, scholars continue to debate how to understand disability and its relationship to myriad other identity categories and subject positions. Each political and academic intervention into the meaning of disability must have, at some point or on some level, emerged from a pause in which the status quo was called into question.

Questions about disability circulate among people with bodies and minds and within and across spaces and places, and they are shaping and shaped by how we relate those bodies and minds. By exploring disorienting encounters with disability, this dissertation examines the experience and meaning of disability, specifically those moments in which its meaning is uncertain. In these moments, we pause before bodies and before the disabled body in particular. We pause when confronted by ideas of the disabled body, in the presence of a person with a disability and at the thought of our body being or becoming disabled. And, we pause with bodies—other bodies and our own. In this dissertation, I use different orientations towards disability to interrogate the meaningful differences between these pauses. Writing about the meaning of bodies, disability and the moments in which their coming together disorients us requires thinking about them as they are lived and paying attention to what makes some bodies more disorienting than others.

“Coming face to face with questions of meaning,” argues Titchkosky, “requires not explanation, but rather exploration of that which grounds what is already said and already done” (Question 15). In other words, disability studies and phenomenology, like any scholarly (or social) movement even the least bit animated by a desire for transformation, must begin in or with disorientation. Before we can articulate strategies of transformation we must first be aware of how things typically work, how disability usually makes sense. Annemarie Mol’s The Body
Multiple: Ontology in Medical Practice presents an analysis of the ways that multiple meanings of disease—atherosclerosis in particular—are enacted through various practices, within and across different departments of a hospital. In an outpatient clinic, for instance, atherosclerosis is pain while walking and poor circulation. Seen through a microscope in a pathology lab, on the other hand, atherosclerosis is thickened lumen within a cell. Mol’s primary argument is that “pain while walking” and “thick lumen” are not two different ways of talking about the same thing; rather, they are two different things that go by the same name. This is, in a sense, how disability works and why thinking about it in terms of orientation and disorientation is beneficial.

Multiple meanings of disability (medical, social, cultural) co-exist within and across the sites in which they are enacted. In a medical encounter, for instance, disability could be lack or loss of functioning. This medical meaning has a certain practicality to it because it grants access to treatments and services. The cultural and social enactment of disability is more complicated as multiple meanings exist alongside one another in the same space. When epistemological and ontological meanings of disability meet, they do not always mesh. Misunderstandings, conflicts and clashes are more common as epistemic and ontological “realities” collide. This is where “disability” becomes a problem: in the store, on the street or at a job interview. This does not lead to a pragmatic or pluralistic view of diseases or bodies whereby one meaning is better (or more true) than another depending on which part of the hospital we are in. Rather, as Mol explains, “in practice the body and its diseases are more than one, but this does not mean they are fragmented into being many” (VII-VIII). Multiple practices lead to a multiplicity of meanings, and these meanings coexist. Attending to how meaning is enacted, rather than constructed or performed, she argues, “suggests that activities take place—but leaves the actors vague,” and further, that, ”in the act, and only then and there, something is—being enacted” (33).
The meaning of disability informs and is informed by our bodies, the organization of private and public spaces, the shape and purpose of technologies, and the rhythms of everyday life. Some of my reasons for conducting this study are personal. My daily life is filled with numerous encounters with, and experiences of, disability: I study and teach disability studies; some of my students have disabilities, some of my non-disabled students have friends and family members with disabilities, and some of my students are studying to become doctors who will one day work with patients with disabilities. I am visually impaired; I share my life and work with friends and colleagues with disabilities, many of whom also work in disability studies; together we read, write, and ask questions about disability and its multiple meanings. Further, I, we and all of us live in a world where disability takes up and takes on many meanings as it, and I, and we appear together in various places. Though personal, these reasons are not mine alone. This brief collection of justifications for being interested in the uncertainty of meanings of disability in everyday life could also be read as a list of the ways that these meanings unfold day-to-day. In other words, I am interested in everyday encounters with disability because that is where and when meanings of disability emerge as well as where and when the consequences of those meanings play out.

It is difficult to think about disorienting encounters in which these moments occur as anything more than inconvenience without a consideration of disability studies, phenomenology and ethics. Each of these domains and particularly how they blend into and with one another is essential for this project. Bringing these domains together provides an opportunity to consider not only how meanings of disability “hang-together” (Mol 55) in day-to-day interactions between people and the world, but also the chance to wonder on a broader level about what precisely is disrupted when these encounters appear disorienting. Taking Heidegger’s assertion
that "every questioning is a seeking. Every seeking takes its direction beforehand from what is sought" (3) as a methodological directive, this section outlines the fundamental starting points required to begin as well as to sustain this project.

1. **Disability studies**

   This project is firmly located in—and in conversation with—disability studies, particularly its grounding thesis that “disability” exists not in individual bodies and minds but rather *between* those understood as disabled and the people and places that make up the world. Also, it begins with the premise that disability (and impairment) always appear in relation to an unspoken master narrative of able-bodiedness. Starting from a place well informed by and indebted to disability studies, this project contributes to the field’s current articulation of disability by thinking through (and about) these perspectives *as* orientations, and by exploring the unique questions and consequences of this view in light of the fact that disability can sometimes be disorienting.

   Disability studies is a highly inter-, if not trans-, disciplinary field and encompasses a wide variety of scholarly disciplines and research practices. Titchkosky attributes the field’s versatility to the omnipresence of disability. She writes that “the social significance of disability, its exclusion and inclusion, can be tracked and traced in and by every discipline” (*Reading* 37). The diverse work produced in this field echoes the variability of disability itself: the array of embodied differences and meanings associated with them but also their ongoing development across space and time. Disability studies exemplifies an alternate way of approaching disability and, in turn, of asking questions about it. As Catherine Kudlick (763) writes, “disability studies takes for its subject matter not simply the variations that exist in human behavior, appearance, functioning, sensory acuity and cognitive processing, but more crucially, the meaning we make
of those variations.” Like the physical variations and contingent meanings it questions, disability studies, as both theory and praxis, are always in flux.

Despite its multiplicity, the central aim of disability studies is and has been to re-orient the social, political and cultural meanings of disability. Attempts to confront and counter traditional understandings of disability can be seen clearly in the foundational texts of disability studies and continue to underlie even the most recent work produced within, and even proximate to, the field. As Davis notes, disability studies serves to, “unite a variety of ongoing work” (“The End of Identity Politics” xvi). In this regard we might think of disability studies as a continuing decision on the part of scholars and activists to rigorously pursue, through coalition and contradiction, a trajectory beginning with a different understanding of what disability means.

Davis articulates the shared trajectory of disability studies scholars, writing that “disability is not an object–a woman with a cane–but a social process that intimately involves everyone who has a body and lives in the world of the senses” (Enforcing Normalcy 2). Disability studies thus represents a paradigm shift whereby disability no longer signifies embodied differences as such but instead references vast and overlapping processes by which we understand, value and live (our) bodies. Disability studies is tied to the social model of disability, which is the notion that disability emerges between people and the world rather than simply in particular bodies and minds. This model developed in and through the work of scholars and activists such as Mike Oliver, Vic Finklestein and Colin Barnes and followed the direct social and political engagement of the Union of the Physically Impaired Against Discrimination. Framing disability as a political issue, the social model distinguishes between impairment and disability. As Barnes explains:

Impairment concerns the biological ‘lacking part of or all of a limb, or having a defective limb or mechanism of the body’ – and disability is about the social:
‘the disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. (citing UPIAS 1976, 14)

Impairment is not the cause of disability but rather the occasion for the marginalized social and political position(ing) and material disadvantage(ing) of people with impaired bodies and minds.

With the social model of disability as its originary theoretical framework, disability studies has begun to develop, mature and divide. Some scholars working within disability studies—particularly those with training in the humanities and social theory—have begun to reevaluate the social model’s sharp distinction between impairment and disability. Reacting to the Marxist definition of disability implicit in the initial formulation of the social model, these scholars are developing what has been called “critical disability studies” to address impairment and disability more broadly in terms of discourse, culture, psychology and ethics. This iteration of disability studies is more closely influenced by post-structuralist thinkers and critical theorists, and expands the definition of disability studies itself to include “a critique of specific approaches to disability; a project to evolve an interdisciplinary frame that can be incorporated into multiple disciplines; and a new sphere of scholarly work that has a similar legitimacy to women’s studies, black studies and queer studies” (Meekosha and Shuttleworth 49).

Further, feminist disability studies has emerged as a way to acknowledge and explore the inter-connectedness of disability, gender and race as embodied standpoints. Feminist disability studies does not simply conflate gender, race and class with disability but does, according to Garland-Thomson, show that “disability—similar to race and gender—is a system of representation that marks bodies as subordinate, rather than an essential property of bodies that supposedly have something wrong with them” (“Integrating Disability” 1557-58) and concerns itself with the overlapping and inter-relation of each with the other. Thus, disability studies is
the study of the relatedness of the experience and meaning of being or of being in proximity to a body-mind that is alien(ated), marginal(ized) and anomalous. Disability studies research, whether in the humanities or social sciences, asks questions about the processes, practices and even policies implicated in and by the establishment, maintenance and living of this positionality.

Although it is a vast interdisciplinary and even transdisciplinary field of research, more than anything else disability studies is an approach: a way of beginning to formulate and attend to particular nonconventional questions about disability. By disability, I mean the socio-cultural positioning of particular bodies and minds because of their embodied differences and the lived experience of that positionality. Not only does disability name the interlocking systems of marginalization which serve to “disable” nonstandard bodies and minds, but it also denotes the embodied or lived experiences of occupying that marginal space and, more broadly, of the world as it unfolds from that standpoint. This dissertation is indebted not only to the scholars who developed the social model of disability but also to their critics and interlocutors. Using critical and feminist disability studies, this study explores how disability forms and is informed by our understanding of our place in the world. Disability studies’ revolutionary disruption and dislocation of the meaning of disability demands a social, cultural and political reorientation towards not only how we understand disability but, more fundamentally, how we relate to disabled people. My conception and deployment of disability studies in this dissertation is irreducibly linked to and shaped by developments in critical and feminist disability studies. Using critical and feminist disability studies in particular, this study opens up a space in which to rethink, reimagine and revalue all bodies and minds, especially those traditionally marginalized because of embodied differences.
2. **Phenomenology**

The experiences and meanings of disability always emerge within contexts already given through our embodied engagement with the world and with others. Whether the meaning of disability is that expressed by social model thinkers, scholars building on or countering that position, or disabled and non-disabled lay-persons, phenomenology allows us to explore how those meanings unfold and how they shape and are shaped by our experience of being in the world. As Michalko notes, this is because “disability and non-disability alike make their appearance in the world together and their appearance is made by the world.” (N.d.) In phenomenological terms, the world in which disability and non-disability appear and that simultaneously makes them is the “life-world.” Husserl describes the life-world as the, "actually intuited, actually experienced and experienceable world, in which practically our whole life takes place" (qtd. in Welton 355). The Husserlian life-world provides the context in which the meaning(s) of disability and non-disability as well as the significance of bodies and minds emerge, interact, are sustained or dwindle as we interact with people and things. Because the life-world provides the context of experience without determining its content, disability and non-disability, when they do appear, may appear differently in accordance with factors both internal and external to an experiencer. As Elizabeth Ströker explains, "every lifeworld in its concreteness changes from society to society, and even in the same society a change takes place in the course of its history" (304). Husserl’s work is particularly useful for this project due to his definition of experience. Explaining experience, Husserl writes:

> experience is not an opening through which a world, existing prior to all experience, shines into a room of consciousness; it is not a mere taking of something alien to consciousness into consciousness...experience is the performance in which for me, the experiencer, experienced being ‘is there’, and is there *as what* it is, with the whole content and the mode of being that experience itself, by the performance going on in its intentionality, attributes to it. (233–34)
Thus, our experience of disability is always an experience of something that we understand because of the ways in which it appears to be disability.

Husserl’s work has shaped the way phenomenologists conceptualize experience and the world, whether they agree with him or not. Maurice Merleau-Ponty brought Husserl’s thought to France but also changed phenomenology’s direction from focusing on perceptions of the life-world to embodied engagement with it. In his analysis and discussion of embodied experience, Merleau-Ponty emphasizes that our sense of ourselves, the world and our place in it are not distinct but rather that each is co-given through bodily engagement. For him, “the body is the vehicle of being in the world” (94). Rather than the body being simply a means of locomotion and the directing of consciousness, the body and consciousness are intertwined. This articulation of embodiment means that whatever disability means when it appears, its meaning is lived and enacted; it is made in and through our bodies as well as between the bodies of others and the world. Along these lines, Emmanuel Levinas’s analysis of the “face-to-face encounter,” though very different than Husserl and Merleau-Ponty, is nevertheless phenomenological. In these moments, the proximity of “the other” issues a demand “to justify one’s life and one’s construal of the world before another whose body is vulnerable…” (Perpich 6). Levinas reminds us that the appearance of “the other” in and through these encounters is a fundamentally ethical moment. For Levinas, and for this study, encounters are not about getting to know—in a definitive way—who or what we encounter but rather are moments of relation and relating-to that can open up new ways of being.

While the themes of phenomenological research have changed with subsequent theorists—from Husserl’s emphasis on the structures of thinking to Merleau-Ponty’s discussion of embodied consciousness—its central concern remains the same. Seamon expresses this
concern as an ongoing attempt to describe the “meaning [of experience] in the concrete lives of human beings” (4). In this regard, the emphasis on meaning and ways of experiencing found in phenomenology make it particularly useful for the present exploration of disability, bodies and meaning. In the introduction to their anthology of the field, Moran and Mooney write that, "the phenomenological approach is primarily descriptive, seeking to illuminate issues in a radical, unprejudiced manner, paying close attention to the evidence that presents itself to our grasp or intuition" (1). I use the notions of the life-world and of embodiment in order to describe “the ways in which sense is being made” of disability in everyday encounters with it (Seamon 4).

Phenomenology has already contributed to theories of disability and disability studies scholarship including critical and feminist disability studies. Not only the work of Husserl but also that of Merleau-Ponty and, often less explicitly, of Levinas, provide disability studies a broader way of emphasizing and problematizing the meaning and experience of living in or as, having or being, a nonstandard and marginalized body and mind. Paterson and Hughes use Husserl’s distinction between the lived body (leib) and the body-as-object (korper) to further develop the meaningful difference between impairment and disability set up by the social model, explicating both as lived experiences that come together in processes and practices of disablement. Toombs examined the experience of medical encounters to distinguish between illness and disability. Gleeson and Titchkosky examine the ways that space and place organize and regulate meanings of disability. Working through Merleau-Ponty’s notion of embodiment, Michalko, Manning, Gibson, and Kleege provide rich and nuanced accounts of disabled embodiment by describing the experience of what Michalko calls living-with disability. In doing so, they have shed light on what it is like to live in or as a nonstandard body, which I will later address as the lived experience of disorientation.
The importance of phenomenology, taken broadly, to disability studies and for this project specifically is its ability “to describe,” as Weiss (2008) notes, “the familiar after it has been rendered unfamiliar through the bracketing of the presumptions one usually brings to bear on one’s everyday experiences” (2). Phenomenology provides a way to explore how people and ideas, things and places, already make sense. In this way, phenomenology is crucial for addressing the question of what it means for disability to be disorienting. It insists that we regard disability and disorientation as an object in terms of already making sense to us but also as the locus of sense-making. The already said and already done meanings of disability in circulation and new meanings of disability that appear in embodied encounters take place within "the unthematized background context that structures daily life" (2008, 2) and the rigorously interrogated positioning of disability on the social and cultural stage. The experience and meaning of disability appears as a relation and in relation to disorientation precisely because the already given contexts in which disability “makes sense” are themselves relational and differential. In other words, whether we “know” it or not, disability always “makes sense.” The key to this claim is that disability is more than an epistemic category but also has ontologically and ethically relevant. Wendell contends that “disability creates different ways of being that give valuable perspectives on life and the world” (31). Similarly, Sandahl proposes we conceptualize disability as “states of being that are in themselves generative and, once de-stigmatized, allow us to envision an enormous range of human variety— in terms of bodily, spatial, and social configurations” (19). In contrast, disability theorist Mairiam Corker proposes that de-stigmatization is not a necessary first step in understanding disability differently. She argues that “incommensurability can become the occasion for creativity and protest as new hybrid concepts emerge from clashes between dissonant and incommensurable ontologies in such a way that
impairment itself is destabilized” (41). By exploring encounters with disability—my own and those of others—and by paying close attention to the conditions under which conventional (legible) narratives of disability fail to appear as well as experiences of that disorientation, this dissertation explores how these moments reveal competing, discordant and often incommensurable ways of knowing and relating to disability and, in doing so, open up the possibility that it may mean something else. Corker is not interested in maintaining a difference between the experience and meaning of disability and impairment but rather in examining how a sense of disability structures our understanding of each.

She asserts that sensibility “engenders ways of being in and knowing our world that are materialized in contradictory bodies in process, and performed in shifting aesthetic, ethical, and political values” (41). In this context sensibility makes up the “and so on” that Price and Shildrick claim circulates between the borders of identity politics and the often passed over “unintelligibility” (Butler 22) that connects the material and corporeal elements of disability. In many ways, Corker’s notion of sensibility informs the articulations of orientation and disorientation that I develop in the following chapters. Corker insists that one’s sense of disability constitutes what she calls “sensory ontologies” (39)—ways of knowing and being that, though they reflect social and cultural values, leave those values open to embodied interpretation and criticism. In Waist-high in the World: A Life Among the Nondisabled, Nancy Mairs provides a phenomenological rendering of what this sort of ontology entails and, as the title indicates, how it relates to other nondisabled perspectives. Coining the term “sitpoint theory” to describe Mairs’s work, Garland-Thompson argues that in “articulating a perspectival account of experiencing the world from a wheelchair,” Mairs not only portrays the life-world as experienced by disabled people but politicizes it as well. In effect, Mairs does not simply write about the life-
world of her embodiment but rather she writes the body, the world and their mutual unfolding as a lived experience of disablement. This particular sort of writing seems at once informed by and a response to both disability studies and phenomenology. It is this sort of writing that I turn to in an effort to capture experiences and meanings of disability in proximity to orientation and disorientation.

3. **Somatography**

To capture the experience and meaning of disability, this dissertation continually explores what G. Thomas Couser calls “somatography.” This genre of life-writing includes traditional memoir but also describes essays, documentary film and academic writing. Couser explains that unlike non-fiction that takes disease, impairment and people who have these conditions as its subject, somatography expresses “what it’s like to have or to be, to live in or as, a particular body—indeed, a body that is usually odd or anomalous” (2). The works selected for analysis in this project are broad; they include traditional autobiography, documentary film and creative works but also autobiographical fragments in larger, more traditionally academic writing. The reason for this is simple: the issues and themes addressed in these works are often introduced in and through stories, just as I began with the story of encountering a store manager. These narratives are not simply a convention of writing; they provide a starting point for both reader and writer from which to develop a sense of disability.

Building on Davis’s sense of the connection between disability and stories, I am interested in how not only current meanings and counter-narratives of disability are revealed in these moments but also how a different sense of disability emerges in and through them. That is, disorienting encounters with disability do not only expose ways of knowing disability but also they implicate impairment and disability as ways of being and particularly of being-in-relation.
Further, in addition to demonstrating multiple ways of knowing disability, they outline ways of not knowing, which suggests that disorientation is itself a mode of experience. The events and stories referenced below unfold in the course of everyday interactions. My recounting of them is intended to express the spontaneity of their occurrence and their uncertain affect. These stories exemplify interactions and conversations that at one time or another caused me, as well as the authors whose writing I analyze, to consider the relationship between bodies, embodiment, and the meaning and experience of disability. Titchkosky (2010) suggests that this kind of interpretive analysis exposes “the meaning we are making of our lives together” (42). Therefore, though they can be placed in a sequence, I hope that these narratives will instead open a space in which disability can mean otherwise or suggest alternate sequences and different ways of relating. Focusing on the disorienting character of these stories allows us to consider not only the conditions in which what is said and done “makes sense” but also the possibility that a different sense of disability can be produced in and through these encounters.

One of my earliest discoveries when beginning this research was that for the most part people with disabilities love talking about their unexpected encounters with and questions about disability, even though the actual encounter may be very distressing. Awkward interactions, uncomfortable interrogations and surprising moments between or across disability and non-disability are the subject of countless conversations, listserv discussions and Facebook status updates. Max Van Manen suggests that phenomenological analysis often requires “shaving” anecdotes in order to move beyond their pathos. He does not dismiss anecdotes but, on the contrary, argues that they are particularly valuable for phenomenological research. “Anecdote,” writes Van Manen, “particularizes the abstracting tendency of theoretical discourse: it makes it possible to involve us pre-reflectively in the lived quality of concrete experience while
paradoxically inviting us into a reflective stance vis-à-vis the meanings embedded in the experience” (121). However brief and personal they may appear, the narratives analyzed in this dissertation are not anecdotes; they are somatographies. The meaning of disability is inextricably linked to stories. In Claiming Disability, Linton argues that the conceptualization of disability as a “problem” is directly linked to the relational and differential ways in which it has traditionally been studied. In opposition to this tradition, she argues that disability offers “an account of a world negotiated from the vantage point of the atypical” (5). As both an object of thought and as a lived experience, disability provides a unique standpoint from which to experience and know the world as well as illustrates a different way of being in it. The notion that disability forms and is formed by experience is both central to disability studies and fundamental to phenomenology and, according to Siebers, “makes it easier to understand that embodiment and social location are one and the same” (23). Further, in characterizing somatography, Couser responds indirectly to Linton, imagining this kind of disability narrative “not as a spontaneous self-expression but as a response—indeed a retort—to the traditional misrepresentations of disability in Western culture generally” (6–7). Couser suggests that these types of stories are always subversive or at the very least the act of writing or telling them makes them so. In contrast, the narratives I analyze tend toward the mundane and explore instead small moments in which “ordinary” meaning and experience is exposed. That said, the telling of everyday encounters can be subversive, especially because, as we will see in the next chapter, in those everyday encounters the impulse is to ignore or elide them.

In this way, somatography is both in line with disability studies and particularly suitable for phenomenological analysis. Every scene of disorientation that appears in this work begins by situating disability as a question posed within a constellation of senses and sensing in which the
interaction of bodies, spaces and objects enact meanings. These narratives present and re-present everyday enactments of—and encounters with—meaning of disability. Further, these somatographies demonstrate that meaning is itself an encounter between concept and corporeality. In *Waist-high in the World*, Mairs contends that “disability is at once a metaphorical and a material state, evocative of other conditions in time and space…yet 'like' nothing but itself.” Mairs’ work is poignant and intimate without resorting to pathos or pathology; it offers nuanced and richly textured accounts of daily encounters with disability. On the inter-relatedness of experience and meanings of disability, she affirms unapologetically, “I can not live it or write about it except by conflating the figurative and the substantial, the 'as if' with the relentlessly 'what is’” (85). In this work, encounters are conceived of as the act and activity of those moments and meetings, both large and small, social and personal, through which we move and are moved beyond who and what we are or, at the very least, called to recognize that our existence is neither singular nor static but rather caught up in the movement of becoming in the world. When we pause *before* or *with* disability, for instance, we do so precisely because at that moment it stands out from the “unthematized background context of everyday life” (Weiss 2008, 2). Ahmed (2006) insists that, “the moment of production [of a subject] is only possible given a prior history of encountering, which allows certain subjects to be faced, at the moment they are constituted, as such” (173). Calling us to face, and face up to, our coconstitution in and with the world and others, encounters have great ethical significance. There can be no singular phenomenology or ontology of disability because its meaning, when it appears, is always multiple and each time many. Instead, phenomenologies must be multiple because disability itself is always multiple and each time many. I will face and face up to the
complex encounters of multiple meanings by exploring varied and diverse somatographic accounts.

E. An Overview of the Chapters

Giving an account of disorienting encounters is not the same as accounting for them; it calls for exploration and description, not explanation. The work of exploring lived experiences of disabled people in and through disorienting encounters and, in the process, of addressing disorientation as a lived experience reanimates the notions of impairment and disability within disability studies. By unpacking the relational nature of disability and disabled embodiment in and through notions of orientation and disorientation, this dissertation provides a different way of organizing and relating to the organization of multiple meanings of disability. In a sense, regarding disability in this way leads to a more sophisticated understanding of not only what disability does and can mean but also of what disorientation does or can do.

I begin in the next chapter by considering disability as and in relation to orientation. This accomplishes two things. First, it situates disability as a relational term and disabled embodiment as a site and source of meaning. Second, it offers an alternate to intersectional analysis by approaching impairment/disability as an ongoing and ever-shifting form of bodily and embodied being. Understanding disability “at a crossroads” in chapter two as both a conclusion one reaches as well as the starting point of embodied experience, I explore how meanings and experiences of impairment/disability unfold in and through the relations between bodies and spaces. Further, I explore the notion of the body as home that questions of orientation raise. Specifically, I consider the usefulness of orientation as a way of understanding how disability shapes one’s sense of the world and his or her place(ment) in relation to others.
Disorienting encounters with disability not only involve epistemologies of disability—ways in which it is known—but also ontologies of disability, or ways of being and being in relation to include ways of not knowing. Building on my description of impairment/disability "at a crossroads" through Ahmed's 2006 discussion of orientation, I articulate the lived experience of disorientation in chapter three. With and across disability studies as well as every day discourse, disability often unfolds as and in relation to notions of disorientation. Taking this reality as a starting point, this chapter demonstrates that disorientation describes being turned around by objects that typically help us—disabled and non-disabled people—find our way, thus offering a place from which to think or think again about what impairment/disability can or might mean.

Disorientation, I argue, is the uneasy slippage of body and world (one's own and those of others) from the background of experience to the foreground. If disorienting encounters with disability turn us, however briefly, from the paths that usually help us find our way home, then disorientation is the multimodal lived experience of being turned around. That is, rather than simply being the lack or loss of orientation, I argue that disorientation is a rich and textured way of being and being in relation.

The ethical implications of disorienting encounters are closely linked to their ontological status. Broadly speaking, disorienting encounters involve moments in which meanings and experiences of disability are called into question, and in turn, one's bodily and embodied perspective is rendered questionable. I take up the ethical implications of disorienting encounters with disability in Chapter IV as a question of relation. That is, what disability means shapes and is shaped by the value we, as individuals and as a culture, place in the bodies and lives of disabled people. I highlight this in my fourth chapter by looking at various somatographic accounts of being open and, sometimes, left open to the relations in and through which
meaningful experiences of disability are shaped. In addition to describing the ethical dimension of disorienting encounters, this chapter also tentatively formulates an ethics of disorientation that makes itself at home within disability studies as well as continental philosophy.

F. Conclusion

This chapter introduces the general topic and primary research questions of this project. Through it, readers will become familiar with the interdisciplinary approach of this project. I began with an illustration of “disorienting encounters with disability” in answer my own story of an unexpected encounter with a store clerk. Through this story I introduce, or perhaps remind, readers that being disabled often means being questioned and, in turn, finding oneself occupying a questionable position or status. This questionability, and the moments in which it emerges, is my focus of research. Following this, I articulate the theoretical and methodological approaches that guide this project and provide an outline of the chapters that follow.
II. AT A CROSSROADS: DISABILITY AND ORIENTATION

‘So you want to embrace disability?’ he asked. ‘Me too, the trouble is…disability is so hard to find.’ (Kuusisto 97)

[W]e—all of us—are making sense of this thing called ‘disability’ that is many and shifting, and are endowing it with particular and divergent meanings. (McGuire, “Disability, Non-disability”)

A. Chapter Summary

In the last chapter, I explored the connection between phenomenology and disability studies and stressed the need for an embodied account of disability experiences. The point of this chapter is to argue for an account of disability and impairment as orientation. Also, I show how orientation reveals epistemologies and ontologies of disability. I argue that disability and impairment are linked and lived through bodies and should both be taken account of as lived experiences. I begin this argument with a discussion of the relationship between impairment and disability within disability studies to outline the benefits of thinking these two phenomena together. Next, I consider the usefulness of two contemporary conceptualizations of the body in relation to disability: Eli Clare’s location of non-normative bodies at a crossroads and Jasbir Puar’s notion of “switchpoints of bodily capacity.” Then I offer Ahmed’s notion of orientation as a means of understanding disability and impairment through an embodied relation to space and objects. Specifically, I turn to experiences of the practice of orientation and mobility training described by visually impaired and blind people. Finally, I move from this discussion of how impairment and disability make sense in the world to discussing how they contribute to a sense of the world. Ultimately, this chapter contributes to my larger project of theorizing disorienting encounters with disability by framing disability as a matter of orientation.
B. **At a Crossroads**

Disorienting encounters with disability occur within contexts already given. In this section I am interested in how these contexts shape and are shaped by meanings and experiences of disability that make sense. For our purposes here, these contexts include legible narratives and understood relationships between impairment, disability and the variety of bodies defined in relation to them. Here, I examine these contexts through the conceptual relationship between impairment and disability as well as notional renderings of the disabled body.

The various meanings that disability takes on and takes up, and the sense that disability makes, are intimately related. In this chapter I aim to uncover, and in some cases recover, the richness of the notion that disability makes sense by exploring some ways that it does so by focusing on the questions of *how*, to *whom*, and *for whom* that go unspoken on the periphery of this statement.

In May of 1990, just before my thirteenth birthday, an ophthalmologist lowers the lights in his office, turns on his Snellen Chart, covers my right eye and asks, “What can you see?” The moment is disorienting. Although I “know” what to expect, I can not see the large E at the top of the board or even recognize it as an illuminated rectangle in the darkness. I hesitate, feeling that saying what I can see—a smudge of light—would be unacceptable and wrong. It is the doctor’s turn to pause when I eventually describe what I see as “just some light.” Until this moment I have been a young boy with low but stable vision and already, even before leaving the exam room, I am becoming a (legally) blind person. As stories of acquired impairment go, mine is not unique. And like any storied encounter with disability, it makes sense. It takes place in a medical setting where several recently experienced sensory and physical differences become a collection of symptoms leading to a diagnosis. Importantly, “disability” is not addressed. Instead, there is a
recitation of my visual field and acuity compared to “normal” vision as well as the probable cause of this situation. The doctor and I never talk about the disturbing weeks before my visit: the migraines, mood swings, loss of balance, or what it was like to look out at the walnut tree across from my bedroom window that had multiplied and become monochromatic overnight. These experiences were only significant as signposts pointing towards a particular causation. Neither blindness nor disability are mentioned at this visit, and though the doctor may have listed some jobs I would be disqualified from, he makes no mention of how what I can see will shape my day-to-day experience of the world or my interactions with other people.

In many ways, “what can you see?” remains my entry point into issues of disability and impairment. This inevitable question shapes the contours of encounters with disability as well as the various meanings that disability and impairment acquire in daily life. Like “what’s the story?”, it is an orientating device used to make sense of disability and of disabled people that simultaneously articulates a sense of disability, disabled people and the world in which they appear. My continual response to this question, both as a disabled person and a disability studies scholar, is to echo it in an effort to discern its source and contours. In the two sections that follow, I pose this question to disability studies itself, looking specifically at how the relationship between impairment and disability has been articulated within the field, and considering the implications that these articulations have for giving an account of impairment/disability.

1. **Disability is relational**

   Paterson and Hughes contend that the sharp distinction between impairment and disability made by the social model, though useful when it first appeared, shuts down discussions of the lived meanings of bodies. “The distinction between disability and impairment,” they argue, “de-medicalises disability, but simultaneously leaves the impaired body in the exclusive
jurisdiction of medical hermeneutics” (330). Instead, they propose a sociology of impairment that directly counters Oliver’s sweeping assertion that “disablement has nothing to do with the body…impairment is in fact nothing less than a description of the physical body” (4-5).

Disability is relational; its meaning emerges at the intersection of social discourses concerning impaired bodies and minds but also in and through the embodied experiences of people labeled disabled--for whom impairment is an everyday part of life. Within disability studies there has been and continues to be great interest in the relation between impairment and disability. My aim here is to explore the possibilities and limitations of disability studies’ articulation of this relationship. In this effort, sense and sensibility are crucial: presence and absence, seeing and being seen, touch(ing) and points of contact define the encounters in which meanings of disability and impairment are enacted as well as their meaning(s). Sandahl recalls heated debates about embodied experience of impairment and disability that occurred at the first Humanities Institute on Disability Studies in 2000. As she states, these happened ad hoc, mostly as hallway conversations. In these conversations, scholars addressed the challenges posed by the social model of disability. Particularly, they talked about its sharp distinction between impairment and disability that makes it difficult to articulate some of the social and bodily nuances of living with an impairment, the psycho-social dimensions of disablement, hidden or invisible disabilities, and the affective and experiential elements of living not only with but also as a marginal(ized) body. In reading the story about my encounter with the ophthalmologist, for example, a strict social model thinker would draw a firm distinction between the lack or loss of vision that made it impossible to read the letters on the Snellen Chart (impairment) and the inability to find a job as an ESL instructor years later because an employer thinks it is not a good job for blind people (disability).
Most importantly, a strict interpretation of the social model establishes a unidirectional causal link between impairment and disablement. In doing so, however, one passes over the plethora of meanings and meaningful moments that lead from the one instance to the other as well as different ways that the former situation could potentially positively affect the latter. For instance, increased attention to sounds and speech patterns might make one more attentive to the nuances of language fluency—particularly phonics—that are crucial for language learners. Also, a strict social model thinker would focus on the interlocking technologies of disablement that keep someone labeled disabled from obtaining a job and not the equally interlocking situations and attachments that motivate this ambition (as though oppression is all that matters and lived experiences that exceed experiences of oppression are not important).

With this in mind, Sandahl tells us, scholars wanted to bring impairment and disability closer as a way to acknowledge embodied experiences and meanings of impairment that would include but not be exhausted by the limitations, stigma and marginalization traditionally embedded in “disability.” Or, as Sandahl puts it, they sought theoretical language that would express and affirm the notion of impairment and disability as “a different way of operating in and experiencing the world” (22). Thus, they formulated a collective question about disability, asking, “What does the body know through impairment?” (Ibid). Though it is not directly mentioned in Sandahl’s account, psycho-social aspects of disablement were beginning to be recognized as significantly absent within traditional social model thinking. Since then, Thomas, Reeve, Gill and others have argued that in addition to focusing on epistemology—what the body knows—we must also attend to the psychic or psychosocial dimensions of disability or what/how people with non-normative body-minds feel, from within processes of disablement and through impairments. How disabled people feel and are made to feel about themselves and their relation
to the world and others (the psycho-social/affective environment) is just as disabling as the built environment and requires the same amount of attention. In an attempt to address this and to shore up the social model’s divide between impairment and disability, Gareth Williams asserts that “the trick is to see the thing nondualistically, to recognize impairment/disability not as something that is either-or but as simultaneously and ontologically both personal and public” (123). In other words, neither disability nor impairment is static and wholly or consistently in bodies and minds or society; rather, disability—like impairment—waxes and wanes or is focused or diffuse as it occupies the foreground or background of experience, as scholars in phenomenology remind us (though not always in relation to disability). In this regard, I am not concerned so much with the fact that disability means different things to different people but rather that different orientations to disability appear from the perspective of impairment—not because they can lead to a different generalizable worldview but because they reveal particular views. My effort in this chapter to position disability at/as a crossroads is the beginning of a response to Davis’s call for a “new ethics of the body” that would “begin with disability rather than end with it” (“The End of Identity Politics” 237).

2. **Bodies at/as a crossroads**

Regarding impairment/disability ontologically demands a conceptualization of the body and embodiment that encourages thinking of these together. Disabled and queer activist-poet Eli Clare evokes the commingling of embodied meanings of impairment and disability, echoing Williams’s point about their simultaneity, when he argues that both coexist in and are lived through the body. Clare writes, “I stand at the crossroads where private and political, public and personal meet” (Marrow’s 9). In this chapter, I take Clare’s crossroads seriously as a starting point for a discussion of lived experiences of impairment/disability as well as of other marginal
positions and positionalities. Crossroads emphasize that place, space, and time are *lived* and that the appearance of impairment/disability as meaningful experience occurs within ongoing situations. Like a crossroads, disability appears when and where multiple paths–ways of knowing and being–meet and would not appear if these paths ran parallel. Like disability, crossroads invite reflection and comparison as varied bodies enter into proximity. Crossroads offer us a place where we may pause and get our bearings before continuing on a pre-planned course or setting off in a new direction. Crossroads are not sustainable meeting points, but rather they come into being when different epistemologies and ontologies meet. In this way, unlike intersections (or intersectionality), crossroads are a space of discombobulation, discovery and creativity within which we find ourselves and, specifically, find ourselves question-able. Thinking about disability at, and perhaps as, a crossroads allows us to recognize both disability and impairment as the beginning of something new and simultaneously as a conclusion one reaches. In taking Clare’s crossroad seriously, I want to foreground it as a way of approaching lived experiences and meanings of disability.

I deploy Clare’s crossroads in this chapter for several interrelated reasons. First, it emphasizes that the meaning and experience of impairment/disability is tied to (situated in and lived through) bodies. Second, it demands a thinking of impairment/disability as the appearance or coming-to-be of (at least) two perspectives. Third, it suggests that alternate meanings of impairment/disability appear within tangential space and temporarily disorient the spaces and places in which they appear, whether this is social or bodily space. Ultimately, the crossroads of impairment/disability are created in the moment that bodies and ways of relating to them come together, whether they contradict or complement one another.
In *Exile and Pride* (1999) and *The Marrow’s Telling* (2007), Clare refuses to regard impairment/disability, race, class, or gender/sexuality within separate categories but rather understands each together as constitutive of lived experience. As a trans man who endured childhood sexual abuse and multiform oppressions, Clare allies himself with a variety of marginal(ized) groups of people who have, as he puts it, “stolen” bodies. Much of his work disarticulates the “stolen” body by illuminating instances of its theft and re-orienting it as a place of home (1999). He accomplishes this in two ways: by reclaiming the oppressiveness of “crip” and “queer,” and by illustrating intimate and social encounters in which his crip/queer body is pivotal. Clare begins with the body because he understands that bodies are the starting point of our engagement with and relationship to ourselves, others and the world.

The majority of Clare’s work deals with the presence and presencing of non-normative bodies, including the bodies of women, people of color and people with impairments. The poems collected in *The Marrow’s Telling* are particularly “tied to the body” (8), specifically a body that is inexplicably tied to the world. The body in Clare’s poems (his body?) is always moving and being moved—by the insults and stones hurled at it as much as by its connection to the environment and to “home communities.” This peculiarly tethered motion is writ large in the six “interludes” that serve to distinguish between one group of poems and the next. I say “distinguish” here because the interludes are specifically not chapter breaks. They bring together as much as they separate groupings of work that, at times, bear a family resemblance to one another. Although *The Marrow’s Telling* is accessible to the average reader, it does have a particular audience, and the interludes establish this group and welcome them to find their place. With the interludes, readers who identify as or with women, survivors of abuse or members of trans, queer and crip communities—in other words, those who recognize their marginalization as
an active process—are invited to recognize themselves as involved in the world in similar ways. In moving out of the marginal spaces they (are assumed to) occupy, Clare’s target audience is encouraged to move together and in doing so to recognize their inter-connection.

Although each interlude names a particular physical or bodily motion or way of moving, readers are told to understand them as “pauses” and as “exhortations for each of us to tell a tangle of stories, to translate them across chasms and listen hard for our home communities” (9). Each interlude builds on the initial story of flying a kite as a child either by extending the story or using it metaphorically. The first of these, “Tug,” emphasizes the orienting power of language. Here, Clare emphasizes language’s ability to push people apart and pull them together and that labels are used to put “us” in “our” place. The second, “Updraft,” extends this line of thinking to the stories that are told of “us” and of “our place.” These stories are never smooth or singular but vary from one telling to another and change over time. Readers are told to tell “our” stories but to tell them from where “the breaks, ruptures, contradictions, [and] repetitions live” (37). Further, Clare points out the importance of recognizing whether the stories we tell are in fact “ours” and of constantly questioning who is intended each time “we” is uttered. In “Reverberate,” he reminds readers to ask “whose stories, what communities, which histories do you choose, and how is your choosing shaped?” The answer to each of these questions is significant, Clare argues, because each answer forms a “specific time and place.” In the interludes Clare demonstrates the need for marginal people to tell “our own” stories by telling stories from our own perspective and that we understand to be “ours.” In “Reach,” Clare repeats the call to tell our own stories but also recognizes a number of reasons that this can be difficult. Reaching “across chasms of power and privilege” (74) can make one feel stretched to the limit by the courage it takes to speak up and like doing so is sticking one’s neck out too far.
While it is important to tell our own stories of disability and disablement, doing so is not always easy. These stories originate from our perspective and emerge in our tellings, but often people with disabilities do not go around telling our stories. Rather they are, as my example in the last chapter demonstrates, demanded. My experience with the store clerk that began this project illustrates the often necessary—and necessarily troubling—demand for a story of disability. Clare furthers this point by choosing to tell (a particular) story that not only positions people with and without disabilities in relation to one another but also suggests these stories, as the story of our place, perform the work of self-positioning. Crossroads allow disability to exist in its coexistence with a tangle of stories about it as well as about other people and their bodies. The tangled talk of disability—of having, being and of living with or as disability—is precisely what makes it possible to tell stories that are different.

Clare situates the crossroads of disabled embodiment as a kind of pause. The six “pauses” in *The Marrow’s Telling* resonate with the five criteria for thinking of the body as “home” that Clare lays out in *Exile and Pride*. “The body can be understood as home,” he insists, if and only if “it is first understood that:…1) bodies are never singular, but rather haunted, strengthened, underscored by countless other bodies…2) place and community and culture burrow deep into our bones…3) language too lives under the skin…4) bodies can be stolen, fed lies and poison, torn away from us…5) the stolen body can be reclaimed” (10-12). The tug and reach of Clare’s embodied story of disability does not move via switchpoint. It does wax and wane, and come and go, but it does so like a tremor never wholly absent from the body.

Clare's crossroads are motivated by the notion that impairment/disability is embodied and, as such, lived socially as well as bodily. In this way, impairment/disability may commingle with a plethora of other ways of being that might also be viewed as identity categories. My concern is
that a focus on intersectionality as the coming together of disability, race and gender, for instance, suggests that disability, race and gender are already “here” or “there,” always already one among many intersecting elements that are in themselves some way stable. Crossroads, on the other hand, suggests that disability is something that appears at particular times and in particular places because of the spacing, placing and timing of body-minds across and within space. They also suggest these spaces and moments are inhabited unlike intersections that we wait (and often can’t wait) to get through. Crossroads also imply movement, though not necessarily progression, in space through our encounters. Intersections are busy places: the hustle and bustle of traffic, the belligerent honking of drivers trying to get where they are going or unhappy because they cannot. People just want to get through an intersection. In this regard I am mindful of the warning advanced by Ann duCille and later used by Chris Bell in his pointed critique of the “whitewashing” of disability studies: namely, that “one of the dangers of standing at an intersection… is the likelihood of being run over” (“True Black Womanhood” 593). Occupants of crossroads are less likely to be run over, as crossroads themselves are less likely to be rushed through.

In Terrorist Assemblages, Jasbir Puar suggests that the usefulness of intersectionality should be rethought. Her primary critique of the theoretical and methodological tool is that it relies upon a sense of race and gender as foundational in the same moment that it asserts their instability. That is, however intersected they are by other identity categories, “women of color” remain(s). Elsewhere, Puar summarizes her critique, writing, “all identities are lived and experienced as intersectional--in such a way that identity categories themselves are cut through and unstable--and that all subjects are intersectional whether or not they recognize themselves as such.” Thus, according to Puar, the theory and method of intersectionality establishes “women of
color” as the persistent other that is intersected by additional identity categories. In other words, it depends on an essentially othered identity, “women of color,” that exists essentially and fundamentally however cut through. Invoking intersectionality as a theoretical and methodological starting point thus entails beginning with a taken-for-granted sense of (sexual, racial, gendered or physical/sensory/cognitive) difference as something—the only thing—that matters. While this is Puar’s primary critique of intersectionality within feminism, it mirrors her caution about the ways that disability and nondisability are articulated within disability studies.

My focus on disability as a crossroads is motivated by, and in part a response to, Puar’s recent discussion of disability/ability and normative/non-normative bodies existing on or in relation to “switchpoints of bodily capacity” (“Coda” 150). Puar invokes “switchpoints” in an effort to move away from imagining disability/non-disability as an either/or state. Instead she stresses, along with Brian Massumi, that the body “passes from one state of capacitation to a diminished or augmented state of capacitation” which, as she explains, emphasizes that the body is “always bound up in the lived past of the body but always in passage to a changed future” (“Coda” 155). To this end, Puar places both impairment and disability in relation to Berlant’s “slow death”—a way of existing in a state of ever-mediated health. Extending Rose’s discussion of the appearance of depression in the U.K. and the U.S. (as both prevalent but also disaggregated), Puar argues that a turn toward an ongoing continuum of debility rather than one of ability and disability allows for analysis not simply of a larger variety of populations but of the population itself as larger homologous variation.

Puar also promotes “switchpoints of capacity” as a critique of the evolution of ableism within disability studies. Just as Bell points out an assumption of whiteness within disability studies, Puar worries about an over-emphasis on already recognized and seemingly stable
impairment types. She is also critical of what she sees as attempts to link non-normative bodies of all sorts. Here, she is cautious of reproducing a binary categorization and thus missing the subtler and ever-shifting continuum of embodiments expressed in and by debility. “Even as the demands of ableism weigh heavy and have been challenged by disability scholars and activists,” Puar warns us, “attachments to the difference of disabled bodies may reify an exceptionalism that only certain privileged disabled bodies can occupy” (“Coda” 153).

I am in full agreement with Puar’s assertion that “if the signification and representation (what things mean) are no longer the only primary realm of the political, then bodily processes (how things feel) must be irreducibly central to any notion of the political” (“Coda” 151), and her overall point is well taken. It is my hope that by emphasizing disability as/at a crossroads discourages binary categorizations through its spatial and temporal implications. Moving as she does from ability/disability to debility, Puar stresses that while all bodies move up or down on a spectrum of ability/debility, some bodies experience an ongoing breakdown of capacity. Unlike switchpoints, crossroads insist that we remember that bodies are always coexisting with other bodies. To be quite literal about it, two trains meeting at a switchpoint would be disastrous whereas two persons meeting at a crossroads might have positive consequences. To me, the ongoing state of disability is not only a function of capacity but a particular register of being. That is, disability does not name a category of persons with objectively “different” bodies but rather, along with impairment, describes a wide array of experiential perspectives and ontological possibilities. Moreover, a focus on disability as orientation only further supports Puar’s goal while also allowing attention of the lived-experiences of a multifaceted body including the placing and spacing of these bodies but also their pacing.
I suggest that the purpose of both the body as switchpoint and disability/impairment as crossroads is not either’s articulation of the ground or foundation upon which these lived places rest but rather the movements toward, within and away from them. This is why I emphasize orientation understood as negotiation or “making sense” of the dynamic shifting of each. Orientation is relevant to my discussion of disability because it helps give an account of how disability appears in the world as always already involved with it.

In describing people with disability as “at a crossroads,” Clare emphasizes that impairment/disability (along with race, class, gender and sexuality) appear amidst a bustle of other subjects and subject positions. In contrast, Puar’s “switchpoints of bodily capacity” focuses on the ongoing shift of (socio-cultural) bodies themselves between states of greater and lesser capacity. While it is ephemeral, Clare’s crossroads is in some ways much more stable than Puar’s switchpoint because, if nothing else, it manifests between bodies in and through their proximity. In contrast, the body as switchpoint between ability and debility (as opposed to impairment/disability) is a space of approximation: bodies either approximate ability or they approximate debility. How one conceptualizes the relationship between impairment, disability and the body makes a difference for how he or she understands and values the place of people with disabilities in the world. To further develop this point, I turn now to a discussion of Sara Ahmed's analysis of orientation. Specifically, Ahmed's work on orientation points out that facing any direction precludes facing other directions. Further, she argues that the objects that "help us find our way" are those that lead us in a particular direction or to a conclusion that, in time, we feel “at home” with. Applying Ahmed’s understanding of orientation to meanings and experiences of impairment/disability illustrates that taking disability to mean “lack or loss of
ability” leads one in an entirely different direction than if it is taken as a source of identity, culture or pride.

C. **Orientation**

Before we can understand what it means to be disoriented by disability, we must first consider what it means to be oriented and, specifically, how disability exists in relation to orientation. In this regard, Ahmed’s initial definition of orientation is very useful. She asserts that “to be oriented is to be turned towards certain objects, those that help us find our way” (*Queer Phenomenology* 1). It is no coincidence that Clare’s crossroads directly reference way-finding while articulating disability in at least two ways: as a conclusion one reaches and as the beginning of something new. In this regard, objects that help us find our way to/from disability are crucial. We find our way to (i.e., become oriented to) disability through the interaction of objects and bodies in place.

1. **Orientation in phenomenology**

I want to stress that the phenomenological notion of orientation is fundamental to any understanding of disability. From a phenomenological perspective, orientation is not merely a matter of distinguishing between up, down, left, right or what is above us from what is below. Instead, orientation underlies and describes our (ways of) making sense of the world and feeling at home with our place in it. Specifically, I turn to orientation for its capacity to account for embodied experiences of the body, of place and space, and of our relation(s) to the world of people and objects.

An examination of classic and contemporary phenomenological literature shows that orientation describes how things and people, including ourselves, appear from our point of view as embodied subjects. In the second volume of *Ideas*, for example, Husserl references the way
that objects and bodies present themselves perspectively (from one point of view or another) in order to describe how the world and our experiences of it unfold in and through our bodily orientation to them. He argues that, “each Ego has its own domain of perceptual things and necessarily perceives the things in a certain orientation…things appear and do so from this or that side, and in this mode of appearing is included irrevocably a relation to a here and its basic directions” (166). Heidegger expands Husserl’s definition of orientation from ways of knowing the world to ways of being in it. He writes, “I necessarily orient myself both in and from my being already alongside a world which is ‘familiar’” (Being and Time 144). Heidegger’s sense of familiarity presupposes orientation by seeing it as fundamental to our experiences and as that which makes them “ours.” As Schutz and Luckmann explain, orientation is “the place in which I find myself, my actual ‘here,’ is the starting point for my orientation in space” (36). For Schutz and Luckmann, and indeed for many contemporary phenomenologists, it is important that orientation not be thought to establish a distinction between absolute space that is always “there” and relative space that is forever “here.”

2. **Normative geographies**

It is worth noting that the discussions about impairment and disability mentioned by Sandahl were not part of organized panels in the first Humanities Institute on Disability Studies but rather unfolded spontaneously as scholars and artists with disabilities made their way from place to place or as they waited for something else to happen. Other somatographic accounts of disabled embodiment also demonstrate that lived experiences of impairment/disability emerge within what Marc Augé calls “non-places.” For him, this term describes interstitial and tangential spaces such as highways and airport lounges intended to be moved through rather than occupied. In his study, Augé argues that the term non-place “designates two complimentary but distinct
realities: spaces formed in relation to certain ends…and the relation that individuals have with these spaces" (94). In other words, he contends that the lived meaning of these spaces is immediately multiple and includes the ends to which they were created as well as other, perhaps fleeting, meanings. Importantly, as he explains, non-places “mediate a whole mass of relations between the self and with others, which are always indirectly connected with their purposes” (94).

Normative geographies, though they may make room for people with disabilities, are not necessarily made for people with disabilities and, even less, are constructed to foster alternate understandings of disability that they may initiate. It can be difficult to enact or articulate alternate meanings of disability within them. In contrast, Augé’s non-places that are intended to be functional and temporary (such as airports, parking lots and hallways) can sometimes act as significant places where people with disabilities can gather, even if that gathering is a result of being stuck, to compare and discuss issues relevant to their perhaps-shared sense of the world.

In My Body Politic, Simi Linton gives a beautiful example of the generative possibilities of non-places. She had recently moved to Berkeley, California to live on her own for the first time since acquiring an impairment. On her way out of a grocery store (made remarkable by the lack of attention she and her wheelchair received), Linton spots three non-disabled women and a man in a wheelchair on the corner. The group is dancing and laughing together, and they are throwing yogurt at one another. She describes the incident in some detail:

There was yogurt in their hair, running down each and every chest, dribbling down one woman’s thigh, another’s forearm. It lingered in belly buttons, between toes, and in the spokes of his wheels…they leapt about on their bare feet, he swiveled his chair back and forth, doing a kind of wheelchair twist. He snaked in and around them, and they jumped to get out of his way. …I seemed to be the only one to take notice…whoever else was out and about just walked by as though nothing marvelous was happening. (42-43)
This brief encounter had a profound effect. When she finally made it home, Linton contemplated what she had seen, and it was then that she thought for the first time: “Yes…if that’s disability, I can do that. He made it look fun and sexy. Not woeful and sick-like” (43). While it is worth wondering, as I will later, where her sense of disability as “woeful and sick-like” came from, what is important about this incident for our purposes is that it occurred unexpectedly on a sidewalk as Linton made her way home and as the man and women presumably did the same. These sorts of places seem to offer disabled people, individually and collectively, a chance to reflect upon and share their own positions and experience. And it is from here that we can better understand those experiences. Often these experiences expose a jagged distance between various meanings of impairment and disability.

3. **The disabled body orientins in space**

Applying Ahmed’s analysis of orientation to issues of impairment and disability has a profound effect on how we understand each phenomenon separately and together. Her work highlights the interrelation of socially located epistemologies and embodied ontologies that are a central focus in both disability studies and phenomenology. Both fields have long been concerned with how to understand the body and, especially for disability studies, the consequences that any particular conceptualization has for actual bodily subjects. From a phenomenological perspective, disability and impairment necessarily appear as standing out from an unthematized and thus unquestioned life-world. However, as we occupy and participate in the life-world in and through our bodies, disabled embodiment and bodily impairments disappear. Leder summarizes this significant yet paradoxical position of the lived body within experience. He writes, “in one sense the body is the most abiding and inescapable presence in our lives, it is also essentially characterized by absence” (1). Space is explained by Merleau-
Ponty as being rooted in the body. He writes that “spatial forms or distance are not so much relations between different points in objective space as they are relations between these points and a central perspective—our body” (5). Grosz summarizes this point by saying that for Merleau-Ponty we do not simply “have” bodies but rather we are bodies. Similarly, we might say that for Merleau-Ponty, orientation is not something we “have” towards things and bodies but rather that it encompasses and characterizes our relation to them. Merleau-Ponty’s articulation of the lived body in *The Phenomenology of Perception* emphasizes that our experience of ourselves, the world and objects in it is not merely achieved with our bodies but is rooted in our perspective as a body. The significance of the lived body for our discussion of orientation is made clear in Merleau-Ponty’s claim that the body is the “horizon latent in all our experience…and anterior to every determining thought” (92). In other words, orientation is always embodied orientation. With this in mind, Ahmed asserts that “orientations are about how we begin; how we proceed from ‘here,’ which affects how what is ‘there’ appears, how it presents itself” (*Queer Phenomenology* 8). The body—my body—is always the starting point of orientation. Through his dissection of embodied experience, Merleau-Ponty argues that multiple and overlapping layers of perception are synthesized in such a way that we experience our bodies not just with motility, vision or touch but with each co-given in our experience. He writes that “the body is the vehicle of being in the world” (82). It may be argued that orientation characterizes this synthesis as the integration of perceptions, positions and others in our sense of the world. From a phenomenological approach, then, orientation is generative in its shaping of our experiences of and between one’s body, the things or people we encounter, and the space they inhabit.
Orientations towards disability play out in everyday life with concrete as well as conceptual consequences for people with disabilities. For instance, one night a man approaches me on the street. We are neighbors and have met before. We talk for a few minutes before he asks, “What can you see?” Apparently he has been wondering about this for some time but was unsure how to bring it up. I reference some brake lights and street lamps in the distance but he wants to know if I can see him or anything around us. I say that I can, but this does not stop him pivoting from side to side during our conversation, watching whether my eyes follow him. Finally, I notice a white and orange halogen lit sign hanging above our heads about seven feet away. I announce with certainty, “I can see that Harris Bank sign.” “But,” he presses, “how do you know it’s a sign for the Harris Bank? It doesn’t have the name of the bank on it.” Now, this sign is roughly thirty feet from my front door, I walk past it countless times daily, and during the day the ten-foot letters on the other side of the building that spell “Harris” are unmistakable even across the street. Furthermore, where we stand—the building, bank, street and shops around us—are my everyday geography; we are literally surrounded by the places that fill the space of my home. In other words, I just know. Then again, looking at it like this, perhaps for validation and verification, I am caught off guard. The sign is confusing and I’m not sure why. Eventually it dawns on me: the logo that the sign displays is an optical illusion. Horizontal orange and white lines along with curved perpendicular lines, a patch of white with a slash of orange in the middle combine to depict a lion’s head in profile. That is, they do when seen “properly.” I point this out to the man and offer my confusion as an excellent example of how people can “see” the same thing but interpret it differently. Unfortunately, he is not buying any of this and replies flatly, “No, it’s just a lion’s head.”
This story is important for several reasons: it shows an orientation towards disability playing out in everyday life as a belief about impairment resulting in a specific regard for disabled people. Importantly, the man does not discount my perception (of colors and shapes) but refutes my interpretation of that perception. In doubting my ability to “know” the places of my home, he calls into question my ability to be at home in this location and, more fundamentally, my own body. For Merleau-Ponty and Ahmed, knowing one’s home in and through an embodied relation to space is a fundamental experience. In one of several personal examples in *The Phenomenology of Perception*, Merleau-Ponty explains: “My flat is, for me, not a set of closely associated images. It remains a familiar domain round about me only as long as I still have, ‘in my hands’ or ‘in my legs’ the main distances and directions involved, and as long as from my body intentional threads run out towards it” (130). His primary aim in giving this example is also useful for the current discussion of orientation. As the passage suggests, he is arguing that places, such as one’s home, are not an idea but rather a series of relations between one’s body and space.

Neil Smith and Cindi Katz tell us that for geographers, “‘location’ fixes a point in space, usually by reference to some abstract co-ordinate systems [whereas] ‘position,’ by contrast, implies location vis-à-vis other locations and incorporates a sense of perspective on other places” (69). Similarly, in his *The Production of Space* Lefebvre insists that orientation implies relation to other people and places and not a fixed boundary. He writes: “I speak of an orientation advisedly. We are concerned with nothing more and nothing less than that. We are concerned with what might be called a ‘sense’. An organ that perceives, a direction that may be conceived, and a directly lived movement progressing towards the horizon” (423). Scholars working in the field of human geography adopt a similar view towards orientation in their conceptualization of space as “a dimension in which phenomenon are distributed” (Curtis & Jones, 27). Space, then,
is not only where social actions take place but is that which structures and in turn is structured by those actions and interactions. Gleeson argues in Geographies of Disability that any analysis of disability concerned with either social relations or everyday experiences must entail considerations of space.

Ahmed and Merleau-Ponty argue that it is from the “zero point” of my orientation that things appear as either near or far, familiar or strange, and it is only from my perspective that distance constitutes a marker of difference. What is at stake for people with disabilities in this analysis of disabled embodiment and embodied space is the danger of not being taken seriously as knowing subjects or not being regarded as knowing subject at all.

D. Orientation as a Lived Reality: The Case of Mobility Training

As my analysis of orientation has shown, the meaning of impairment/disability is particularly dependent on bodies and space. However, orientation is not only about the commingling of disability with itself or with non-disability in the abstract; it is also a marker of particular disabilities. Here, I want to explore the connection between orientation at the conceptual level and the lived experience and practice of orientation.

For instance, orientation and mobility training (O&M) is an important part of many blind and visually impaired people’s lives whether their blindness is congenital or acquired. This state-funded training can go on for years with sessions taking up as little as an hour a week or, especially when O&M is incorporated at a school or other long-term training program, as much as several hours a day for weeks or months at a time. In other cases, one may participate in training very rarely in order to focus on a specific skill or task. The learning outcomes of O&M sessions depend on trainees’ needs as well as their age at the onset of their impairment. Sessions are usually related to way-finding but can include other “life skills” as well. For instance, a
young person or someone with a newly acquired impairment might focus on cane technique or street crossing whereas more “advanced” training could emphasize different transit systems, trip planning or cooking.

Accounts of orientation and mobility training present some of the clearest opportunities to apply Ahmed’s work on orientation to impairment and disability because this training so explicitly hinges on lived experience. This training is designed to create foundational moments in which trainees learn how to navigate. Trainees also learn what blindness means to and for them. Michalko (2002) addresses this in relation to the question of knowledge and knowing in an essay that relates themes of both phenomenology and postmodernism to everyday experiences of blind people participating in O&M training. In this essay, Michalko writes of an opportunity he had to accompany a congenitally blind young girl, Jenny, on an orientation and mobility lesson with her trainer, Cheryl. As the trio walk along a suburban street, Jenny’s cane connects with something mysterious standing between the sidewalk and the road. Curious as to what it is, she begins touching it. It is round, rough and tall--taller, at least, than her. Is it a tree? No, she does not detect any roots, nor can she feel branches, hear rustling leaves or feel the shade they would provide. “What is it?” Jenny asks Cheryl, but as a good trainer, she responds by asking Jenny what she thinks it is. After several incorrect guesses and with growing frustration, Jenny asks Michalko to name the strange thing. Without hesitation he identifies it as a telephone pole. Like any curious child, Jenny wants to know more: is it called a telephone pole because there is a phone on top (she did not feel one when examining it), and for that matter how tall is it? The story gets particularly interesting when Jenny asks Michalko these questions. He writes:

Because of my visual impairment, I could not see the top of the pole and even though I never had before, I now wonder whether there was a phone up there, maybe for maintenance purposes; I really didn’t know. (177)
That telephone poles exist to hold up telephone lines that in turn make telephone calls possible is a fact of our modern era, but their dimensions and appearance are a taken-for-granted visual “fact” given only in and through a visual orientation to the world. However tall they are, telephone poles extend beyond both Michalko’s and Jenny’s perception and attention to them only results in uncertainty.

This encounter reinforces the notion of disability as/at a crossroads, especially when we learn what happens after Jenny was taken home. She rejected Michalko’s tongue-in-cheek suggestion that telephone poles are “as high as the sky” because she has flown before and reports that, despite turbulence, she has never heard of a plane having to avoid hitting one. Eventually this conversation ends and the lesson continues. However, the issue resurfaces as Cheryl and Michalko drive back to the training center. Cheryl is not pleased with Michalko’s assertion that telephone poles are as high as the sky: they are not and he knows they are not. Cheryl worries that his suggestion will disrupt Jenny’s “concept development,” and give her an unrealistic impression of the world. To incorporate the lessons of O&M training and thus become a “good” blind person, “Jenny must cross the border from blindness to sightedness and she must, according to rehabilitation, leave blindness behind in order to make the crossing effectively” (179). This is the lesson of O&M training. In his analysis, Michalko outlines the work that must be done with and by Jenny in order for her to understand the world and her place in it. As he explains, “she must be convinced that her sensory experience of the world is defective and that this defect is detrimental both to her coming to know the world and her participation in it” (179). Not only must Jenny learn to distrust her embodied experience of the world and how it unfolds and presents itself to her, but she must come to know herself as a body gone wrong and her world as always already incomplete.
Orientation and mobility training also emphasizes the phenomenological notion of orientation through its emphasis on bodily senses and our embodied relation to objects. The lessons of orientation and mobility training appear to be working, as this perspective is echoed far and wide in autobiographical accounts of disability and experiences of blindness. Accomplished poet Stephen Kuusisto begins his memoir *Planet of the Blind* with this sentiment. He explains, "often a blind person experiences a series of veils: I stare at the world through smeared and broken windowpanes" (5). French feminist philosopher Helene Cixous presents blindness in the exact same way in her semi-autobiographical short story “Savoir.” Importantly, Cixous’s account of myopia and the world-as-it-appears in and through blindness is not incomplete; rather, is inconsistent. Describing her protagonist’s lived experience, Cixous explains: “She and Doubt were always inseparable: how did things go the way or else wasn’t she who mis-saw them? She never saw safely. Seeing was a clustering of believing. Everything was perhaps. Living was in a state of alert” (6).

Kuusisto and Cixous’s comparisons of blindness to looking through broken or blurry windows is problematic even as they reinforce a sense of disability as orientation. In both somatographic texts, blindness is understood almost exclusively as a source of doubt and disorientation. Eventually, Kuusisto learns to navigate with a white cane and dog guide, at which point his blindness gains some appreciable qualities. This transition occurs explicitly via his relationships to white canes and dog guides. Only through them is he able to develop a sense of blindness as a place of home. Through the experiences described by Kuusisto and Cixous and the meaning ascribed by Cheryl, one cannot help but have a negative orientation toward disability. Yet even in these accounts we can appreciate the significance of disability as and in relation to orientation.
E.  **The Sense that Disability Makes**

Through orientation we come to know our geographical location and social position. In Ahmed’s articulation of orientation in particular we get a sense of our position relative to others and, in disorienting encounters, a sense that our position is always a positioning affected via bodily and embodied relations to objects and others. In this regard, understanding orientation as “a question...of how we come to ‘feel at home’” (*Queer Phenomenology* 7) is particularly important for appreciating lived experiences of impairment/disability. The various encounters with disability addressed in this chapter depend on some very specific objects: a Snellen chart, a bank’s logo and a telephone pole. Each of these objects has helped us find our way to particular meanings of disability. At the same time, each of these encounters has gestured toward, if not led directly to, a different sense of disability that has shaped and has been shaped by different meanings. In each case, the way-finding potential of these encountered objects depends upon orientations towards disability that entail a broader and often unspoken sense of ability and disability. Building on Ahmed’s understanding of orientation in this section, I consider this in terms of the sense that disability makes. We can see this different sense in Linton’s account, in which disability itself comes to mean something else. There is also a sense of this sense in Michalko’s story about Jenny. There, blindness informs both his and her experiences of the world and also his analysis of the relation(s) to the (ableist) world that she finds herself in. If we understand that orientation is not simply about finding our way but specifically finding our way "home," then disability as and in relation to orientation must describe different ways of finding oneself and particularly of finding oneself at home.

Michalko takes the phenomenological view of orientation as a starting point for analyzing the lived experience of blindness. In doing so, he articulates multiple orientations towards
disability that shape and are shaped by different senses of the relationship between impairment and disability and in turn generate different senses of the (disabled) body and its place(ment) in the world. First, he describes living-with blindness and the experience of visual impairment as being tangential to—and disconnected from—one’s sense of self. This approach, he asserts, relies on a body/subject distinction such that blindness is nothing more than an anatomical defect with no consequence for the person other than perhaps making it difficult for her to physically navigate her environment. To live-in blindness, on the other hand, means that an individual feels at home in the world through their embodied engagement with it as a blind person. By pointing to ways that disability is a home of its own, this chapter—as well as this project as a whole—articulates how this sense of home and particularly this sense of the body as home works and does not work to show how and why disability operates in relation to orientation and (in the next chapter) disorientation.

As a starting point, orientation necessarily limits the range of possibilities available for making sense of whom and what we encounter. As Crary notes, disability tends to appear only though a “prescribed set of possibilities” (6). Ahmed writes that we might think of orientation in terms of sense, specifically, “that sinking feeling, when the very contours of spaces recede from view, becoming background, like furniture” (*Queer Phenomenology* 168). This is certainly what we mean when we say that something “makes sense” when it fits in and does not stand out from our understanding of the world. The problem (of disability) arises when we forget that people and things we encounter that “make sense” do so for us and not necessarily constitute the sense of the world.

This supports the argument that the “sense” that disability makes, though not universal, is in part made up of a sensitivity to space and place. Ahmed recognizes this possibility in her
analysis of embodied orientations as being more or less “involved” with the world. She posits: “Perhaps when you are not at home, the world does not recede. The table turns when it does not provide a dwelling place. Turning the table is the promise of reorientation given material form” (Queer Phenomenology 168). Turning the tables is precisely what I mean when I talk about disability as orientation (and this will be explored further in the next chapter).

In "Postcards to Sophie Calle," Joseph Grigely tells a story that reveals a different sense of disability as orientation. Grigely writes:

One evening an acquaintance of mine, visiting New Orleans, went straight to the French Quarter for the sort of reasons people go to New Orleans: for the vibrations of jazz, the rhythms of blues, and the carnivalesque atmosphere that makes the French Quarter what it is. For her it was an inviting thing to do, and for a while at least it was inviting indeed. But then, early in the evening, something happened. A policeman had noticed her unsteady gait and stopped to ask a few questions. She could not, however, understand him very well, nor did he understand her responses. He was a smart policeman and knew intoxication when he saw it. She was arrested for public drunkenness. The arrest record cites her "slurred speech," her "uncomprehending behavior," and her "erratic movement." She spent a very long night alone in jail trying to understand why she was arrested for being everything she was, everything she could possibly be: a young deaf woman with cerebral palsy. (43)

Just as New Orleans is “what it is” because of the vibrations and rhythms that animate and incubate its atmosphere, so too is Grigely’s friend defined (and found) by her bodily rhythms and the vibrations of relation(s) moving between her body, others’ bodies and the spaces and places that they share. While Grigely’s story features the lack of assimilation targeted by orientation and mobility training, it also introduces a different sense of disability. This different sense of disability is a counterpoint to Linton’s earlier conceptualization of disabled embodiment as either sick or sexy. For Grigely, the sense that disability makes (of the world) as an orientation includes the possibility of being arrested. He and his friends know, and know too well, that they are out of place, and yet simultaneously they know that this “out of” place is their own. Grigely continues:
when I first heard it—I—along with 14 students who shared a room with this woman—recognized at once not the verisimilitude of the story (for there is almost none), but it was: for us, all 16 of us deaf, familiar, too familiar, a familiar surrealism that makes our lives inexplicable and unbelievable to everyone except ourselves. (44)

Here, Grigely is actively wondering about the conditions of possibility that characterize what today we understand as ableism. Further, in the conclusion of the postcard that highlights this incident, he provides a very simple articulation of disability culture and what, in the next chapter, I call disabled embodiment.

F. Conclusion

In this chapter I have shown that impairment and disability are made meaningful in and through conceptual and embodied relations between bodies and spaces. Through these embodied relations, disability becomes both an "object" one faces as well as a "way" that one finds by facing a certain direction. The generosity of Ahmed's notion of orientation is that it allows us to think both the “way” and “direction” one faces through embodiment. The challenge of orientation is that it demands finding a way of relating to directions one does not like.

The usefulness of Ahmed’s articulation of orientation is that it allows both theorizing of what disability means in the world and also what the world means through disability. In other words, my interest is in the sense of sense that disability provides, including the different ways of knowing and being in the world that impairment/disability presents in very concrete examples, but also in the questions about knowing and being that disability opens up. For instance, Garland-Thomson’s sit-point theory begins with the very concrete premise that not everybody stands. What sit-point does is emphasize embodiment as a (privileged) point of understanding the world. This is often used to talk about the importance of human variation and diversity. If we take this argument to its extreme conclusion, it might look something like Nick Watson’s study
in which participants report not thinking of themselves as disabled because despite having impairments, they do not feel particularly oppressed or disadvantaged. As I have argued in this chapter, the point of conceptualizing impairment/disability as ways of being is not to do away with the differences that lead to impairment but, on the contrary, to open up a space where other ways of knowing and being generate alternate meanings.

In this chapter, conceptualizing impairment and disability in terms of orientation has led to considerations of how disabled and non-disabled people feel at home in relation to their and others’ embodiment. Often, this sense of home is called into question and experienced as uncertain. Building on this chapter’s analysis of disability and impairment in relation to orientation, I now turn to the conditions and character of disorientation.
III. BEING DISORIENTED

What are the terms of coexistence? It is an encounter that causes disruption, necessitates negotiation and invites complicity. Here we have the paradox of the increasing proximity of the hitherto outside with the inside proper…with the somatic norm. (Puwar, *Space Invaders: Race, Gender and Bodies out of Place*)

A. **Chapter Summary**

Conceptualizing disability in proximity to orientation in the last chapter accomplishes two things. First, it affirms disabled embodiment as a site and source of meaning. Second, it presents a compelling avenue for critical study of the epistemic, affective and ontological dimensions of disabled embodiment. Moving forward, this chapter focuses on disorientation as the lived experience of multiple, competing and sometimes contradictory orientations (toward disability). Building on Ahmed’s assertions that orientation names the processes, practices and places entailed in turning and being turned towards things that “help us find our way,” I argue that *dis*orientation describes being turned around by objects that typically help us—disabled and non-disabled people—find our way and thus offer a place from which to begin again.

Disorientation is an embodied experience that unfolds on corporeal and social levels. Disorienting encounters with disability entail social interactions between people with and without impairments; they also arise through embodied experiences with bodies (our own and those of others) and with the world. In each case, disorientation describes the character of relation between body and world. Kumari Campbell points out that encounters with disability depend on a coming together of a somatic norm and bodyminds that do not resemble it. Leder’s articulation of dys-appearance offers a similar description whereby one’s body is disorienting (and one is disoriented) when the body moves from the background to the foreground of perception. David Wills contends that this sort of turning is characteristic of experience itself. Building on these points, I demonstrate disorientation is the lived experience of a turning of the
lived body/world from the background to the foreground of perception. In this chapter I present several modes of disorientation that shape and are shaped by meanings of disability that turn and are turned by ableism.

This chapter explores disorientation as a mode of being-in-relation-to-disability. First, I illustrate the conceptual and real-world implications of these concepts by re-visiting the notion of the body as home introduced in the previous chapter and reflecting on alternate readings of home provided by Fiona Kumari Campbell’s *Contours of Ableism* (2009) and Harilyn Rousso’s recent memoir *Don’t Call Me Inspirational* (2013). This discussion problematizes the earlier articulation of home, demanding a more nuanced examination of disabled embodiment. Then, I provide a preliminary sketch of the scope of disorientation through consideration of what I call *ontic disruption* and *ontological disorientation*. Next, I illustrate these experiences via Leder’s notion of dysappearance along with Paterson’s and Hughes’s application of Leder’s work to issues of disability. Finally, I address an expanded sense of embodied disorientation through Jean Luc Nancy’s philosophically inflected somatographic account of heart transplantation and Brian Lobel’s writing of a body that is at once disoriented and disorienting.

**B. On Being Disoriented**

“In order to return bodies back to difference –in-the-human,” Kumari Campbell argues, “a re-conceptualisation of knowing (episteme) is paramount. Only this knowledge is of a carnal kind, where thinking, sensing and understanding mutually unfold” (15). By exploring disorienting encounters with disability in this chapter, I emphasize the meanings of disability that emerge from sensing it not when it makes sense but when, however briefly and for any number of reasons, it does not. In these moments we get a sense of the sense that disability can make and ultimately an opportunity to grasp the possibility that some of those senses can be unmade. To
continue with Kumari Campbell’s point, I argue that not only is a re-conceptualization of knowing required but also a reconceptualization of not knowing.

Ahmed offers a perfunctory analysis of disorientation in the conclusion of *Queer Phenomenology* that, though brief, is significant. “Moments of disorientation are vital,” she argues, because “they are bodily experiences that throw the world up, or throw the body from its ground” (197). Like Ahmed, I believe that disorienting encounters can tell us a great deal about what it means to be oriented. Further, I think disorienting encounters with disability can teach us more about how experiences and meanings of disability unfold. My use of disorientation in this chapter is broad. Disorienting encounters include brief moments of what I will call *ontic disruption* but can also extend to prolonged experiences of *ontological disorientation*. In the preceding chapter, for example, Jenny’s bumping into a telephone pole illustrates that impairment/disability shape and are shaped by concrete interactions with the world. Linton's yogurt story, on the other hand, demonstrates that a simple unexpected encounter can be life-changing. By attending to the character and impact of disorienting encounters with disability, this chapter articulates disorientation within the myriad surprises and unexpected moments of daily life but also, as Ahmed suggests, as a state of being. In this regard, if orientation, as she insists, is about facing, then disorientation is about turning and being turned.

Different conceptualizations of disability in circulation today share a common denominator, even if they do not always recognize it as such. That is, a sense that disability implies or entails disorientation. Put another way, there is a common belief that disability *is* disorienting. The disorienting character of disability can be found at the root of traditional conceptualizations of disability (tragedy/charity/deficit models) but also in alternatives to these orientations. It is this sense of disorientation that Mitchell and Snyder have in mind when they
assert that “nearly every culture views disability as a problem in need of a solution” (1). Even when disability is not seen as a personal tragedy (personal disorientation), scholars argue that its meaning is rooted in the socially disorienting effects of unruly bodies (Barnes 66) and that efforts to repair or resituate them aim to diminish their disorientation. David Serlin’s (2004) analysis of the Hiroshima Maidens provides an excellent example of this “problem.” The “maidens,” a number of Japanese women disfigured in the U.S. bombing of Hiroshima, were brought to the U.S. after the war to receive extensive facial reconstruction surgeries. By Western standards the procedures were a success, but the women were ridiculed when they returned to their home for appearing too “Western” and because their surgical enhancement made them appear “unnatural.” True, Mitchell and Snyder are not referring to the physical or life-activity limitations that define disability in a medical context but rather the problem of how to interpret disability as a concept and what to make of people with disabilities in their various cultural locations. In this respect disability is seen as disorienting for several reasons; it disrupts “normal” physiological, biological and psychological functioning such that it is seen as a disorientation of typical ways of moving in, being in and knowing the world. Murphy attributes this sense of disorientation to the liminal cultural status of people with disabilities. In the literary context, Ato Quayson argues that the appearance of disability within literature produces “aesthetic nervousness” that “short circuits the protocols of expectation” (14) for non-disabled readers and characters alike. In both of these arguments, the proximity of disability and disorientation is due to the absent presence of the normative lived body. When disability or a disabled body-mind appear before ability—and, often, actual disabled and non-disabled people as well—it is recognized by what it cannot do and by its being out of place.
Miho Iwakuma argues that “as long as the body is a focal point of perception, ‘objective’ truth represents the most shared agreements among humans, which is nothing but ‘subjective’” (84). If this is so, then the disorienting character of disability has less to do with either “impairment” or “disability” but is instead a function of the lived experiences and corporeal practices that shape our relations to bodies—our own and those of others. Iwakuma helps us understand that the body demands recognition of subjectivity as vital for meanings and experiences of disability without individualizing those meanings. She also reminds us to think about the embodied practices of actual people with particular bodies. In this regard, it is significant that the essay in which she makes this claim is found in one of the first anthologies to bring together postmodern theory and disability studies. Her focus on embodied practices is, in many ways, a move toward incorporating disability into a discussion on the ways embodiment is tied to ontology. Just as ways of knowing and being known (orientation) shape and are shaped by the relations between bodies and the world, so too are ways of not knowing.

In Contours of Ableism, Kumari Campbell writes of "a disorientation faced by all disabled people" (194). Building on Ahmed’s articulation of orientation as being about facing objects that help us find our way (home), Kumari Campbell describes this disorientation ontologically as "the lived experience of facing at least two directions: towards a home that has been lost...and to a place that is not yet home" (194). Taking this description of disabled embodiment as its starting point, I am interested in the question of what it means to be disoriented through a variety of experiences provided by disabled people. Disorientation, broadly defined, entails an uneasy slippage of body and world from the background of lived experience to the foreground. That said, I want to stress that disorienting encounters are not only difficult to live through; they are difficult to write about. With that in mind, it is best to proceed cautiously.
Disability can be disorienting for a number of reasons and, at the same time, on a number of levels.

C. **Leaving Home**

The lost and not-yet home that Kumari Campbell refers to is the body-minds of disabled people or, more accurately, disabled embodiment produced in and through ableism. She defines ableism not as ways of knowing impairment but rather as a network of meanings “that produce exclusionary categories and ontologies” (19-20). My discussion of disability in relation to orientation in the last chapter focuses on epistemological experiences of disability in which disability is more or less known. Moving forward, this chapter is concerned with not knowing as a way of relating and thus of appreciating ontologies of disability. With this in mind, the first thing I want to do in this chapter is complicate the notion of home, specifically a notion of the body as home, which grounded much of the preceding chapter’s discussion of disability and orientation. A sense of home is no less important in this chapter, and in fact, focusing on disorientation demands a more nuanced interpretation of notions of the body as home and disabled embodiment. This more nuanced interpretation begins with a demand to leave home. Home and a demand to leave it animate much of Harilyn Rousso’s recent memoir *Don’t Call Me Inspirational*. All told, Rousso presents three senses of home: sanctuary, potentially restrictive bond (of relations and habits) and community. Each of these equally meaningful ways of understanding home depends on unquestioned relations; and though the first two senses do not question relations for fear of disrupting the flow of expectations, the latter form does not question in an effort to affirm openness to difference and to relation itself. The passage of time is significant in many, if not all, of Rousso’s stories of fleeing, finding and feeling at home. Readers are repeatedly told that strangers (children and adults) who do not know her (might)
think or feel one way about her but then given time feel differently. Importantly, Rousso seems to regard herself in the same way. Whereas Clare describes the (disabled) body as a home that is or can be broken into, Rousso emphasizes the body as a home in transition. In her work, this home often begins with uncertain relations and then turn to some semblance of familiarity, trust and connection. This is the case with even the briefest of encounters.

In her narrative, instances of leaving home appear almost more important than moments of feeling at home. Rousso is terrified, for instance, on the day her mother insists she go away to college. She is not put off by the prospect of suddenly having sole responsibility over the daily minutia of independent living. At that time she had had some attacks of separation anxiety and still enjoyed her mother’s help with school assignments, but Rousso is not afraid of being away from her family and friends. Instead, she is afraid of leaving home. As in the last chapter, Rousso’s sense of home was defined by the security of relations and relationships between the people, places, things and activities that gave her life meaning. The terror she felt had less to do with navigating the world of unexpected places or things and more to do with not knowing how she would negotiate ableist encounters with strangers on her own. While Rousso grew up, her mother served as her advocate by confronting institutional barriers and discrimination. And though her mother was less helpful in dealing with the psycho-emotional dimension of these encounters, she was at least there. Her mother’s absence and the uncertainty it created were paramount in Rousso’s fears about leaving home. As she writes:

I was afraid that if I left home to go to college, I would be faced with endless stares from people who didn't know me, with no one there to defend me…I couldn't imagine fending off all by myself the stares, the questions, and the emotional distress they caused. (46)

To be clear, it is not the case that Rousso does not know what to do in these situations but rather that she is unsure of her ability to manage these encounters successfully. Rousso’s analysis of the
situation is succinct; she writes, “I was too vulnerable” (44). At home, everyone knows her, and everyone she knows is familiar with how she walks and speaks, but more importantly, she knows that they know, and she knows them. In this way, her vulnerability is tied to her disabled embodiment—her ways of being—and not, she insists, her impaired body. Both her sense of home and her sense of disabled embodiment are defined by how she lives in the world. Home, specifically the body as home, is understood as an overlapping series of certain relations. The source of Rousso’s fear is motivated by the ableism that shadows her encounters and her vulnerability to its appearance. This passage stresses her awareness of ableism as a feature of disabled embodiment. Again, it is important to note that Rousso does not lament an inability to negotiate her embodiment but rather an uncertainty about how exactly to do so. Grigely’s story about his friend in the previous chapter illustrates this very point: people with disabilities (many of them, at least) know they are marginalized and discriminated against, but this does not mean that they always know when or where they will be oppressed. Rousso is scared by the uncertainty in and through which ableism will appear once she leaves home. In many accounts provided by people with disabilities who leave home, the thought of leaving raises questions about how one is oriented to and oriented by disability. Here, Lucy Yardley’s definition of disorientation presents a particularly apt description of the experience. In counterpoint to Ahmed’s assertion that orientation entails facing objects that help us find our way (home), Yardley tells us that “someone who feels disoriented is uncertain about their relationship to the environment, and hence their capacity to react appropriately” (118). This, I feel, describes Rousso’s account of her experiences quite well.

The secure relations that constitute Rousso’s sense of home include buildings, neighborhoods, habits and interactions with people but also, perhaps most importantly, her
relation to herself. While describing the unease she felt at the thought of leaving home, Rousso explains, “my vulnerability partly resulted from the fact that I hadn’t yet figured out how to make sense of my disability” (44). We know from the previous chapter that making sense of disability is in part a matter of how one understands the meaning and experiences of their embodied relation to the world and others. In this instance, Rousso is very clear that this sense of sense is precisely what she has in mind. As a child she interpreted the stares and questions of others as a reflection of an overall deficiency on her part. She tells us that at the time and into adulthood, she felt as though acknowledging these feelings of negative assessment and value would somehow affirm them. Further, she quickly notes the sense of relief she felt later in life upon discovering that other disabled people felt the same way and, specifically within the disability rights movement in the U.S., saw this as a defining characteristic of their disablement.

The theme of leaving home continues as Rousso recounts her experience of buying a car by herself for the first time (at age 46). Once again, she expresses concern about not knowing how she will manage uncomfortable interactions, but rather than worrying about these imagined encounters with strangers, she is more concerned about how her father will react. While her mother had always provided support at the writing table, Rousso’s father took great pride (or so she believed) in his role as advisor about all things automotive. She felt as though her desire to select and purchase a new car was more than simply leaving home but, more emphatically, running away (71). What makes this experience feel like running away from home is that she actively wants to do it independently with little to no paternal input. She worries that this move will create unnecessary tension in her otherwise close family. Although her father has not expressed an intense desire to help her in this search, she clearly identifies this as (part of) his role in her life. Although it may seem like a relatively simple endeavor, the process takes three
months as she scours “Consumer Reports,” and learns not only which type of vehicle she wants but also musters the courage to negotiate a fair price. As a disabled woman, she worries about a double discrimination. In the end, she neither upsets her family dynamic nor gets cheated.

Rousso’s multiple stories of leaving home do not simply articulate the joys of new adventures and relationships; they constitute a call to people disabled by physical and other differences to leave behind the belief that they must take shelter by remaining in their literal and metaphorical homes. Like Minnie Bruce Pratt’s discussion of the value of exposing oneself to a variety of peoples away from the comfort of one’s familiar home, Rousso’s call to leave home is an affirmative demand. She concludes her story about buying a car, for instance, with the declaration that “the road away from home is not one way” (75). Here, we see Rousso’s sense of home expand beyond traditional or habitual roles and relations towards a coalitional politics of embodiment.

Such coalitional politics of embodiment appears in Rousso’s memoir through a sense of home as community. She finds this in the disability rights movement but also among people who inhabit her everyday space(s) of home. This coalition is not based on similar impairment categories but rather openness to other varied bodies and ways of being. We see this in one incident that could have only taken a few minutes. While she enjoys breakfast in her favorite café, Rousso notices a woman staring at her and muttering under her breath. Noticing this, a waiter (who Rousso knows well) inserts himself between the two women and strikes up a conversation with the stranger. The woman stops glaring long enough to talk to the waiter about the area; she wants to move into the neighborhood. In almost no time at all, this stranger stops eyeing Rousso and strikes up a friendly conversation when it becomes clear that she lives here.

In this instance in particular, Rousso is presented and presents herself as a local, as someone who
belongs and—most importantly—as someone who belongs more than this other woman whose presence is tentative. In and through the waiter’s positioning himself (physically and coalitional) between Rousso and the woman, he and Rousso enact and express a sense of home defined by shared space and openness. Together, Rousso and the waiter reclaim her sense of self and her sense that this location is a place of home. Ultimately, these transitions from one sense of home to another do not result in a “new” (static, whole or permanent) place (as though Rousso will never find herself in an uncomfortable situation again). The sense of home that Rousso ascribes to the disability community is not defined; rather, it is disclosed in the turning of disorientation away from a home which cannot be and toward one that is always emerging.

Ableism contributes significantly to Rousso’s fear over leaving home, but it also informs her conclusion that leaving home is the necessary first step toward creating new homes. As she describes it, this is an issue not only of orientation but, more importantly, of disorientation. Rather than being afraid of disorienting encounters, Rousso comes to feel connected to others through them. Just because these encounters ended pleasantly does not mean that Rousso’s sense of home was not disrupted; it certainly was. Through each experience described above, Rousso’s definition of home expands to include more people and places but also a larger, more flexible and more open relation to being disoriented. Rousso stresses that, for her, home is portable and porous, formed by and found in corporeal and embodied relations. Rousso’s sense of home and—to borrow from Clare, the body as home—appears as a space that not only must be left but must always be leave-able so that it may be appreciated. For Rousso, a sense that disability is or can be understood as home increases the more she gets involved with and feels a part of the disability rights movement. This is affirmed when she describes the various stories that make up her memoir, and the ones about home in particular, Rousso suggests that they are what she calls
“coming-together narratives” as opposed to overcoming narratives. In this regard, Kumari Campbell's definition of disorientation is wholly appropriate for describing the experience of disabled embodiment within an ableist worldview. The sense of home I have addressed in my reading of Rousso's memoir articulates the space between the lost and not-yet-home that constitutes disabled embodiment.

Rousso’s text is also significant because it demonstrates that disorientation—the question-able relations of bodies and world—is at once corporeal and material. Experiences of disorientation can be protracted or prolonged, and disorientation is not simply a disruption of typical ways of being but is itself a way of being. In the next section, I articulate the scope of disorientation in the everyday lives of disabled people.

D. **Ontic Disruption and Ontological Disorientation**

Disorienting encounters can range from the mundane to the profound. Often, a deeply meaningful experience can be set off by the simplest of incidents. The same is true of disorienting encounters with disability. The point of this section is to provide some context for my discussion of disorientation. My overall argument in this chapter is that disorientation is not merely the absence or lack of orientation (just as disability is not defined by or as the lack of ability). Instead, disorientation describes various ways of relating to the world and, here specifically, to disability. For this reason, it is necessary to build on the definitions of orientation discussed earlier. I emphasize this point now because it would be very easy to imagine some of the disorienting encounters addressed below as simply a lapse in orientation. Moving forward in this section, I use a phenomenological distinction between ontic and ontological phenomena to frame the vast range of disorienting encounters with disability as either ontic disruption or as ontological disorientation.
The first category, ontic disruption, includes small moments that remain small, incidents that may be surprising or unexpected but nevertheless leave the person or persons involved relatively unchanged. Ontological disorientation entails life- and perspective-changing experiences. Although it is tempting to say that this project is more concerned with one category of experience rather than another, the two are not so easily separated. More accurately, what is of interest here is the lived experience of the movement (itself a turning) from one mode of experience to the other. In starting with a discussion of ontic disruption and then moving to ontological disorientation I do not mean to suggest a causal link between the two. Rather, the relationship between ontic disruption and ontological disorientation, and the difference between them, is one of intensity. Both modes of disorientation are characterized by a dysappearance of the world and/or the body (Leder 26) but ontic disruption ceases to be and recedes to the background relatively swiftly while ontological disorientation leads to a turn in our orientation to the world as well as the body. As I demonstrate, disorienting encounters with disability, and disorientation as a lived experience, can arise in social interactions but also in isolation. Both encounter and experience may play out in public or remain within ones innermost experiences.

In her essay, “Blind Faith,” disability studies scholar and author Georgina Kleege gives an account of ontic disruption that is itself an encounter with disability. This story takes place in her home on an otherwise unremarkable, if somewhat dreary, day. “It had been a lowering, overcast day,” Kleege writes, “but the clouds had lifted enough at the horizon to reveal the sun as an intense orange disk set off by the general grayness of the darkening sky” (57). She sits quietly to enjoy the view. She watches, and watches, and watches some more. Eventually, she notices just how long she has been watching. The discrepancy between the time she had been looking
and the usual time it takes the sun to set (when it is already orange) was her first clue that something is strange. Kleege writes:

It remained in the same place I had first noticed it, and appeared to be the same size and shape. Also, the sky was growing steadily darker, even though the sun’s light stayed at the same level of intensity. Still I continued to watch, thinking that if this seemed strange to me it was only because I had not been paying enough attention to sunsets lately and had grown unfamiliar with the natural course of the phenomenon. More time passed, and at last I recognized my mistake. The orange light I had taken for the sun was in fact only a sodium vapor street lamp. (57)

Although she initially frames this incident as a mistake on her part, Kleege uses this experience to open up a larger discussion of blindness as a way of knowing and being that is informed by everyday uncertainties and not knowing. In turn, this discussion provides a working understanding of ontic disruption. According to Kleege, this incident is ultimately neither an error in judgment nor a lack of knowledge. Based on her experiences of being blind for more than forty years, she argues that blindness provides an epistemically rich position. Blindness renders a world that is at once know-able and full of meaning but also rich in meaningful unknowns. In this way, Kleege suggests an ontological dimension to blindness (and disability) that implicates disorientation as a way of being.

Kleege’s account teaches us a great deal about ontic disruption. First, it demonstrates that disorientation can unfold in the course of everyday life in such a way that one becomes aware of experiencing without being "thrown" by it. Second, it shows disorientation as an experience of being turned around by everyday objects. Third, it further emphasizes impairment/disability as generative of (an) orientation that can be disrupted rather than as a state of ongoing disorientation. Further, she suggests that disorientation, even when it is a common experience, is not analogous to being lost. For Kleege, blindness has been a starting point for the majority of her life and it is this orientation that is disrupted. Thus, she reverses the traditional sense of
blindness as lack or loss of vision that is always already disorienting, stressing, “my eyes always deceive me but my blindness never lets me down” (58). The first part of this statement echoes Cixous’s account of myopia addressed in the previous chapter, but importantly, Kleege’s discussion moves beyond or turns away from an understanding of blindness as a disruption of eyes that would and should see clearly. For her, blindness—as a lived experience—can be replete with uncertainty but this uncertainty, because it is a lived experience, need not be alienating.

In contrast, Nirmal Puwar’s *Space Invaders: Race, Gender, and Bodies Out of Place* offers a vivid description of ontological disorientation that articulates it as a way of being, and being-with, others and the world. Puwar studies experiences of women and people of color who now occupy spaces from which they have traditionally been barred. She refers to them as space invaders. Her primary research site is the British Houses of Parliament where the very presence of these “space invaders” disrupts protocols of expectation and the sense of belonging for those with bodies that are assumed to be in the right place. Puwar’s analysis of the disorienting impact of women and people of color in Parliament is readily applicable to people with disabilities (many of whom are women and people of color themselves) even in more mundane settings. “‘Known’ through a limited set of framings,” she explains, “these bodies jar and destabilize an exclusive sense of place” (11). As I indicate above, ontological disorientation exceeds disruption. Puwar supports this characterization by explaining that as the “unknown” disorienting bodies “defy conventions and boundaries, they represent the potentially monstrous, whose somatic arrival invades the social and psychic” (Ibid). It is in this capacity that her account is particularly useful for a discussion of disorientation as a state or mode of being in relation to disability. Puwar studies social or worldly disorienting encounters and emphasizes the affective dimension of disorientation as a relation between bodies, spaces and meanings in a manner that resonates
with Ahmed’s articulation of orientation. She writes that “the coming together of bodies and spaces that have been juxtaposed induces a whole set of anxieties…it represents a physical somatic collision…people are ‘thrown’ because a whole worldview is jolted” (43). Although the worldview jolted by Puwar’s “space invaders” is explicitly one that assumes the socio-cultural dominance of white men, disorientation does not require specific spaces (or bodies) to be jarring.

Writer Lynn Manning presents numerous examples of ontological disorientation that unfold, seemingly, anywhere in his semi-autobiographical one-man play, *Weights*. Manning’s account of ontological disorientation, like Puwar’s, is rooted in a taken-for-granted orientation to the world that once disrupted can never be retrieved. The play is a mix of monologues and poetry reflecting Manning’s experiences of growing up non-disabled, acquiring impairment and then developing his sense of blindness. Manning's account of the night he acquired impairment, dramatized almost twenty years later, is full of affective and narrative description. Together, these details set the scene for an ordinary night in the life of a young artist who is finally enjoying some recognition.

Manning awoke in a hospital bed. A stranger who he had been arguing with earlier in the evening had shot him in the face. He could not see. This is a fairly straightforward account of violently acquired impairment. Manning, however, turns away from the traditional overcoming narrative. *Weights* is not the story of a slow-but-sure psychophysical recovery and acceptance of blindness. Instead, it is a story about coming to (live *with*) blindness, its embodied meaning(s) and the sense it makes. Although his injury was traumatic, it was still, at first, only an ontic disruption. This is evident in his early efforts at "recovery" and rehabilitation. Manning explains, for instance, that he did not live "like a blind person" for some time after his injury. For a number of weeks after he was shot, he had little to no independence and relied on his doctors and
his family to take care of him. A regime of medical professionals and family members set (low) expectations and helped him meet them. In terms of the last chapter’s definition of orientation, he only knew what it was like to suddenly be without sight and not what it meant to be blind. His efforts to regain (re-orient to) his sighted sense of the world left his blindness at the level of ontic disruption. Rather than “coming to terms” with the loss of his sight as his rehabilitation counselor had suggested, he thought that the best way to adjust to blindness was to learn how to live as a blind person. As an important side note, the distinction between ontic disruption and ontological disorientation, particularly as it is illustrated in Manning’s account, raises a significant philosophical issue between, for example, the National Federation of the Blind and disability studies scholarship. One of the NFB’s central principles is that with “proper training,” blindness can become no more than a “physical nuisance.” This statement is problematic from a disability studies perspective because it renders blindness as an individual physical “challenge” that can (and should) be overcome without questioning the multitude of other “barriers” that blind people face as disabled people. Further, it disallows the possibility for thinking of blindness (and disability) as a way of being and casting every experience from blindness as always only ontic disruption as though there is a proper way of being that blindness is blocking or interrupting.

As I demonstrated earlier, orientation describes the processes, practices and starting points that shape and are shaped by experiences and meanings of disability. Manning’s account illustrates that orientations are in turn shaped by moments of disorientation and the relation between ontic disruption and ontological disorientation. Finally, Manning describes his experiences of ontological disorientation as providing a new starting point. For Manning, the real experiences of disorientation begin on his first orientation and mobility lesson and, more
importantly, when he receives his first cane. He learns basic cane techniques quickly: “tap to the left when I step with my right foot and tap to the right when I step with my left foot… I can figure out how to make it look cool later” At this early stage he relates to his cane as a simple tool with a singular purpose. Disorientation occurs during his first “homework” assignment, a trip around the block. He sweeps his cane from side to side as he moves forward. His cane bumps into something, then something else. One hit after the next, Manning begins to feel assaulted by the unseen world. He gives up after his cane has connected with countless objects not even halfway around the block. Exasperated, he wonders, “Why the hell can’t I walk straight?” His O&M instructor explains, “that’s what the cane is for; when you hit something you know where it is” (2007). This exchange encourages Manning to relate and experience his cane and the world differently. He experiences what Merleau-Ponty and Leder call “incorporation.” His cane is no longer simply a tool that he knows how to use more or less effectively but becomes an extension of his bodily and embodied experience of the world. This means that his bumping into things does not have the negative connotations of, say, a new driver bumping into something. The bumps are not bad; rather, they are moments of connection and interconnection shared between himself, his cane and the world. Approaching his impairment and disability in and through this burgeoning orientation with his cane from this new perspective is itself ontologically disorienting. He writes:

A whole new way of knowing the world was opening up to me…through my nose, through my ears, through my feet, through my pores, lights and shadows took on physical dimensions, became solid bands of heat and coolness that swiped at me as I passed…I began to appreciate the Doppler effect of sound, the way it swells when near and diminishes to a vanishing point in the distance…sound is not so different from sight in this way except this auditory horizon is much closer, the world much smaller, only the sound of a jet plane cruising high in the atmosphere can ever expand the world to near its former infinity…in absence of that I came to recognize the overwhelming distraction that sight had been. (2007)
Manning’s account of ontological disorientation, like Puwar’s description, details an experience of the exposure of otherwise taken-for-granted orientations to the world that once disrupted can never be covered over. Reflecting on this experience as a way of experiencing, Manning notes that “blind people had to have known all along” about this particular way of being in and knowing the world. Not only does this gesture toward what I have referred to as “dis-orientation,” it also highlights the ontological dimension of disorientation. I consider Manning’s account an experience of ontological disorientation because he is unsure of his place in and relation to the world in his own body. Finally, Manning's story suggests that experiences of ontological disorientation occur when one realizes that an encounter has led to a different sense of being in the world or, more accurately, the realization that he or she is already in the world differently.

It is worth noting that the story that began this project (my encounter with a store clerk), though only a moment of ontic disruption for me, could very well have been or could have become an experience of ontological disorientation for the clerk. For instance, after our interaction he might have realized that there was nothing particularly unusual about a blind or visually impaired person buying a television because, after all, one can always listen to television programs and may have sighted friends or family who would enjoy the device as well. If this realization or something like it occurred to the clerk, it would (or could) present him with an opportunity to understand and relate to people with disabilities and the world differently. This, by definition, would be a moment of ontological disorientation. I do not want to give the impression that experiences of disorientation (ontic or ontological) are simply a matter of beliefs and changing opinions. As the above examples have shown, disorientation is about turning and being turned by the relatedness of bodies, things and people. In the next section I take up the
question of how encounters with disability occur in bodily, embodied and social experiences of disorientation through a discussion of Leder’s analysis of “the absent body” and, later, Paterson’s and Hughes’s application of this analysis to issues of understanding and relating to disability.

E. The Absent Body

The lived body, as Merleau-Ponty articulates it, is an able body. Impairment and disability do appear within *The Phenomenology of Perception* and elsewhere but do so almost exclusively as examples of a body gone wrong. This is further demonstrated in Leder’s observation that “the body seizes our attention most strongly at times of dysfunction: we then experience the body as the very absence of a desired or ordinary state, and as a force that stands opposed to the self” (4). The compulsory able-bodiedness of the phenomenological body thus makes it difficult, but not impossible, to imagine and affirm disabled embodiment.

Leder’s *The Absent Body* makes a significant contribution to this study. Leder understands both disappearance and dys-appearance as modes of embodied being that are meaningful for experience rather than simply the absence of experience. Further, he develops the notion of dys-appearance to describe the uncomfortable self-presencing of (parts of) the body that otherwise go unnoticed. Extending his work into the realm of social relations helps us understand not only how the body disappears in everyday experience but also, as Paterson and Hughes address, how certain bodies (are made to) disappear. The discussion that follows is greatly informed by Leder’s analysis of bodily absence. Then, I take up Paterson’s and Hughes’s application of Leder’s work to issues of impairment. In this exploration I focus on the imagined and real narratives that these authors provide because these stories offer compellingly different senses of disability. Paterson and Hughes, who themselves work through Leder’s text, intentionally craft their narratives to reflect the sense of disability they want to highlight. Leder, on the other hand,
almost implicitly offers a taken-for-granted sense of disability that can, at times, approach ableism. In putting these two texts and their various somatography together, I posit embodied disappearance as a vital element of disorienting encounters with disability.

1. **Disappearance**

   Taking a phenomenological perspective, Leder begins with an understanding of the body as a site and source of experience and meaning. The crux of his argument is that Merleau-Ponty’s articulation of the lived body emphasizes bodily presence within experience while largely ignoring the multitude of absences that condition the possibility of outward perception. “The body,” he reminds us, “not only projects outward in experience but falls back into unexperience-able depths” (53). To illustrate this point, Leder imagines himself leaning against a fence overlooking a field with a tree at its center (11). As he looks out at the field, his body disappears. While focusing on the tree, for instance, he is not aware of his legs holding him up, of the sensation of his arms or hands on the fence, or of the wind on his face. Somewhere even further in the background of his experience of the tree his heart pumps blood through his body while his eyes, optic nerves and brain work together to facilitate the experience of “seeing.” Though unexperienced, the absent body is just as significant to embodied experience as surface perception is, if not more so.

   Leder provides a very specific definition for his use of disappearance. Rather than describing something that was once present but is no longer available to perception or awareness (as in common usage), Leder uses disappearance to describe "that which never shows itself for structural reasons" (27). “To disappear,” he explains, is “simply to not-appear” (Ibid). This specific definition of disappearance is enough to make *The Absent Body* important for my analysis of disorienting encounters with disability and of disorientation in relation to disability in
general. However, his further elucidation of these "structural reasons" makes this work essential. When Leder attributes bodily disappearance to "structural reasons," he is referring to phenomenological structures of bodily perception--specifically, Merleau-Ponty’s “figure/ground” and Polanyi’s “to–from.” However, Leder's articulation of disappearance as "to not-appear" in contrast to a more mundane understanding of it as, for instance, "currently absent" resonates with Kumari Campbell's account of disorientation in the lived experience of disabled embodiment and my own understanding of disorientation within disorienting encounters with disability. What is important about this aspect of Leder’s work is his argument that for specific perceptions and actions—both in the moment they occur and as a condition of their occurrence—something must disappear. When Leder observes the tree, for instance, his eyes disappear. I suggest that disability, as both the process and lived experience of disablement, requires and is characterized by similar kinds of disappearance occurring on the bodily and social level.

Leder’s analysis of disappearance is framed by Polanyi’s to-from structure of perception. In his study, Polanyi describes perception as moving from the body to objects in the world. As most of our action and attention is directed outward from “the here and now body,” Leder explains, “one’s body is rendered subsidiary, not only as a physical means to an end but within the accompanying structure of attention” (18). The vast majority of the body necessarily disappears in the course of everyday action and awareness. Leder identifies three primary modes of bodily disappearance (focal, background and depth) that each in their own ways make experience—as we know it—possible. The first, focal disappearance, describes "the self effacement of bodily organs when they form the focal origin of a perceptual or actual field” (26). Leder, following Merleau-Ponty, presents the most obvious, if ableist, example of focal disappearance in pointing out the absence of our eyes themselves in visual perception.

The
phenomenon of focal disappearance and the parts of the body that most readily participate in this form of disappearance illustrate Polanyi’s to-from structure of perception. Organs that are not (for the moment if at all) the focal origin of experience engage in what Leder calls background disappearance. In their background disappearance, organs or parts of the body may be acting in a "supportive role" (the spine, for instance, in the act of looking at something while standing up), while at other times these parts of the body may simply be "out of play" (the feet, for instance in the act of looking at something while sitting). These forms of disappearance are characteristic of the perceptual field of embodied experience as Merleau-Ponty articulates it in *The Phenomenology of Perception*.

Focal and background disappearances characterize experiences of the body (its parts and processes) but also describe embodied experience of body and world. In performing everyday skills or routines, organs, parts and our sense of our body participate in these forms of disappearance. A smooth transition between the two forms of disappearance is essential for the "everyday" character of activities. Also, for the most part they are definitive of a “normal” body. The un-question-ability of these forms of disappearance are rooted in a third, even more taken-for-granted mode of disappearance.

This third type of bodily recess goes beyond those discussed at length in Merleau-Ponty’s account of embodied perception and in many ways serves as the start of Leder’s original contribution to the topic. Depth disappearance concerns the myriad of organs and processes that enable surface bodily presence. Here, he is concerned with the visceral goings-on (indeed, with viscera) that are most often absent from our lives and experience. A clear example of this is the ongoing process(es) of digestion that we usually only concern ourselves with at its beginning or end. I emphasize “usually” here to highlight the reality that the desire to eat and to relieve one's
self of digested food can lead to some of the most intense experiences of bodily self-presencing. This can be especially true if there is (or was) a problem somewhere along the digestive tract or in an element of viscera that conducts this process. This is an important construct in Leder’s project but ultimately not in my own. He deploys depth disappearance as an entrée into a larger discussion of what he calls “dysappearance.” It is this concept, bodily and embodied dysappearance, which is most significant here.

Leder's sense of disappearance as "non-appearance," in contrast to a more mundane understanding of it as "currently absent," supports Kumari Campbell's use of disorientation to describe disabled embodiment, especially as she does so in the context of dissecting ableism. Her primary argument concerning ableism is that it operates (most effectively) through its own self-effacement. This is why "the disabled body" carries broad-ranging but largely unspoken corporeal and conceptual meaning while "the able-bodied" does not. The able-body, or to be more accurate, able-bodiedness, disappears. In this context, socio-cultural phenomena such as McRuer’s “compulsory able-bodiedness” serve to point out socio-cultural practices as well as to mark ontologies that "simply do not appear" (Leder 26). In defining ableism and compulsory abled-bodiedness Kumari Campbell and McRuer, respectively, force us to dwell with its presence rather than simply acknowledge its appearance. This can be both uncomfortable and in many senses disorienting. Leder develops a phenomenological account of uncomfortable bodily self-presencing in his notion of dys-appearance. His analysis of this phenomenon offers a clear link between bodily and embodied (including social) experiences of impairment/disability. Specifically, he provides the foundation for my discussion of disorienting encounters with disability as being, at least partially, the forced self-presencing of orientations towards disability.
2. **Dysappearance**

Building on his discussion of the body’s presence in surface perception as well as focal, background and depth disappearance that undergird this, Leder articulates another mode of embodied experience. He labels this new modality “dys-appearance” (84). Leder’s notion of dys-appearance provides the foundation for my interest in and interpretation of disorientation in relation to disability. The body dys-appears in and through dysfunction or abnormality precisely as dysfunctional and abnormal. As Leder describes it, dys-appearance entails the self-presencing of the body as a body gone wrong—wrong in itself or wrong for a specific action. While it is a distinct mode of experience, dys-appearance is intimately related to both other forms already discussed. It exposes the otherwise non-apparent body and lays bare the relationship between bodily presence and disappearance. In and through dys-appearance, “the body appears to explicit awareness” affecting, as Leder understands it, “an attentional reversal" (86). Rather than going unnoticed in its normalcy, the body becomes the center of (our) attention.

Perceptually speaking, dys-appearance simultaneously shrinks the world and enlarges the body in which we live. It is a mode of experiencing that disrupts Polanyi’s from-to structure and causes the body to transform; it is no longer a site from which we perceive but rather an object to which we attend. Dys-appearance can lead to a disruption of attention, intention and movement. Leder describes this as intentional disruption as well as perceptual and motor constriction. The dys-appearing body effectively cuts us off from the rest of the world such that the body takes on an “alien presence” (74). To illustrate this point, Leder asks us to imagine a tennis player who is thoroughly engaged in a vigorous game until, in the midst of the match, he feels tightness in his chest. At first, he tries to ignore it. Then, he begins to sweat (more profusely) and finds it difficult to breath. Soon his focus on the game and his opponent are gone completely. The
feeling in his chest is both all Leder’s tennis player can think about and all he cares about. Describing dys-appearance of the appearance of the body as a body gone wrong thus means many things: a sign that something is wrong with some disappeared part of the body and that this “something” is now making itself present as wrong (abnormal).

Leder’s articulation of dys-appearance immediately draws the attention of readers committed to an understanding of disability in relation to orientation. Not only are his primary examples tacitly reliant on a normative sense of the body, but also his more "common sense" claims explicitly render impaired bodies "out of play" in the world. Someone paralyzed from the waist down, for instance, is “mocked” (23) by out-of-reach objects. The problem with this way of understanding dys-appearance as a mode of bodily being almost necessarily leads to an ableist ontology. To be clear, dys-appearance is neither the cause nor effect of sudden or situational abnormality; rather, it is the lived experience of the sudden self-presencing of something (the body) that previously had not (ever) caught our attention. That something, then, does not appear neutral but instead as bad or “in the way.” This problematic formulation of dys-appearance is further evidenced in Leder’s characterization of the body present(ed) in dys-appearance as an "alien presence" (77) that is “opposed to the self” (4). By contrast, disability studies scholars, activists and anyone informed by a political orientation towards disability might argue that the body (or parts of a body) that cannot disappear is not the same thing as the dysappearing body. Manning’s account of the early days of his impairment, for instance, shows him turned around by his embodied relation to the world but not overwhelmed by his body’s presence as a body gone wrong. Some disability studies scholars have taken up Leder’s work as a means of analyzing the impact of ableism on the lived experience of disabled embodiment. This work de-
personalizes bodily dysappearance by emphasizing psychosocial elements of lived experiences of being disabled.

F. **Impairment as Dys-appearance**

Paterson and Hughes use Leder’s discussion of pain as a mode of experience to make the case that impairments, specifically those that do not result in physical pain, participate in dysappearance. Their argument is in part a response to what they see as dichotomous thinking on the part of disability studies scholars (at the time) who treated pain as a private personal problem and focused instead on explicitly social oppressions. Paterson and Hughes’s argument, in brief, is that social oppression and cultural marginalization are a form of (non-biological) pain that causes the bodies of people with impairments to dys-appear. Whereas pain makes the body present to itself because something “is wrong,” impairment dys-appears and makes the body appear as a body that is wrong. As they summarize: “the impaired body ‘dys-appears’ as a consequence of the profound oppressions of everyday life. It is stunned into its own recognition by its presence-as-alien-being-in-the-world” (603). In contrast, Kuppers acknowledges the importance of pain on the experience and perception of bodies, however, she arrives at the opposite conclusion from Leder. Whereas Leder understands experiences of pain as experiences of bodily dys-appearance, Kuppers suggests pain can at least potentially be "concretiz[ing] of the body by "foreground[ing] it experientially" (qtd. in Mintz 246). In turn, Mintz writes that "in relationships with others, in social structures, in forms of work and productiveness, pain becomes affirming rather than negating, an avowal of the self’s aliveness and even kinesthetic impact on the world beyond its boundaries" (246).

Paterson and Hughes’s conceptualization of impairment as dys-appearance reintroduces Eli Clare’s criteria for understanding the (disabled) body as a place of home. Recall that Clare’s
primary criteria for thinking of the disabled body as a place of home begins with an implicit understanding that that home can be invaded, broken (into) and disregarded. In other words, as I suggest towards the end of the previous chapter, the disabled body is essentially homeless (at least in the traditional sense). Paterson and Hughes take up this very issue as they articulate impairment as dys-appearance. “Any body that is excluded from making a contribution to the construction of the social world,” they argue, “cannot find a home in it. Exclusion, even oppression is a kind of homelessness” (604). Their choice of the term “homeless” is a reflection of the typical connotations of home as a haven or place of security and belonging. By contrast, the disabled body or, more specifically, the body disabled by impairment (a dys-appearing body) is not a home and does not belong. They explain their reference to home as follows:

It implies a world of bodily discomfort, of being left out in the cold: all of which makes the body present, makes it “dys-appear”. The information that animates the world is dominated by non-disabled bodies, by a specific hegemonic form of carnality, which excludes as it constricts. (204)

Paterson and Hughes’s discussion of dys-appearance departs from Leder’s original formulation through its emphasis on the world of intersubjective/intercorporeal relations as a catalyst of dys-appearance. Embodied self-awareness (self-presencing) depends on inter-subjectivity, as Leder freely admits: “my awareness of my body is a profoundly social thing, arising out of experiences of the corporeality of other people and of their gaze directed back upon me” (90). Yet his discussion of dys-appearance in this context is primarily concerned with how the dys-appearing body cuts us off experientially from the world of others. He illustrates this, for example, when his tennis player is “cut off” from his opponent in the midst of their game. For Paterson and Hughes, on the other hand, impaired bodies dys-appear in (are disabled by) how they appear and are made to appear in a world of environmental—but especially sociocultural and attitudinal—norms. People with impairments appear (to others and to themselves) as though they are in the
way. In this regard, impairment as dys-appearance retains Leder’s sense of the body as alien presence but extends the space in which this alien presence is and what it can be.

Paterson recounts two personal experiences of dys-appearance. His embodiment (speech and mobility, specifically) is shaped by cerebral palsy and so are his interactions with others. It is in and through these encounters that he experiences his impairment as dys-appearance, particularly in social encounters organized by temporal norms. Through these narratives, Paterson highlights the temporal and intercorporeal elements of dys-appearance. In addition to dissecting dys-appearance, Paterson and Hughes’s point here is to suggest a "critical politics of time" that would parallel and compliment the politicization of space already achieved by disability studies (605). In the first narrative, Paterson finds himself sharing an elevator with someone who begins asking him questions. Paterson’s impairment (a speech impediment) dys-appears the moment he realizes that these questions are more than casual conversation and that any meaningful response he may want to provide will require more time than either of them have together on the elevator. Rather than reply as he would like (which would also show him to be an informed interlocutor), all he can do in the allotted time is smile and nod. Here we can see a different sort of analysis than we might expect from a perspective informed by the social model of disability. There is no traditional environmental barrier in this story. It takes place on an elevator rather than in the absence of one, as we see in many other narratives of disablement. Instead, the temporal conventions of everyday life compliment and parallel the structural conventions that serve to oppress people with disabilities.

Paterson and Hughes’s most significant application of Leder’s notion of dys-appearance for this project is their claim that “an integral element of the ‘dys-appearance’ experienced by disabled people is the everyday reality of condescension” (606). To illustrate this
point, Paterson recounts an encounter he had in his late twenties. Answering the door to his home, Paterson is met by a delivery person who almost immediately asks whether or not his mother is home. The delivery person assumes, he believes, that because he neither looks “normal” nor speaks "normally," he must not be a "responsible adult" (606). It is significant that this (value) judgment was made "instantaneously." In calling for a radical politics of time, Paterson and Hughes stress that everyday experiences of dys-appearance are initiated by and last for moments while their consequences for disabled embodiment can last a lifetime. In this way, Leder’s ableist understanding of dys-appearance appears in sharp contrast to Manning’s account of disorientation as opening up “a whole new world.” This, I believe, is because what Manning describes is not dys-appearance—the sudden presencing of the body as a body gone wrong—but rather an experience of what I will call dysorientation—the lived experience of an orientation as being (or having been) turned around. It is in this regard that I want to begin shifting focus away from bodily experiences of (impairment as) dys-appearance to explore what other experiences of disorientation can teach us about disorienting encounters with disability.

G. **The Dysoriented Body**

Ontological disorientation, as I have demonstrated, does not simply occur in a moment, nor does it last only moments. Rather, as Manning’s and Hughes’s accounts suggest, ontological disorientation is ongoing and always already shaping how we go on. Anthropologist Robert Murphy (1987) explicitly makes this point about disorienting encounters with disability in *The Body Silent*. Recounting numerous instances of disorientation (both ontic and ontological) that shape and are shaped by assorted understandings of impairment and disability, Murphy emphasizes the importance of (haptic and affective) intimacy and touch for meanings and experience of impairment and disability. He writes, for instance, that his relationship with his
wife that had always been emotionally and physically supportive becomes stressed after he begins using a wheelchair not because he needs more support than usual or because she is unwilling to provide assistance but rather because he—and perhaps she—relates to his body and bodily needs differently. Elsewhere, he notes that physical touch became more significant to him and others after he began using a wheelchair. For example, he stops seeing his regular dentist after the doctor pats him on the head during an appointment and notes that students touch him more frequently. It is not the case that Murphy reports a greater sense of touch; rather, touch—as an intimate relation—means more. This gets to the heart of the question of disorienting encounters with disability. As I indicate at the outset of this project, this is not a question of what disorients us but rather how we experience disorientation or what it means to be disoriented. Murphy’s narrative emphasizes that intimacy and touch are vital to knowing, as well as not knowing, disability.

In this regard, Leder’s dysappearance seems all too temporary both as an experience and as a way of relating to disabled/impaired bodies when compared to Kumari Campbell’s description of disorientation as “the lived experience of facing at least two directions” (194) Recall that for Leder, the body suddenly stops participating in disappearance as its self-presence takes up our attentional and intentional awareness. Then, perhaps just as suddenly, it recedes once more. In their application of dysappearance to issues of impairment, Paterson and Hughes thus have no choice but to extend the duration as well as the implications of dysappearance as they expand its scope to include the meanings of disability and disabled bodies generated in and through social encounters. That said, their examples constitute ontic disruption as they—Paterson himself and, presumably, the people he interacts with—are not forever changed by these encounters. Instead, they (re)enforce an ableist logic. Building on Leder’s articulation of
dysappearance as well as Paterson and Hughes’s application of this mode of embodied perception to the perception and experience of disabled embodiment, I address another, perhaps more deeply felt, sense of disorientation that emerges in relation to disabled embodiment. I call this dysorientation. While this label is in part only a placeholder to distinguish between this experience and other types of disorientation, dysorientation connotes something a bit different. Specifically, it is more explicitly embodied and ontological; it is the lived experience that Kumari Campbell invokes as an experience of the lost and not-yet-home of disabled embodiment.

Below, I examine dysorientation through a discussion of French philosopher Jean Luc Nancy’s 2008 essay “L’intrus” (“The Intruder”) and Brian Lobel’s series of plays published as Ball and Other Funny Stories About Cancer. Each of the bodily changes that these accounts address--Nancy's heart transplant and Lobel’s testicular cancer--could be understood as instances of bodily dysappearance. These works share an insistence that there is something about encounters with (disabled) embodiment that is characterized by the kind of disorientation that Kumari Campbell describes. Specifically, Nancy’s essay and Lobel’s plays address an epistemic and ontological strangeness framed by uncertainty and exposure. Put another way, they demonstrate that the dysoriented body is always already exposed and that this exposure is strange. Emphasizing the questionability of the body as home and, in turn, home as (a space of) belonging, these somatographic narratives complicate Leder’s definition of disappearance as “not appearing” by describing instead what seems like an experience of non-disappearance. This interests me, as it suggests the possibility of an alternate corporeal relation to disability that begins with, rather than is interrupted by, disorientation.
Strange relations

There are several factors that distinguish Nancy’s and Lobel's accounts from Leder’s or from Paterson’s and Hughes’s. First, they give an account of bodies that accounts for, rather than discounts, disorientation. Second, their accounts are decidedly haptic and highlight touch and (points of) contact between bodies as generative of meaning rather than as experience of a body gone wrong. Third, by beginning with (a sense of) disorientation and focusing on touch, Nancy and Lobel open up the question of sense in our relation to and with the world. While this last point is more important in the next chapter, it bears keeping in mind as we consider what it means to be disoriented. “L’intrus” specifically gives an account of ontological disorientation as a lived experience but more significantly as a way of being (dysorientation). Here, the value of Nancy's work is his refusal to apologize for disorientation or imagine his body or embodiment as a problem. Recall that Leder formulates dysappearance through the example of a tennis player who feels a pain in his chest, seeks medical attention, receives a diagnosis and treatment, and then recovers. By contrast, though Nancy and Lobel identify precise moments of diagnosis and prognosis as well as receive treatments (Nancy has a heart transplant, and Lobel has his cancerous testicle removed), this does not manifest as merely an experience of dysfunction but instead exposes a more fundamental relation to bodies. Upon hearing that he needs a new heart, “something broke away from me,” Nancy writes, “or this thing surged up inside me, where nothing had been before: nothing but the ‘proper’ immersion inside me of a ‘myself’ never identified as this body, still less as this heart, suddenly watching itself” (163). Similarly, Lobel reports thinking, “No, this isn’t good, I should have this checked out” (23) when he first feels a lump on his testicle, but his performance centers on the social, sexual and otherwise embodied implications of his cancer. Although, or perhaps because, Nancy and Lobel live through their
experience, their experiences do not resolve in the recovery of a normal body but instead turn away from a conceptualization of "normal" bodies because for them disorientation persists.

Admittedly, the sentiments expressed above sound a lot like dysappearance. However, Nancy specifically rejects any notion of the body and Lobel concludes his play by embracing the realization that “bodies change a ridiculous amount over time” (85). These experiences contrast with Leder’s description of dysappearance. Instead of bodies participating in disappearance, Nancy and Lobel begin with bodies that go unnoticed. The difference between disappearance and going unnoticed is illustrated in Ball and specifically in Lobel’s self-discovery of his cancer. The lump was not detected during a medical check-up or through a traditional self-exam but instead while he was masturbating. As Lobel stresses, this was not his first time with this activity, and he believed himself quite familiar with this region of his body. There was no pain or loss of function, and yet there was a lump. This echoes Nancy’s relation to his unnoticed heart, which he describes as “hitherto as absent as the soles of my feet while walking” (143). Nancy never had a specific sensation of wrong-ness in regards to his heart; it simply went unnoticed, and yet it needed to be replaced. Going unnoticed accounts for the reality that experiences and meanings of bodies are always already situated in particular personal, social and temporal contexts in a way that dysappearance does not.

This notion speaks to and is, in part, influenced by Alison Kafer’s *Feminist, Queer, Crip.* Here, Kafer develops a “political/relational model” of disability that addresses the material-corporeal production and circulation of meanings of impairment/disability between people with and without impairments. She proposes this model as a way to “speak to the reality that disability is experienced in and through relationships, it does not occur in isolation” (8). This chapter has shown that the relationships in and through which disability is experienced include interpersonal
relations as well as the relation of bodies and the world. What Nancy and Lobel’s work demonstrates is that disorientation, like orientation, is also an embodied experience that persists between one’s “own” body and her “self.” In doing so, they not only challenge Leder’s notion of dysappearance but also Paterson’s and Hughes’s use of this term to describe encounters with disability.

2. **Touch**

The centrality of touch and intimacy is highlighted early both in Nancy's essay and Lobel’s plays; it is precisely for this reason that I offer them as accounts of dysorientation. Lobel’s first piece, *Ball*, highlights several important touches (not the least of which is the one mentioned above). The two most significant touches occur in the latter two plays, *Other Funny Stories About Cancer* and *An Appreciation*. The first incident takes place several weeks after his third cycle of chemotherapy while watching a play with a friend. During intermission, Lobel and his friend notice that his ex-lover is also in attendance. The three speak for a while until, when the show begins again, Lobel and his former partner sit next to each other. Cancer was not the only "problematic" situation, that had for a time gone unnoticed. At this point, Lobel’s sexuality was at a crossroads. He had only recently come out to his family, and his sexuality remained a source of uncertainty and mixed feelings. Loss of virginity was high on his list of musts, and as his cancer treatment loomed, this made him uncomfortable for many reasons. This fact was not helped by his initial encounter with this man. Lobel and this older man, a former instructor, had spent one night together after which Lobel was informed that this was, from the other man's perspective, a huge mistake never to be repeated.

As they sit, they touch. Specifically, their forearms touch. This touch is disorienting. Lobel explains:
We rubbed forearms, I thought accidentally, he smiled and looked right at me. He smiled beautifully but strangely, I had never seen that smiling used before…He kept his forearm pressed against mine. (72)

This touch--particularly its duration--elicits many questions: is this man interested in him despite his earlier statement to the contrary? If so, is he interested? What signs should he look for to determine what this means? How can he be sure? Initially, Lobel thinks nothing or very little of this contact, but as time passes Lobel soon suspects and then “knows” that this touch means something. Based on this touch he “knows” that his former theatre instructor/ex-lover wants to have sex. Despite his knowing, the moment remains full of an uncertainty that only touch can quell. As the man smiles, looks away and smiles again, the smile proves to be an insufficient source of certainty because, as Lobel notes, “it was so foreign” (72). Finally, a touch on the hand confirms what he already knows. Although the pair remain seated, looking straight ahead at the play, their desires are in proximity, and this shared desire is evinced by their touch. Lobel reminds himself: “keep the forearms in contact. Perfect” (73). Suddenly, Lobel rises to use the bathroom. In and through these moments of contact his definition of virginity changed and allows the possibility that having sex with a man would “count” just as much as with a woman, especially as this suited his orientation. His quest to end his virginity was over. Then, just as quickly, his certainty turned. When he enters the bathroom, Lobel catches a glimpse of himself in a mirror. This glimpse does not put an end to his internal interlocutor, but it does change his line of questioning. Lobel explains:

I saw why he was looking at me, the instant I walked into the bathroom. I looked at myself in the mirror and there it was. There I was, an it. A cancer patient…Adam was smiling nervously at mortality, not a cute boy… I'm sure he didn't know what it was that I had, but I'm sure he didn't want it. (73–74)

The questions about what this touch means for his burgeoning sex life then turns to self-directed questions about his intelligence, maturity, attractiveness and whether or not he is “in touch” with
reality. Here, strange and foreign describe not only Adam’s smile but also Lobel's relationship to him and to himself. As the site of their caress, the armrest was a place of questioning that fostered a strange relationship (Lobel’s relation to himself) that existed prior to Lobel’s sitting down and that persisted long after he left the theater.

Contact, touching and being touched is the central question of “L’intrus.” “The intruder," Nancy writes, “introduces himself forcefully, by surprise or by ruse, not, in any case, by right or by being admitted beforehand” (151). In other words, the intruder (Lobel's cancer, Nancy's heart—old or new) is not the dysappearing body that shows itself in times of dysfunction as a problem but rather a (part of the) body that has been around for who knows how long by going unnoticed. As with Lobel, Nancy is moved to ask many questions in the face of this strange relation. Moving beyond (or at least extending) dysappearance to the realm of ontology, Nancy insists that his failed heart calls into question the very notion of the body, the proper unified and bounded body (le corps propre). Instead, the body written (about) in his essay, like the essay itself, entails multiple and overlapping interruptions and uncertainties of touch. He demonstrates this uncertainty at the start of the essay where he articulates the occurrence of his transplant surgery. Nancy writes:

    I (who, "I"? This is precisely the question, an old question: who is the subject of this utterance, ever alien to the subject of its utterance, whose intruder it certainly is, though certainly also its motor, its clutch, or its heart) – I, then, received someone else's heart. (162)

In Nancy’s essay, “L’intrus” simultaneously refers to the transplanted organ and the one removed as well as the bodies/selves that are and must be lived-with. Also included under the name “intruder” are the myriad medical procedures Nancy undergoes, the immunosuppressant drugs he takes (and the lowered immune system they create), the countless medical professionals who carry out these operations and the lasting material trace of their intrusion. He insists that the
intruder must always, for as long as its intrusion persists, remain an intruder and a stranger. This insistence serves at least two purposes. First, it reflects the ongoing state of Nancy’s lived experience (which is in part made possible by the living heart of another). Nancy purposely retains the sense of strangeness that he lives with and as. Derrida emphasizes this strangeness in his analysis of Nancy’s philosophy. Derrida (2005) writes:

he is touched by a strangeness that no longer has anything to do with the quasi-transcendental strangeness that refers us to all our “I’s” or our own bodies. And yet, in their possibility, the two strangenesses keep making signs toward one another and implicating each other (97).

This strangeness—the intruder and intrusion, the strange body as well as the strange relation to body—Nancy writes about is always already disoriented specifically because it touches and is in touch with other bodies. Nancy's heart does not dysappear but rather is at the heart of his dysorientation. That is, his heart's intrusion is ongoing. Lobel’s testicle and cancer are the intruder in his plays. They are the intruder not because they go unnoticed until he detects the cancer, but because it continues to intrude after that.

3. **Being dysoriented**

The accounts provided by Nancy and Lobel illustrate a “strangeness” that simultaneously describes objects (including bodies) and ways of being in relation to them. Specifically, Nancy’s essay presents dysorientation as an ongoing turn or persistent being turned around by the body, the world and our relatedness to each while still being in touch with (and touching and being touched by) that relation. Disorienting encounters with disability—at least ontologically disorienting ones—are disorienting precisely because we remain in-relation with body and world rather than temporarily feeling cut off (as in dysappearance and ontic disruption). In writing the self and body characterized by strangeness through the "law of intrusion" that binds Nancy to himself, he exposes a related-to body whose relation is always
already one of disorientation. As Perpich explains, "the self-enunciating I is nothing more than the formal index of an iterative chain of intrusions, and the body exists as a series of contiguous states or points of contact between various sites and situations" (82). Dysorientation does not remove one from his or her relation to the world but rather, as Nancy’s essay concludes, explicitly puts one in touch with relation.

The ontological status of these dysorienting encounters is itself disoriented. Something (body, world or their relation) takes on a different sense. This includes, but is not limited to, the constant sense of having one’s self questioned. Nancy’s and Lobel’s writings are dysorienting, as Derrida’s comments suggests, because they themselves are dysoriented. Lobel acknowledges this in his introduction. After signing the Amateur Performing Rights clause that allows others to perform the plays, he comments that it is strange to think about—let alone to watch—someone else perform his work. “It is,” after all, “my body that is being written about – my scars, my ball. And yet, it isn't” (20). The span of time between when he first wrote the plays and now is equal, if not greater than, the difference(s) between himself and the stranger performing his words. Moreover, Lobel emphasizes the intimate proximity between his body at age 20 (the one that had a lump) and his body at age 30 (the one who signed a publishing contract). This body is necessarily dysoriented. As he admits, “Sure, it shares the same scars, but they have different meanings now” (20).

In a way, Lobel enacts the disorienting character of dysoriented bodies in his final piece, An Appreciation. Here, he plays with the multiple meanings of the word appreciation. In a medical context it refers to visualizing or detecting, as when his tumor was “appreciated” through ultrasound. In everyday parlance it means to admire. After a brief explanation of these different meanings, Lobel takes off his pants and invites five audience members to appreciate, in
either sense, his genitals. He provides these volunteers with rubber gloves and a shot of whiskey as well as a note card and pencil. After they drink the whiskey, they are asked to "appreciate" his genitals and then describe them on a note card in a single word. As they appreciate and record their notes, Lobel explains that he never noticed much of a difference between having two testicles compared to only one except in the reactions of others. The point he is trying to make in and through *An Appreciation* is that the meaning of bodies, even the meaning of one's "own" body, emerges in relation to others and to the world over time. Lobel’s note cards—and there are hundreds at this point—do not constitute distinct knowledges of his genitals, but rather they represent not-knowings as appreciations of impairment, of difference and of Lobel himself. Throughout *Ball and Other Funny Stories About Cancer*, as well as within “L’intrus,” we can appreciate the full impact of disorientation on the experience and meaning of bodies and especially disabled bodies.

**H. Conclusion**

This chapter has addressed the proximity of disability and disorientation through a variety of modes of lived experience. Thinking disorientation through Ahmed and Kumari Campbell, I approach it as a being “thrown” in (one’s) relation to the world that entails the exposure of multiple and often contradictory orientations. Each of these modes (disappearance, dysappearance and dysorientation) articulates a different relation to impairment/disability in which it is either not known or does not “make sense.” Rousso’s discussion of leaving home provided a substantial starting point for this work, as she frames leaving home (traditional, conventional, habitual relations and locations) as a necessary first step in relating to disability differently. Leder’s formulation of dysappearance presented a somewhat problematic account of the body’s absent presence within embodied experience. Paterson’s and Hughes’s application of
dysappearance to lived experiences of impairment illustrated disability or disablement as the dysappearance of bodies affected through social interactions via structural as well as temporal norms. Finally, I used Nancy’s and Lobel’s work to complicate Paterson’s and Hughes’s understanding of disorientation by rendering it as not only an experience of an individual body’s relation to society but also as an embodied relation of the body to itself. It is here that Nancy’s and Lobel’s emphasis on proximity and touch force a return to the questions of home and specifically the body as home that began this chapter.

How and where do impairment and disability touch? This chapter answers this question by emphasizing the sense of relatedness of bodies and the world that emerge in and through disorientation. Building on Yardley’s definition of disorientation, I have demonstrated a variety of ways in which one may feel uncertain in relation to his or her environment but also to himself or herself. Lobel, for instance, comes to live in his disorienting body specifically through the ways that other people appreciate him and his body. His (literal and figurative) play on appreciation therefore is a commentary and demonstration of not only what it means to be disoriented but also how to live with disorientation. Lobel is not trying to "live strong" but lives his body in a mundane way by delighting in (points of) contact between bodies—his own and those of others. The importance that Lobel and Nancy give touch and connection offers a way to appreciate impairment/disability beyond accommodation, tolerance or empathy. Through their non-sentimental writing of bodies, Nancy and Lobel present alternative corporeal relations to Leder’s dysappearing body. They, like Rousso, write bodies that are governed by “the law of intrusion” for which difference and strangeness are generative of meaning. Specifically, their treatment of the medical profession dismantles the medical/social dichotomy through which disability/impairment is typically understood, at least within disability studies. Not every doctor
or nurse in Lobel’s or Nancy’s work is named, but neither are they depicted as objectively removed gatekeepers of knowledge. Instead, Lobel (literally) dances with them, and they remain figures whose proximity give his body and self new meanings. Although their appreciations may have been Lobel’s first, they are certainly not the last. Likewise, though Nancy’s doctors are unable to explain why his heart fails, he insists that they are forever implicated in his being. Being disoriented, then, is being in relation but more than this is a being in relation to or being-with, which is always already exposed. Exposure to relation is disorienting. This is the value of *An Appreciation*; it ensures that the pause between orientation and disorientation, like the points of contact between bodies or knowledge and not-knowing, is productive, open and welcoming.

In the chapter that follows, I continue this discussion of disorientation and openness through an analysis of pause moments within disorienting encounters with disability. I suggest that these moments specifically expose the difference between different types of orientation and appreciation and also the ways they are not separate from each other.
IV. THE ETHICS OF DISORIENTATION

How will our intimacies reflect...the selves we are becoming. (Rowe 23)

My body assembles in relation to yours, in this /moment, in each moment, in our contact attention. /Your body assembles in relation to mine, this touch an anchor, a center... (Kuppers 2011)

A. Chapter Summary

If nothing else, my discussion thus far demonstrates that both orientation and disorientation influence the paths we take as well as our appreciation of “here and now.” However, my analysis does more than this. Locating disability at/as a crossroads demands an appreciation of impairment/disability as a conclusion one reaches about bodies—his or her own and those of others—but also as a starting point of embodied meaning. My articulation of disability as and in relation to disorientation and my analysis of the ontological status of disorienting encounters with disability in the previous chapter achieve several important things. First, it describes the disabled body and more specifically disabled embodiment as a lost and not-yet home animated by uncertainty. Second, it articulates the disorientation(s) experienced in relation to disability as the lived experience of turning and being turned (around) by the people and things that typically help us find our way. Third, it emphasizes that insofar as meanings and experiences of disability emerge in and through disorienting encounters, they do so by opening up and leaving us open to the strange relations between bodies, embodiments and the world. Moving forward, this chapter demonstrates that such an openness not only describes the ontological status of disorienting encounters but also their ethical implications. The ethical implications of disorienting encounters with disability, broadly speaking, involve the bodily, embodied, and social worlds within and for which experiences and meanings of disability matter. That said, by ethical implications—or, more generally, ethics—I am not referring to prescriptive
norms, rules or codes of conduct from which or towards which orientations should unfold. Rather, here, ethics entails a concern for and ongoing interrogation of how meanings and experiences of disability emerge in and through disorienting encounters and also a concern for the variety of ways in which they do so. Ahmed emphasizes this sense of ethics in relation to disorienting encounters, “The point,” she insists, “is what we do with such moments of disorientation, as well as what such moments can do – whether they can offer us the hope of new directions, and whether new directions are reason enough for hope” (Queer Phenomenology 158).

This chapter describes the ethical implications of disorienting encounters with disability by emphasizing the possibilities and possible meanings that they open and leave us open to, but more than this, I explore opening or openness as an ethical relation that is only possible in and through disorienting encounters. I begin by articulating the ethical question of disorienting encounters as, first of all, a question of touch(ing), being in touch and being open through the somatographic/philosophical writings of Harriet McBryde Johnson, Margrit Schildrick and Roxanne Mykitiuk and Rosalyn Diprose. With this in mind, I take up the sense of home and of disabled embodiment as a place of home as it unfolds in Riva Lehrer’s “Golem Girl Gets Lucky.” Here, the body and the body as home are presented as a space that is and must be shared. This discussion complicates as well as compliments Kumari Campbell’s and my own articulation of disorientation by shifting its domain from ontology to ethics. Then, I put Derrida’s formulation of ethics as hospitality in conversation with accounts of the promise and problems that questions of openness raise for issues and experiences of impairment/disability. Ultimately, this chapter demonstrates that disorienting encounters have ethical importance because they demand we remember not simply that “my” orientation is always one among many and always
already only "my own" but also, and at the same time, because this describes a prolonged or persistent sense of disorientation.

B. **Appreciating Encounters**

Disorienting encounters with disability call orientations towards disability, one’s own and those of others, into question. In doing so they open and sometimes leave us open to alternate ways of knowing and being in relation to disability. At the same time, they open and sometimes leave us open to experiences of not-knowing as a way of being in relation to disability. If, as Kumari Campbell demonstrates, the "lived experience of facing two directions" describes the ontological dimension of disorientation and particularly the disorientation of disabled embodiment, then the question and question-ability of openness—of being open and, sometimes, remaining open—describe the ethical implications of this experience and, further, the ethical demand of disorienting encounters with disability. Attending to the question(s) and question-ability of openness for and within disorienting encounters with disability provides a different way of appreciating what such moments do and what we can do with them. Disorienting encounters do not simply expose meanings and experiences of disability here and now; they interrupt them. This interruption, even in the most mild moments of ontic disruption, opens up a space in which to account for or give an account of those meanings as well as for thinking or rethinking meanings and experiences of disability. Simultaneously, they open up the possibility of regarding and valuing disabled people differently. That said, this (sense of) openness is not always welcomed and can in fact be problematic for many reasons and on many levels. In this chapter, I focus on the ethical implications of disorienting encounters in terms of how disability is known and not known and, in particular, how these encounters involve and invoke questions of openness—openness towards what disability does mean as well as to what it could mean.
The ethical implications of disorienting encounters with disability does not simply entail questions of what can or should (or even must) be done with bodies labeled and lived in proximity to impairment/disability. Rather, experiences of disorientation and disorienting encounters open and sometimes leave us open to different questions and particularly different questions of difference. For instance, how does one live in and through disorienting encounters (with the world, with the self and with others) when he or she, as Lobel puts it, "appreciates" that meanings and experiences of bodies—and our relations to and with them—are always situated and that these situations are always already changing?

Building on my discussion of Ahmed’s analysis of orientation and Leder’s formulation of disorientation, I describe the ethical implications of disorienting encounters with disability in and through the experience and sense of strangeness and strange relations that disorienting encounters entail. Specifically, I argue that the disorienting shift of body and world from foreground to background has ethical implications in addition to—and also because of—its ontological implications insofar as the experience of turning and being turned is simultaneously an experience of being with and open to the world and others. Ahmed’s analysis of disorientation as an experience of our relation to the world highlights this experience. "Sometimes,” she writes, “disorientation is an ordinary feeling, or even a feeling that comes and goes as we move around during the day” (*Queer Phenomenology* 157). What makes disorienting encounters, and particularly, disorienting encounters with disability, both ontologically and ethically significant encounters is that they are simultaneously and paradoxically fleeting and prolonged. The everyday ebb and flow of orientation and disorientation goes unnoticed except in moments when it does not. These moments are characterized by the uncertain relation of bodies and world and by the movement of each (and both together) from the background to the foreground of
experience in and through moments of disorientation. This relation, or rather our experience(s) of this way of being in relation, is strange. Earlier, I described this strangeness as an ontological aspect of what it means to be disoriented. Here, I demonstrate that this strangeness also characterizes the ethical relation to ourselves, the world and others that is disclosed and through disorienting encounters. Despite, or perhaps because of, the unpredictability of disorientation and disorienting encounters, this sense of strangeness never ceases to be strange even if it is or becomes an ordinary feeling.

Ahmed illustrates the unpredictability and persistence of disorientation through an example of being distracted while concentrating on reading a paper. As we focus, she explains: “the edges of the world disappear as you zoom in. The object …becomes what is given by losing its contours” (*Queer Phenomenology* 157). Here, both one's body and the world participate in background disappearance. In fact, the more intently we focus on what is in front of us, the more cut off we are from the world and our bodies as the object of attention becomes the whole world. Somehow, this experience of concentration does not in and of itself feel alienating. “Then,” Ahmed continues, “behind you, someone calls out your name” (Ibid). Suddenly and without warning, the world and our place in it rushes to the foreground of attention and perception. Without thinking we turn (our attention and perception) away from the paper to see who is behind us and what it is they want. In and through these movements, Ahmed asserts, “you move out of the world, without simply falling into a new one” (*Queer Phenomenology* 157). She characterizes this turning as an experiential and ontological shift and as the “making present of something that is now absent (the presence of an absence)” (*Queer Phenomenology* 158). This absent presence has (at least) two elements. What becomes present and simultaneously no longer absent is our embodied presence in the world of others and the intensity of embodied orientation
such that an interruption of our attention can produce such disruption. "You blink," Ahmed continues, "but it takes time for the world to acquire a new shape" (Ibid).

In the final pages of *The Absent Body*, Leder argues that “the notion of the lived body can give rise to important social and ethical implications” (156). The lived body is always already implicated in its own experience(s) and meaning(s) through its encounters with and relations to itself, other bodies and the world. This, for Leder, means that experience(s) of these encounters and the sense of relations and of being in relation that they reveal describe and hopefully inspire an “embodied ethics” that he identifies as an “ethics of interconnection” (160). Leder’s formulation of this ethics extends his thinking of bodily absence and presence to one’s embodied relation(s) to the world and others. Also, though he does not emphasize this point, Leder’s discussion of ethics reflects his understanding of dysappearance. Dysappearance entails the self-presencing of an otherwise absent body. This, at least potentially, brings about experiences of alienation and a sense of being cut off from one’s own body and from the world. If this is so, he reasons, then the absent body that dysappearance interrupts must, in part, entail an ongoing (yet unnoticed) sense of being a part of the world or an experience of interconnection that in turn describes (and demands) ethical relations.

Leder’s description of this ethics emphasizes the (sense of) openness that simultaneously characterizes and is brought about by experience(s) of compassion, absorption and communion (156-176). Although each of these modes of experience is significant for Leder’s project, the second mode—experiences of being absorbed in or by one’s relation(s)—is particularly important for this discussion of the ethical implications of disorienting encounters. Leder illustrates the experience of absorption and its ethical implications through a storied account of walking through a forest. In the first iteration of this thought experiment, Leder (his body,
anyway) is already in the forest, and yet his attention is elsewhere. "I am not," he tells us, “attending to my world in a bodily or mindful way. I am caught up in my own worries...dimly aware of the sights and sounds of nature...the landscape neither penetrates into me, nor I into it" (165). This, he asserts, is how we typically move through the world. We move in proximity to people and things without thinking or, rather, while thinking about something else. Being self-absorbed—fully immersed in our own orientation(s)—describes in part the experience of cutting ourselves off from here and now in order to attend, as Leder does, to the past or simultaneously to the future. As he moves effortlessly through the trees, something changes. This change reflects but also brings about an “existential shift” (165) that describes a profound disorientation.

Rather than describing this experience of disorientation as unfolding at “another time,” Leder emphasizes that it comes about in and through his prolonged exposure to and encounter with the forest. He writes:

> through the rhythm of my walking, the calmness of the scene, my mind begins to quiet. Something catches my ear - the trilling of a bird. I glance up in time to see the bird hopping from branch to branch, its bright colors shining in the sunlight. I gradually become aware of other birds, other songs, and, as if awakening from a dream, realized that I stand in the midst of a wild chorus. (165)

This is what disorienting encounters with disability do. In and through them we “awaken,” however briefly, to our being “in the midst of a wild chorus” of experiences and meanings of impairment/disability. This is an “awakening” to our already being “in the midst.” “At such times,” Leder continues, “we truly become absorbed in our world” (164–165, emphasis in original). His articulation of absorption as a way of being in and relating to the world and things around us parallels and extends my earlier description of orientation and disorientation. I have already shown that disorienting encounters and experiences of disorientation cannot simply occur within or last for a moment but instead can be prolonged by persistently shaping and being
shaped by subsequent encounters and our ongoing embodied encounters in and with the world. What Leder demonstrates is that this prolonging or persistence opens up the possibility of thinking about, and thus relating to, the world and our place in it differently.

To be clear, it is not just “for some reason” that Leder (finally) notices the first bird and in turn the extended world (and beauty) of the forest. Similarly, it is not, or it is not simply, that the world appears or presents itself to his embodied perception. Rather, as he insists, the disorientation of absorption unfolds in and through the experience of finding oneself within and already being (relating as well as being related to) with the world and others. In this respect, absorption stands in contradistinction to his account of dysappearance as alienation. Rather than feeling “cut off” from itself or the world, the absorbed body is connected to and, importantly, feels its connection (relation) to itself and to the world. “Such moments,” he writes, “have an ecstatic quality, bringing a feeling of joyful release…we feel the leaping beyond constriction, the spaciousness of our extended body. We register our flesh and blood chiasm with the world” (166). In other words, unlike dysappearance, which for Leder alienates us from our body and the world, absorption puts us in touch with and lets us feel connected to our bodies in the world in a way that might otherwise go unnoticed.

In his articulation of being absorbed, Leder repeatedly references being “open feelingly” to the world and others. Although this sense of the world and our place it in could at least potentially present itself to anyone at any time, my discussion of ontic disruption suggests that disorienting encounters do not always have this effect. Leder acknowledges this reality and provides an interesting explanation as to why some encounters are disorienting for some people while others are not--or at least not for everyone involved. “For most of us,” he notes, “the extent to which we can open feelingly to the world depends upon the world in which we find ourselves”
He illustrates this point by comparing the serenity of his woodland scene (where it is easy to become absorbed) to the hustle and bustle of a busy urban setting (where absorption would be more difficult). Leder’s description of being absorbed has interesting implications for disorienting encounters with disability.

Disorienting encounters with disability are those moments when we suddenly and inexplicably notice that we are in the midst of a chorus of ways of knowing and not knowing impairment/disability. Also, these moments are at least potentially moments in which we notice that bodies and embodiments—one’s own and those of others—are explicitly shaped by ableism. The force of ableism and ableist orientations is such that we find ourselves absorbed in an ableist world despite and also because of our non-normative body and embodiment. Regarding absorption as a mode of lived experience means understanding that disorienting encounters which disrupt and thereby render explicit one’s involvement (or lack thereof) in the world as an always already ontological moment and ethical encounter. In his conclusion, Leder calls us to take seriously the presence and absence of these sorts of disorienting encounters in everyday life. “We need to cultivate,” he argues, “a world that encourages our involvement” (167). Doing so will provide a way of both marking the boundaries of one orientation and another and also of accounting for the limitations of each. And, at least potentially, it provides a way of relating to one another, our orientations and our disorientations differently. This is the ethical demand of disorienting encounters as well as their promise.

The ethical status of disorienting encounters with disability, like their epistemic and ontological implications, is a matter of relation. Here, being ethical means being open to the relation(s) that disorienting encounters open for us and expose us to. The somatographic narratives of disorienting encounters with disability that I have addressed thus far demonstrate
that disorienting encounters can indeed expose existing meanings and experiences of disability as well as offer or open (us to) new directions—ways of knowing, being and relating to disability. However, this offer(ing) does not imply a resolution of either the “problem” of disability or the experience of disorientation. In this chapter, I argue that resolution is not the point. Here, as in the previous chapter, disorientation describes a way of being or being or being-in-relation to meanings and experiences of disability as well as to bodies and embodiments labeled and lived “at a crossroads.” This includes one’s own. What makes disorienting encounters ethical moments is their unpredictability: we, disabled and nondisabled people alike, do not know when, why or by what we will be disoriented, but we do know with absolute certainty that such moments will happen again. This also means, we know, that oppressive orientations towards disability and disabled people go and will continue to go unnoticed despite our best efforts. In other words, the ethical character of disorienting encounters comes from their revelation of current and potential experiences and also their opening (in us) a sense that our particular orientations and disorientations are always already implicated in these moments and whatever comes after them.

In this respect, I agree with Ahmed’s assertion that what matters in these moments, and why these moments matter is "what we do with such moment of disorientation, as well as what such moments can do—whether they can offer us hope for new directions, and whether new directions are reason enough for hope" (Queer Phenomenology 158). I believe that these moments indeed do something, and because we can do anything with them, there is a reason for hope. That is to say, even though we live in a world and in bodies organized according to rather persistent narratives of disability (the idea that people using white canes do not buy televisions, for instance), these notions can be and are question-able. Thus, disability can come to mean something—or something else—only in and through disorienting encounters. Here, I am
reminded of Brian Massumi’s definition of hope. Masumi articulates hope through the affective work it performs. Hope is important, he contends, “because it…isn’t really settling for less. It’s not exactly going for more, either. It’s more like being right where you are—more intensely.” (“Of Microperception”) Thus far I have shown that this is precisely what disorienting encounters do: they make each of us intensely aware of where we are and aware that where we are is in the world, in bodies, in space, in society, in motion and, most importantly, in relation. In this chapter I describe this awareness and the openness that it implies and demands as the ethical relations implicit in disorienting encounters with disability.

1. **A bit weird…profoundly beautiful**

Disability rights lawyer Harriet McBryde Johnson explores the ethical implications of disorienting encounters with disability in her essay “Unspeakable Conversations.” Her account affirms what I have already said: disorienting encounters with disability involve and invoke multiple orientations (towards bodies and the world) as well as experiences of being disoriented (by bodies and the world). However, her account also extends my analysis of disorienting encounters by emphasizing their ethical implications with regard to what disability means and also how we relate to impairment/disability and people with disabilities in moments of disorientation. In the spring of 2002, McBryde Johnson met with ethicist Peter Singer on the campus of Princeton University. He invited her to discuss the disability rights perspective on end-of- and right-to-life issues in a presentation before his class and in a public forum. Singer had come to the attention of the disability rights movement through his argument that severe cognitive impairments can diminish or negate personhood and that in turn it is ethically permissible to terminate disabled fetuses in utero. In contrast, the lecture and debate allow McBryde Johnson to present the view that disability does not negate personhood and that
reliance on caregivers or medical and rehabilitative technologies need not limit an individual’s quality of life. At the moment, I do not want to enter into this highly controversial debate. Instead, my interest is in her published account of this event and the number of disorienting encounters she describes. In particular, I am intrigued by her illustration of encounters in which meanings of impairment/disability unfold through disorientation but do so very explicitly as (an) orientation. Her account articulates the ontological dimension of disorientation as always already ethical. Put another way, her essay offers the occasion to think of disorienting encounters with disability as ethical moments.

Like many somatographic narratives of disorientation, McBryde Johnson’s essay is animated by multiple uncertainties. Interestingly, she frequently articulates this uncertainty through hesitation. When first meeting Singer, for example, she hesitates to shake his hand and wonders about the uneasy crossroads of social justice and etiquette. Later, when he describes the sadness of a disabled child watching her friends run and play on the beach as an example of the diminished quality of life that comes with disability, she takes a moment to decide whether she should point out that in her youth she was that child on the beach, and as best she can remember, she had a lot of fun even though she did not run alongside her friends (6). She hesitates for fear that this detail will personalize her story in a way that will potentially weaken her point. Finally, she responds to Singer’s invitation to speak at Princeton with “an immediate maybe” (5). The hesitations that ensue during the planning phase of this trip also concern meanings of disability, specifically in terms of knowledge and know-ability. There are questions of what kinds of accommodations she needs and, immediately afterwards, questions of whether or not she really needs them. Meanwhile, she is unsure whether or not this trip is a waste of time. Some of her friends in the disability rights movement discourage her from giving Singer yet another
opportunity to share his views while others are adamant she should go precisely because his views already receive so much time and attention.

McBryde Johnson’s “immediate maybe” is motivated by her acute awareness of the proximity between disability and disorientation. She quickly identifies disorientation as a source of disability discrimination. McBryde Johnson uses a powered wheelchair and freely acknowledges that in social settings, “most people don’t know how to look at me.” (2) For her this is a matter of time in the sense that people with degenerative impairments like hers have only relatively recently begun living into adulthood and entering public space en masse. She is tentatively generous to these nameless strangers and admits that “it is natural enough that most people don't know what to make of us” (2). However, her generosity towards this sort of disorientation only goes so far. No, she explains, she is not particularly courageous for going to the grocery store. No, she is not in constant physical pain and in fact enjoys her life quite a bit. Importantly, she recognizes that the disorientation that emerges in these moments exists in the relationships between herself and these strangers and that it is mostly the result of a clash between their expectations informed by orientations towards disability and her appearance (how she looks as well as her presence). Often, she takes a moment to educate strangers on the value and values that make her life meaningful. More often than not, this is unproductive. “They don’t want to know,” she writes, “that they’re confused, that they’re really expressing the discombobulation that comes in my wake” (3). What McBryde Johnson calls “discombobulation” here is easily recognizable as what in the previous chapter I call disorientation and perhaps also as dysorientation. More importantly, this comment gets to the heart of why disorienting encounters with disability have ethical implications. As her account
demonstrates, the ethical implications of disorienting encounters entail epistemic and ontological openness.

While McBryde Johnson’s and Singer’s time together yields many examples of disorientation, two of the most compelling moments concern the coming together of multiple meanings of disability and of actions that might unfold in accordance with these meanings. In recounting these moments, McBryde Johnson repeatedly considers and asks readers to consider what does or might a particular (course of) action mean for disabled people, for everyone else and for the future. After her lecture Singer takes her for a walk along a route including a lack of steps and steep slopes, which makes it seem planned in advance. As they move together, their talk turns to a story McBryde Johnson told to Singer’s class of a girl she knew as a child. The young woman in question was in what today would be considered a persistent vegetative state. She was entirely dependent on her family for care, and yet she was such a part of the family and community that neighborhood children would spend time with her in her home while enacting, as McBryde Johnson puts it, “their unconditional love” (9). Singer seems intrigued by this story, as it directly addresses issues of caring for severely disabled individuals. As they travel, he suggests that if the girl’s doctors and family know with absolute certainty that she will forever be unconscious, “don’t you think continuing to care for that individual would be a bit—weird?” (9). Surprised but not shocked by his question, McBryde Johnson replies that “on the contrary, done right, it could be profoundly beautiful” (Ibid).

This exchange is important for this chapter’s discussion of the ethics of disorientation and to this project as a whole for several reasons. First, we can identify (at least) two distinct and contradictory orientations towards disability that are in part shaped by embodied perspectives. Second, it demonstrates that disorienting encounters with disability emerge within contexts and
conversations in which “disability” is already present—where its meaning(s) are known (and known well), and yet through the sudden presencing of absences (or the co-presencing of multiple orientations), it is disorienting. Third, this exchange reminds us that the difference between “a bit weird” and “profoundly beautiful” unfolds within and between the intimate distances of orientation and disorientation. Singer’s pause speaks to the uncertainty and transformative potential that disorienting encounters open up for meanings and experiences of disability. He does not—at least not explicitly—impose his view but rather pauses and asks a question about disability. Even if he pauses in order to find the right words to express his interpretation of the situation or to do so in the most polite manner, Singer’s pause is still a searching and an expression of turning and being turned by disability in an effort to find his way.

McBryde Johnson’s essay does not only focus on the space(s) and time(s) she shares with Singer; she also tells a story of them sharing a touch. During a dinner with Singer and his colleagues, the arm that McBryde Johnson uses to hold herself up slips. Rather than simply asking for help from whoever is sitting on her right (Singer) as is her custom, she hesitates. In this moment she weighs the pros and cons of asking him for help. The stakes are high: she has spent the day arguing that disability does not diminish quality of life to a less-than-thoroughly convinced audience, many of whom are now sitting around the table. And he is, after all, Peter Singer. Her simple request could ruin everything. Nevertheless she asks, and he obliges. When she returns home, many of her comrades in the disability rights movement are furious that she would ask his assistance. In the end, McBryde Johnson hopes that this incident will help make her point rather than his. The particularities of an impaired body may lead one to ask for help from a non-disabled person or even from Peter Singer. But rather than diminishing personhood,
she emphasizes that this assistance (the asking as well as the giving) make it possible for them to continue sharing a meal, to keep engaging in rigorous debate and to coexist in a meaningful way.

I begin this chapter with McBryde Johnson’s illustration of the ethical implications of disorienting encounters with disability because it demonstrates that disorienting encounters and their ethical implications always already entail abstract and embodied meanings of disability that pre-exist moments of disorientation. Yet, they are nevertheless called up and called into question in these moments. McBryde Johnson's essay also demonstrates that disorienting encounters are touching moments. That is, they often involve and are involved in moments of physical contact as well as being “touching” with respect to affectivity and ontology.

C. Disorienting Encounters as Ethical Moments

In Corporeal Generosity, Rosalyn Diprose gives an account of the lived experience of disorientation that simultaneously articulates the ethical dimension of disorienting encounters. “Something,” Diprose writes, “gets under my skin, something disturbs me, something elates me, excites me, bothers me, surprises me” (132). Building on my earlier analysis of the strangeness and strange relations of disorientation, I demonstrate in this chapter that what matters in these moments is that “I” am moved and that something moves “me,” but—and this is crucial—“I” am not moved by the particular person or thing I encounter but instead through the encounter itself or the strangeness that it opens and leaves me open to. In the previous chapter, for example, Manning is not “thrown” by what he bumps into but rather by the different way(s) of relating to his body, his embodiment and the world that this encounter opens up. Likewise, Lobel is not disoriented by his ex-lover’s presence, the man’s strange glances or the intimate proximity of their forearms. In fact, each of these elements "makes sense." Instead, Manning and Lobel experience disorientation as an exposure to a sense of the world that still makes sense and yet is
different than what they had previously known or imagined. In this regard, it is important to consider the ethics of disorientation (and orientation) as an ethics of openness and touch. Appreciating meanings and experiences of impairment/disability as and in relation to orientation and disorientation has an ethical significance that grounds but also goes beyond consideration of any particular encounter.

Grigely provides a similar assessment of the lived experience and ethical implications of disorientation. Reflecting on the uncertainty he commonly observes when he asks hearing people to write messages to him, Grigely argues that disorienting encounters with disability in particular have the potential to “reveal the ways we [disabled and non-disabled people] share space, and how one cannot predict the conditions under which this sharing might manifest itself.” (“Beautiful Progress”) Significantly, Grigely does not suggest that these encounters encourage or generate a (sense of) sharing but rather that they “reveal” that, and how, the spaces occupied by disabled and non-disabled people—along with their ways of being and being-in-relation—are always already shared. “When I ask someone,” he explains, “to write down what they are saying...that person, not me, is ‘disabled’ by the encounter.” (“Beautiful Progress”) Admittedly, the hearing person in this situation meets neither medical nor legal definitions of impairment or disability. Grigely’s point is that these moments destabilize the customarily taken-for-granted certainty and certain relations that characterize non-disabled people’s orientation(s) by demanding that they must think about or rethink their way(s) of being in the world and their way(s) of relating to others. Equally important here is Grigely’s reference to the unpredictability of these encounters. Just as we cannot know with certainty whether or not an encounter will be or become disorienting, we cannot know where a disorienting encounter will lead. There is, Grigely
insists, “an awkward beauty in this unpredictability, because it also has a way of bringing out the possibilities of the human imagination.” (“Beautiful Progress”)

It is no coincidence that Diprose’s and Grigely’s descriptions of disorienting encounters are immediately followed by or implicitly entail assertions of their ethical significance. The ethical dimension of disorienting encounters, I argue, lies precisely in experience(s) of turning and being turned around, or in the (sense of) being and being left open to different ways of knowing impairment/disability or in not-knowing as a way of being in relation. The questions and question-ability that these encounters raise with regard to our (sense of) openness with others and in relation to other ways of knowing and being demand and accountability for our orientations and ultimately a different account of difference.

This ethics of openness and touch is nothing new. First, it is in keeping with my articulation of disability and disabled bodies at/as a crossroads. Rather than worrying about how to get out of or away from moments that reveal and generate experiences and meanings of disability, this ethics is concerned with the relations that these encounters expose and the differences or different subjects that they constitute. Second, versions of this sort of ethics are articulated within post-structural thought as well as feminist and post-colonial theory and disability studies. This ethical thinking of encounters is called on and called for within disability studies but also within somatographic narratives of disabled people. Here, these encounters unfold through and in relation to moments of touch. Recall, for instance, that Jenny and Manning each bumped into something with their canes, Linton was “touched” by her encounter on the street and Lobel was touching himself. It is precisely in and through these various moments and modes of touching that they and we are exposed to or put in touch with a variety of meanings of disability and the possibility that it could mean something else. Approaching encounters with
disability in this way, through what Margrit Schildrick and Roxanne Mykitiuk call “postconventional ethics,” is different from thinking about these moments and about ethics in terms of norms, morality or what should be done. Diprose concedes that “even if we grant that ethics is about moral principles and moral judgments, it is also about location, position, and place. It is about being positioned by, and taking a position in relation to, others” (18).

Bodies and embodiment are crucial factors in the locating and positioning at issue in this ethics. Here, I am also mindful of Schildrick’s and Mykitiuk’s assertion that “bioethics is out of touch with bodies themselves” (2). By this, they mean that bioethical—and I would add general ethical considerations of issues related to impairment and disability—tend to begin by regarding it as something about which something must be done. From here, ethical debates focus on what should be done to bodies and why. In contrast, Schildrick and Mykitiuk call for an “ethics of the body” or an “ethics of touch” that would “problematize the hitherto unchallenged certainties of binary thinking” (2). Specifically, they apply this conceptualization of ethics to ethical issues related to disability and impairment. Their essay lends support to what I have been saying from the outset of this project about the benefits of thinking disability through orientation and disorientation. Applying “post-conventional ethics” to disorienting encounters with disability allows for and demands a richer consideration of the encounters themselves rather than an emphasis on what is, or should or can be done in them. On the contrary, as they write, this ethics emphasizes “that things could always be otherwise, and that the answers we give ourselves—often the basis for far-reaching actions—must never be allowed to settle, to take on the timeless mantle of absolute truth or moral rights or universality” (9). As stated earlier, experience and meanings of disability unfold in and through disorienting encounters with disability as or at a crossroads; what we need, then, is an ethics that similarly unfolds in and through particular
moments and also includes, as Schildrick and Mykitiuk affirm, “an acceptance of proportionality, instability, and multiplicity, and an awareness that the task of ethics is never finally done” (9). In this chapter, I take their argument as a point of departure for appreciating the ethical implications of disorienting encounters with disability. I do this not by focusing on what should or must be done in a specific encounter but rather by questioning the possibilities of meaning conditioned as well as opened by different encounters.

D. Returning Home

McBryde Johnson’s essay demonstrates that encounters with disability are animated by a multiplicity of orientations and disorientations and also that these orientations and disorientations play out with abstract and very concrete consequences in the everyday lives of disabled people. “Unspeakable Conversations” illustrates that meanings and experiences of impairment/disability always already unfold in relation to other experiences and other meanings. The crossroads of impairment/disability and the “lost” and “not yet” home of disabled embodiment is not so much a place that disabled people make our way to, even if it is a place we make our way from. Rather, it is a space that we find ourselves turned or re-turning to in and through disorienting encounters. As Schildrick and Mykitiuk describe it, being “in touch” with “bodies themselves” entails awareness of and attention to the ways that bodies—and specifically meanings and experiences of disabled bodies—are made or made meaningful in and through the intimate distance of encounters, physical and otherwise. Although the previous chapter addresses this ontologically, questioning what it means to be disoriented and in turn to be disabled in this chapter focuses on the ethics and ethical implications of disabled embodiment and its emergence in and through disorienting encounters. How does one live (in, with or as) a body whose question-ability opens and leaves them open to disorienting encounters with disability (within as well as between bodies
and the world)? This is the question that must be asked (continually) when impairment/disability is understood as and in relation to orientation and disorientation. The short answer, which I expand in this chapter: carefully.

Appreciating the ethical implications of disorienting encounters with disability requires returning to the question of home and particularly of the body as home. Being careful describes the lived experience of living-with a prolonged or ongoing (sense of) disorientation. As I suggest earlier, people with disabilities—many of them anyway—are well aware that the appearance and presence of impairment/disability is or can be disorienting for and to themselves and others. This awareness that bodies and lives labeled and lived in and through disorienting encounters often requires and sometimes inspires being careful. Here, being careful does not simply refer to the exercise of caution when interacting with others but also describes a sense of and responsibility for the ways(s) that meanings and experiences unfold in and through shared moments and spaces. This, I believe, calls for a slightly different sense of the body and of the disabled body as a place of home. Artist Riva Lehrer illustrates this way of being in and this relation to bodies, embodiments and space in her recent somatographic narrative, “Golem Girl Gets Lucky.”

Lehrer’s work addresses the uncertainty and unpredictability of disabled embodiment through accounts of being at, leaving and returning home. Through these stories she depicts a (sense of) home and of the body as a (place of) home that is always already shared and shaped by different bodies as well as notions of what disabled bodies can and do mean. “Most days,” she writes, “my building’s gauntlet of security gates and doors grants me sanctuary. Each one that closes behind me lets me drop another defense. But not today; today I’m not alone” (231). Lehrer’s account of the journey from the sidewalk to her door is brief—less than two pages—and yet she describes a prolonged and tense encounter. This tension is more than first-visit jitters. For
her at least, it is brought on by a sense that this presumed next step in their relationship is perhaps a step too far. Opening her home to this other person and sharing her space with her is not easy. Lehrer resigns herself to the vulnerability and ongoing disorientation that the moment demands. They stand, together, at the threshold of Lehrer’s home. “The last twist of the key,” she writes, “and we’re in” (232). Before going inside, she turns to look at her companion to gauge the mutuality of their uncertainty or for some semblance of resolution. Neither is possible. “Oh, wait. No, we’re not. Where did you go? When did you go?” (232) Here, the uncertainty of their proximity (physical as well as intentional) dissolves into a certainty that they are, in fact, not even close. The disorientation involved in sharing one’s home or one’s body, and in the experiences of the body as a shared space of home, entails persistent questions of interiority, exteriority and the uncertain shifting of bodily boundaries and embodied borders.

Lehrer’s narrative contrasts with Russo’s in some interesting ways. Whereas Russo is terrified by the prospect of leaving home, Lehrer is afraid her mother will never let her go. “I was,” she tells us, “a frozen child in my mother’s house” (236). Although she literally shares this space with her mother, she also shares it with ideas about her gendered and disabled body. Chief among these ideas is the very apparent notion that she is vulnerable. As a child, being home means being hidden and specifically “remain[ing] unthreatened by the desires of men” (236). This hiding extends beyond the threshold of her home in and through the clothing that her mother makes for her: miniaturized replicas of the older and larger woman's own wardrobe designed (or so she believes) to hide her completely. Although her clothing is gender-neutral, the design of her bedroom is decidedly and insistently feminine. Nevertheless, she notes that, “my gender had a vestigial, dead-end quality. My family assumed that my relationship with a boy was either a hopeless prospect or murkily dangerous” (236). In this way, she lives with and shares her
space with the desires of men even as a child in the sense that she lives-with the threat of them. It is not that her mother is utterly incapable of imagining a future in which she has a relationship but rather only imagines that relationship defined by anything but romance and certainly not sex. “The one great hope,” Lehrer affirms, “was that I’d find a ‘nice crippled boy,’ and we would take care of each other in sweetly platonic fashion” (239).

In another story, Lehrer recounts the experience of going to a (potential) lover’s home for the first time. Here, she quickly notices the differences between this space and her own. “The place I live,” she writes, “is so built to my idiosyncrasies that it virtually wraps itself around my body. Home let me forget myself. Everything fits my scale and my senses” (246). This passage expresses a different sense of home and of the body as home than she knew as a child. Now, being home does not mean hiding and does not require making either her body disappear but rather expresses a keen awareness aware of her bodily needs as well as embodied preferences. She writes: “The furniture is smallish and lower to the ground. The light comes from half a dozen ornate chandeliers, which are oddly practical since they hang low enough that I can change my own light bulbs. There are no rugs, carpets, or any other snares for the unwary on my floor” (Ibid). The new lover's house, in contrast, “is a challenge from the get-go.” Getting to the front door proves just as challenging as moving about inside. The journey to the threshold includes, “three flights of stairs anchored by a very shaky banister.” Once inside, she is confronted by “wall-to-wall shag carpeting that grabs my ankles and nearly throws me across the room” (246). This evening is not going well. When she manages to get further into the apartment, the kitchen seating consists only of backless barstools that are challenging for her to balance on. The wine glasses, which she offers to retrieve, are far out of reach on a high shelf. After dinner they move to the living room, where an enormous couch raises other questions of
where to sit. These questions are not of how she might situate on the couch (though this is an issue) but rather—or more importantly—where the other person will sit in relation to her. If she sits too near the end of the sofa then there is so much more room (and possibility) that the other person will sit farther away. Then again, if she plants herself in the middle, the proximity could be, on the one hand, presumptuous and, on the other, uncomfortable. This is, or so it seems, still early in the relationship. Finding herself confronted by this sort of openness within an unknown apartment during an uncertain evening is, to say the least, disorienting. “For whole moments,” she admits, “I forget to be awkward. True, I am still striving to make shapes with my body that pass for normal. But you're radiating something that is soothing my fears” (247). This sense of being “at home” even in someone else's home inspires her to wonder, finally, “how the pieces of us might find a way to fit together” (247). This sense that her body and other persons might find a way to make sense together is made possible by the openness she perceives.

While she had felt more or less—and usually less—“at home” in her body and with her embodiment for many years, Lehrer remains aware of a sense of the shared space of her home and of her body as home. This sharing is all the more apparent in her account of her first relationship with another disabled person. Finally, she can be in her apartment or on the street and in both places feel at home. Lehrer articulates this (sense of) home through the openness of shared space and the openness that sharing demands. Her bittersweet conclusion brings this sense of home to the fore. “My crip lover,” she writes, “in both senses, you are the first one who ever got me to completely take off my clothes” (250). Ultimately, Lehrer’s sense of the body as a place of home is always already shared with the questioning presence of her mother, the questionable absence of lovers and the absent presence of the ever-shifting relations that define the contours of this space.
E. **Ethics as Hospitality**

Disorienting encounters with disability interrupt us precisely when and because we feel “at home” with orientations towards disability. That is, we are disrupted and disoriented because in these moments we know or think we know what impairment/disability is and who disabled people are and yet they appear to be or to mean something else. More than this, these encounters are ethical moments because they remind us that despite the force of our orientation we are not and have never been home alone. The question then becomes how we relate to this disorientation (the strangeness and strange relations revealed) as well as this other (person and way of thinking/embodying).

Disorientation does not describe an inability to make sense of the people or things we encounter, nor does being disoriented mean that we cannot (ever) find our way (home). Instead, being disoriented means being turned around by the people and things we encounter, being uncertain of our relation(s) to them or being in an uncertain relation with them. This entails an awareness (conscious or otherwise) that our way home and our being at home is and can be called into question. When we find ourselves lost and not yet home we might begin by asking "where am I?" and "how did I get here?" In disorienting encounters with disability these questions are never merely self-reflective nor are they asked in isolation. Instead, these are questions we ask (of) the world (as we examine our surroundings) as well as questions that we ask and are asked by others. In this way, and as I have already said, being disoriented is being questioned. However, I believe that the ethical implications of disorienting encounters begin before any particular question is asked in and through the question-ability of bodies, embodiments and the relations that shape and are shaped by them. Further, my articulation of the ethical implications of disorienting encounters with disability in this chapter begins with the
notion that the question-ability of disorienting encounters is and must be an ongoing interrogation of the relations in and through which meanings and experiences of disability emerge.

The notion of hospitality and particularly the sense of ethics as hospitality that Derrida develops from the ethical writings of Levinas make a significant contribution to this discussion. Although the word hospitality appears infrequently and with little emphasis within Levinas’s work, Derrida insists that the notion of hospitality is central to his project (Adieu 49). Similarly, Mark Westmoreland demonstrates that the question of hospitality occupies much, if not all, of Derrida’s writing on ethics and politics. My analysis of disorienting encounters with disability as ethical moments in this chapter owes a great debt to Levinas’s phenomenological account of the face-to-face encounter as well as Derrida’s articulation of ethics as hospitality. Unfortunately, addressing their work in great detail is beyond the scope of this project. Nevertheless, in this section I briefly outline the philosophical underpinnings of the ethics that inform my analysis of and insistence on disorienting encounters with disability as ethical moments. As I demonstrate above, what makes disorienting encounters disorienting is that they unfold precisely in moments when we are or feel we are “at-home” with the meaning(s) and experience(s) of disability that we know, and then we are not. Suddenly, we are called on by an other (person/orientation). Disoriented, we are turned (around) by the proximity of other bodies and other meanings and by the very possibility of other meanings. An ethics of disorientation needs to provide a way to face (up to) the reality that what is at stake in disorienting encounters with disability is the meaning and meaningfulness of disabled bodies and the lives of those for whom impairment is an everyday part of life. Admittedly, neither Levinas nor Derrida address issues of impairment/disability in their formulations of ethics or of ethical encounters. I include them in
my exploration of the implications of disorienting encounters as ethical moments because they provide insight into how these moments are or might be lived. Further, introducing the question and question-ability of disabled bodies and embodiments into this account of ethics and ethical encounters further describes not only what disorienting encounters (with disability) do but also what we can and must do with them.

For Levinas, the calling into question of one’s being at home is the very definition of ethics (43). Here, being at home describes a naïve, unquestioned and unquestioning way of relating to or being in relation with others. “The face,” Levinas writes, “resists possession, resists my powers. In its epiphany, in the expression, the sensible, still graspable, turns into total resistance to the grasp” (198). The demand that this resistance elicits is not a call to try harder at grasping or mastering but rather a call to relate, to be in relation or to acknowledge and account for the relation(s) that already define us. Building on Levinas’s account of the face-to-face encounter, Derrida understands hospitality not as something mobilized at the moment of an encounter but rather as the description of welcoming or, as he sees in Levinas, of what “to welcome” means. However, this sense of hospitality and of ethics as hospitality is not entirely unproblematic. Ahmed, for instance, suggests that Derrida’s particular rendering of hospitality does not go far enough to hold us accountable to or for who or what we encounter. By putting these formulations of hospitality into conversation in this section, I hope to better articulate the ethical stakes of openness for and within disorienting encounters with disability.

Derrida’s analysis of hospitality as ethics unfolds in and through the experience of being at home when suddenly and without warning someone arrives at the door. As he articulates it, hospitality describes the relation between one and another, between the one who is at home—the host—and the one whose arrival disturbs that being at home—the guest. Although the question
of hospitality applies to the arrival of anyone whether they are a known acquaintance or a stranger, encounters with strangers are particularly compelling. At this moment, in and through this encounter and the relation(s) it calls into question, Derrida discerns two different but interrelated forms of hospitality. The first, which he defines as the laws of hospitality, is conditional and describe codes of conduct or norms of behavior (juridical and economic laws). Mark Westmoreland describes this form of hospitality as “an exchange” between host and guest. “In offering hospitality, in welcoming the other,” he explains, “the host questions and identifies the foreigner…[then]…the host sets restrictions” (2). These laws can and do predetermine not only how a guest should be welcomed but simultaneously where they are welcome and what they are welcome to do. Under this formulation, for instance, a guest can overstay his welcome. This is, in other words, a conditioned and conditional welcome. What these laws of hospitality do, then, is situate self and other as well defined subject positions whose interactions follow well plotted trajectories. Put another way, self and other (or host and guest) do not exist in relation but rather, as Westmoreland notes, they exchange questions for information, goods for services and place for role. Derrida illustrates this through the example of a “code of conduct” that one might have above the bed in a guest room. While guests have already been invited inside when they come upon this list of rules, they are bound for as long as they are guests to abide by this particular set of rules; these rules define their roles as guests and in turn the one who is “at home” as host.

In contrast, Derrida articulates another form of hospitality that he describes as “the law of hospitality.” This hospitality is unconditional and absolute. This, he argues, is the hospitality of ethics, or rather, ethics as hospitality. To be clear, this absolute hospitality does not describe a way of thinking about ethical questions nor is it found in a particular school of ethical thought
but rather, as Derrida insists, unconditional hospitality is “the whole and the principle of ethics” (50). He articulates this sense of ethics much earlier in “Violence and Metaphysics,” where he argues that “ethics” is “without law and without concept” (Writing and Difference 111). We see this lawlessness when, unlike conditional hospitality, one who is “at home” may not and must not ask anything of the one who disrupts their being at home. Elsewhere, in the opening pages of On Touching, Derrida further emphasizes the importance of unconditional welcome when he defines, “a genuine test of hospitality” as “to receive the other's visitation just where there has being no prior invitation, preceding ‘her,’ the one arriving” (1). How can we respond to such an arrival? “Let us say yes,” he urges, “to who or what turns up, before any determination, before any anticipation, before any identification” (Ibid, italics in original). This yes-saying is important; its presence or appearance (its utterance) prior to the appearance or arrival of an other is crucial for ethics as hospitality.

Importantly, Derrida argues that these two forms of hospitality exist in unavoidable and paradoxical relation. “It is as though,” he writes, “the laws (plural) of hospitality, in marking powers, rights, and duties, consisted in challenging and transgressing the law of hospitality, the one that would command that the ‘new arrival’ be offered unconditional welcome” (Of Hospitality 77). That is, according to the law of absolute hospitality, a new arrival must the welcomed inside without question, and yet the questions we typically associate with hospitality (What is your name? How can I help you?) appear as conditions that cancel out absolute hospitality. Encounters between the law of hospitality and the laws of hospitality (disorienting encounters) necessitate a “leap” from the abstract to the concrete or from ethics to politics. But, for Derrida, hospitality is not a response called for in a specific encounter or by a particular
other, but rather it is being welcoming, saying yes and being responsible to or in the context of the unpredictability an other’s arrival.

Ahmed critiques Derrida's formulation of hospitality by describing it as a “forgetting”: a willful forgetting of the positions and positionings or the orientations and disorientations that situate one person “at home” and simultaneously locate the stranger, the other or the guest on the outside of belonging. This is a particularly important critique when applying hospitality to issues of impairment/disability. In a very concrete way, many homes are not welcoming or hospitable to people with anomalous bodies because they are designed with a notion of normative able bodies in mind. Although we cannot ask an other’s name under Derrida's formulation of unconditional hospitality, we can also never ask a more important question: “How did you get here?” To provide a counterpoint to Derrida, Ahmed argues for a hospitality that “remembers” the particularities of and preceding an encounter. Rather than forgetting the questions and question-ability of disorienting encounters with disability, remembering them allows the other to retain his Otherness and simultaneously, leaves me to wonder again and again about my own position and our relations(s).

In the context of disorienting encounters with disability, this might manifest in ignoring or forgetting about ableism precisely as it structures the meaning and experience of impairment/disability and particularly of this disabled body as one’s own or that of an other. Levinas insists that the proximity of the other calls my being at home into question and also that the other or his otherness is always already present. The stranger, as he appears in Derrida’s analysis, appears from somewhere else and so is not only distant but also distinct from me. In the section that follows I highlight a variety of ways that welcoming hospitality emerge in and
through—and as—issues related and relating to impairment/disability. Specifically, I focus on the sense of openness that is central to either mode of hospitality described above.

F. From Etiquette to Ethics

The ethical implications of hospitality—welcoming generosity—are very real and often very apparent in everyday encounters with disability in the lives of disabled people. In this section, I examine the accounts of encounters with disability that illustrate the problems and promise(s) that hospitality brings to disorienting encounters with disabilities. Here, it is worth noting that the disorienting character of disorienting encounters with disability is not simply accounted for or described by the calling into question of my being at home. Rather, it is an experience of being uncertain of my relation(s) to the world and others. What disorients us—each of us—perhaps more than anything else are the repeated attempts to return home as though nothing has happened. Being “in touch” with bodies themselves means being open to meanings and experiences of disability that we do not expect and that sometimes we do not like. This also means being open to the strangeness and strange relations that these encounters reveal. Disorienting encounters take place at the limit—or to use Nancy's phrase, as the limit—between orientation(s) and disorientation(s). Taking seriously the ethical implications of these encounters requires attending to how they open up possibilities of relating to disability and disabled embodiment differently and not, as some ethicists might suggest, resolving them.

Tanya Titchkosky demonstrates the importance and also the challenges of attending to questions and issues of openness as a way of being and specifically being in relation to disability. In the opening chapter of The Question of Access, her analysis suggests in part that the disorienting character of disorienting encounters has or can have more to do with the question and question-ability of openness than with issues of impairment/disability. The book opens with
an extended discussion of Titchkosky’s first few months in the Equity Studies department at the University of Toronto, where she is hired to teach—among other things—disability studies. She notices the abundance of International Symbol for Access (ISA) signs adorning building entrances and washroom doors. Just as quickly, however, Titchkosky notices a problem: few of the entrances that feature this symbol meet legal or even common sense criteria to support their promise of accessibility. Some doorways are not wide enough to admit wheelchair users, others are too heavy and still other doors open onto garbage cans and other objects that block the way inside. Titchkosky’s attempt to undo the (in)exclusion of this situations results in a number of questions. When she speaks with the appropriate university staffer about the inappropriate and useless placement of these signs and suggests removing them, he does not understand her concerns and questions whether or not it really is a problem. “Isn’t something,” he asks, “better than nothing?” (63). For Titchkosky, these signs are "an icon of access" (63) indicating that disabled people are welcome and that their lives and perspectives are valued—in short, that they belong. So, this particular something is in fact much worse than nothing. The presence of persistently misleading signage offers “an ambiguous welcome” (64). This ambiguous welcome can be read in at least three ways. First, the misplaced signs suggest that disabled people are not or are not absolutely welcome. Second, it implies that disabled people (those on the outside but also those already on the inside) do not or do not really belong. Third, the presence of these signs leave open the possibility that disability and disabled people are unwanted by the university, its faculty, staff and students. Through this story, Titchkosky demonstrates openness in a sometimes tense relation between being open to disability and openness more broadly defined. Most importantly, she shows that accessibility and openness are not analogous terms and may in fact
be antagonistic. “Between the issue of access and the perception of disability,” she tells us, “lies an overflow of questions” (7).

This chapter explores the ethical implications of disorienting encounters with disability by examining this overflow of questions insofar as they involve and invoke issues of openness and being open to disability. Here, the ethical question is not one of knowing or not knowing but rather of the openness toward or welcoming of disorientation. Regarding the many questions that arise in relation to disorienting encounters with disability, none is more important than the ethical question(s) of openness: how—not whether—disability and disabled people are understood and valued. Openness is neither deployed nor mobilized in disorienting encounters. Rather, openness describes the relation(s) and relatedness of bodies, embodiments and the world (the horizon of possibilities) that are disclosed (revealed as well as generated) by these encounters. Open is how we find ourselves when we know or think we know impairment/disability and at the same time must acknowledge that this meaning is question-able.

To be clear, disorienting encounters with disability are not or are not simply moments in which openness is called for. They are not instants or instances where one is asked to be open to someone or something unexpected or to different ways of knowing, being and relating to bodies, embodiments or the world. Openness is neither deployed nor mobilized in disorienting encounters. Rather, openness describes the relation(s) and relatedness of bodies, embodiments and the world (the horizon of possibilities) that are disclosed (revealed as well as generated) by these encounters. Open is how we find ourselves when we know or think we know what impairment/disability means and nevertheless know that meaning as question-able.

In her analysis of strangers, or more specifically “the stranger” as a way of knowing others and as a knowable other, Ahmed argues that “the stranger is always a figure, stalking the
streets: there are some-bodies who simply are strangers, and who pose a danger in their very co-presence in a given street” (*Strange Encounters* 3). This argument resonates with my earlier analysis of disability and disabled bodies in relation to orientation and disorientation. That is, disability appears as such (as a known figure or object of knowledge) precisely in and through a variety of bodily and embodied orientations, including those that regard it affirmatively. At the same time, disability or disabled embodiment can present themselves in relation to disorientation as a body or way of being that is or can be understood in terms of lack or alienation. One of my primary arguments in the previous chapter is that disorientation as a lived experience involves the presencing of “strange” relations or the (sense of) strangeness that characterizes the dysappearance of (parts of) the body and its relation and relatedness to other bodies and the world.

In “The Complexities of Giving: People with Disabilities as Help Objects,” independent scholar Rachel Cohen-Rottenberg emphasizes the ethical implications of disorienting encounters by emphasizing the complexities of openness. In particular, she articulates disorienting encounters as the meeting point of multiple and contradictory orientations towards disability by paying attention to the ways that one orientation can overwhelm, shut down or discount another. In this way, she highlights the question of openness but also being open. Cohen-Rottenberg’s story unfolds as she waits at a bus stop “a few weeks ago,” only some months after she begins using a support cane. This detail is significant, as the incident she describes and her analysis of it is shadowed by an awareness that the way she is now treated by nondisabled people is qualitatively different than how she was treated previously. For her, “the cane makes all the difference.” Although she has lived with an impairment for many years and is well aware of the processes and practices of ableism, she is only now becoming keenly aware in situations that are
almost imperceptible. “I was standing,” Cohen-Rottenberg writes, “at the bus stop, holding my cane with my backpack at my feet.” Her story thus unfolds in the non-place while Cohen-Rottenberg herself occupies in a liminal position. She continues:

Next to me was a bench occupied by two people. A young man was stretching out his legs at the far end, and an older woman was sitting up straight at the near end, holding onto her cart of groceries. There was enough space between them for at least two people…After I’d been standing by the bench for a minute or so, the woman looked up at me and said, “Would you like to sit down?” (para 3, 2013)

At first, Cohen-Rottenberg regards this as an issue of etiquette: because the question is asked politely and because she prefers to stand, she politely declines the offer. The seated woman’s response is strange and troubling, and it quickly leads Cohen-Rottenberg to question the ethical implications of this encounter. The seated woman, she explains, “seemed disappointed—and even a little disapproving.” For Cohen-Rottenberg, this reaction, which she describes as “troubling,” is not so much a response to her appreciative decline here and now but is more a moment of disorientation brought about by her refusal to abide by social conventions associated with disabled embodiment.

Cohen-Rottenberg’s description of this moment echoes Kleege’s and Manning’s earlier accounts of disorientation but complicates them through a discussion of the seated woman’s reaction and how it impacts her own sense of embodiment and disability in general. The seated woman’s response is not explicitly described. The moment is “so brief…so apparently simple – and yet,” she tells us, “I was registering a huge amount of discomfort.” Admittedly, Cohen-Rottenberg does not and cannot know with certainty what this woman intended in her offer nor with her “troubling” response. However, it is clear that the woman was, just as Cohen-Rottenberg still is, troubled—or more accurately, disoriented. Something was troubling about this encounter with disability. At first, Cohen-Rottenberg wonders if the woman’s discomfort
involves some breach of etiquette. In retrospect, she decides that the offer was all right, as was her decline. “There was,” she assures us, “already room on the bench. I could quite clearly see the empty space, and if I’d wanted to sit down, I would have. I wasn’t waiting for an invitation or for permission.” So, what is the trouble? For Cohen-Rottenberg, this incident represents a longstanding and widespread orientation towards disability that inextricably links meanings and experiences of disability (as well as able-bodiedness) and at the same time defines appropriate social rules for disabled and nondisabled people alike. This orientation toward disability implies that disabled people need help (charity/generosity), that nondisabled people should help people with disabilities and that in turn people with disabilities should be grateful. From this perspective, “would you like to sit down?” is not at all an act of generosity. Instead, Cohen-Rottenberg contends that both the initial offer and the seated woman’s reaction to its being declined are influenced by the orientation toward disability that does not see her as a (complete) person but rather as a "help object." She explains:

As a help object I was not treated with the presumption that I knew what I needed…I wasn’t a person with an internal experience in which standing was a good thing…I was expected to accede to the other person’s offer so that she would not feel disappointed. Rejecting that offer was akin to breaking the rules of an implied contract I had never signed. (para 11, 2013)

For her, the disorientation that registers as “a huge amount of discomfort” is brought on by an inability, on the part of the seated woman, to imagine or relate to her, as a visibly disabled woman, as anything other than a “help object.” At the same time, she is “troubled” by this interpretation. “I always feel very conflicted,” she tells us, “about moments in which people offer me unneeded assistance.” Here, her feeling conflicted is an expression of and response to the strange relation(s) of being and being left exposed to multiple orientations. In other words, not only is Cohen-Rottenberg troubled by this particular encounter but also—and perhaps more so—
by her recognition of this way of encountering disability. In response to this and similar encounters, she offers three suggestions aimed at non-disabled people for negotiating these sorts of disorienting encounters with disability. First, she advises, “look carefully at the situation to see whether the other person actually needs help.” Second, “respond graciously to a rejection of help;” and third, “consider the impact on the other person.” Her points are meant to encourage non-disabled people to remember and respect that disabled people are autonomous individuals who “like anyone else” are in public most likely in the service of some goal, even if that goal is simply to have a pleasant day outside. In contrast to Cohen-Rottenberg, I believe that it is by being lived-with—and not avoided—that disorienting encounters have the potential to reveal both ongoing and new meanings and experiences. That these moments open and open us up to relationality makes them ethical and not necessarily the understandings they may lead to.

Here, I see a distinction between etiquette and ethics that reflects one commonly made in philosophical literature between morality and ethics. I intentionally invoke etiquette because it describes ways of knowingly relating to others in a way that explicitly shapes social situations. Someone educated in the rules of etiquette knows which fork to use at dinner, how to curtsy or how to “properly” execute a handshake. In this way, etiquette involves bodies and embodiment and also requires the presumption of knowing with certainty one’s own social position and cultural location in relation to others. As etiquette, Cohen-Rottenberg’s suggestions potentially mean that a non-disabled person does not have to think about what he or she makes of the bodies of others because they will already know what to do with them. What has interested me throughout this chapter and this section in particular are those disorienting encounters which unfold through the uneasy meeting of meanings and bodies in such a way that one meaning is (intentionally or unintentionally) overwhelmed or overshadowed by another. In these situations
there are at least two meanings of disability operating, and yet one orientation becomes apparent; and as I show, ossified traditional meanings of disability assert themselves even as authors articulate alternate possibilities.

My primary concern with Cohen-Rottenberg’s suggestions, insofar as they represent narratives of “disability etiquette” broadly, is that they seek to avoid, assuage or remedy disorientation. In an effort to provide practical information to readers, this narrative minimizes the disorientation implicit in the original encounter that she describes. That is, though she attempts to mobilize this moment as ontological disorientation—an encounter that can at least potentially change the way that (nondisabled) people relate to disability—her account almost immediately renders it as a moment of ontic disruption. Her account suggests that she knows more or less why the woman is offering her seat and why she is troubled by her decline. Also, she “always” feels uncomfortable in these kinds of situations. Readers are told what they should think rather than being made to reflect upon the significance of what has happened. Further, by telling readers what they should think and offering prescriptive norms of behavior, she discourages her readers from reflecting on moments when they eventually do interact with disabled people. That is, they do not have to consider what an encounter means to or for them, or for the other person they meet, because they know what to do.

At first blush, Cohen-Rottenberg’s suggestions appear as a call for openness, but what she does is offer a code of conduct or at least etiquette tips. Ultimately, her piece tells nondisabled people what they 
should do, what they 
should think or how to be open to disability and disabled people. In effect, this discourages and perhaps even disallows thinking about how disability is related-to in general and the meanings of disability that define their orientations. Further, it suggests that while all disabled people do not want to be regarded as help objects, they
do *all* want to be treated “like anyone else.” Insofar as it appears uncritically in Cohen-Rottenberg’s blog post, I wonder who or what “anyone else” means. Should they be treated like “anyone else” who does not have an impairment, and thus is not subjected to nor the subject of disablement? If so, I worry that the processes and practices that structure disablement and enact disability will go ignored in these encounters rather than be mobilized, at least potentially, to interrogate existing meanings and instigate new ones. Further, though Cohen-Rottenberg’s essay is given from the perspective of someone who is or seems to be engaged with disability as a political and cultural issue, I worry that regarding disabled people “like anyone else” disavows the political and cultural significance of disability and disabled bodies. Approaching an encounter with a disabled person whom you should treat “like anyone else” presupposes that you can know something or that you can know anything about this person. For Levinas and Derrida, encounters are not opportunities to act in accordance with norms, but rather encounters are moments of exposure to others and—for Levinas in particular—a demand for openness. The disorientation of these moments takes us out of our home and disrupts our feeling at home. Avoiding disorienting encounters with disability by adhering to a code of conduct, even if a disabled person provides it, avoids disorientation and thus ignores those different orientations and the ways that they and we relate. This is by definition an inhospitable relation.

Psychologist and disability justice advocate Norman Kunc further articulates the ethical implications of disorienting encounters with disability in a compelling and controversial interview published as “The Stairs Don’t Go Anywhere.” Here, Kunc, who has cerebral palsy, reflects on the decade he spent in physical, speech and occupational therapy as a child. Specifically, he describes how the processes and practices of therapy shaped his orientation towards disability over time and how through two particularly disorienting encounters he came
to think differently about what impairment could mean and how disability might be experienced. In many ways, Kunc affirms what I have already said about how meanings and experiences of impairment/disability are shaped by bodily and embodied relations to space and to others. In and through therapy, for instance, he began to regard his impaired body as an alien being. “I ended up,” he tells Giangreco, his interviewer, “declaring war on my own body, it was me against my disability; and my disability was my enemy” (33). At the same time, he further demonstrates the ethical implications of disorientation as a way of not knowing or at least of being uncertain of one’s relation(s) to the world and others.

Kunc demonstrates that the ethical implications of disorienting encounters with disability do not only involve the re-orientation of non-disabled people. They can, he shows, reshape the way that disabled people relate to themselves and their place in the world. “One night,” he recalls, “I was at this pub with a bunch of my friends. At one point, one of the guys started imitating my voice. It surprised me and I didn't like that he was doing it” (35). At this point in his life and years after a decade of assorted therapies (including speech therapy), a large part of Kunc’s sense of self and his self-worth are tied to his intelligence and vocabulary and also his capacity to articulate words clearly. When he confronts his friend by asking, “Why did you imitate my voice?” (Ibid), his friend does not hesitate to answer. “Because,” he says, “that's how you talk...why are you trying to be non-handicapped?” (Ibid). Kunc is disoriented. This encounter opens (him) up (to) an entirely different way of understanding and relating to disability in general and to his sense of embodiment in particular.

Over time, Kunc questions the role that therapy and therapists had in shaping this orientation. “I believe,” he explains, “they thought they knew the best destination for me, but they were mistaken” (35). His critique of these mistakes focuses on two aspects of therapy. First,
he identifies the spurious connection between (increased) functionality and (improved) quality of life. He points out that, “nondisabled people often don’t equate the quality of their own lives with their ability to function in a certain way, so why apply it differently to people with disabilities?” (36). Second, he equates some aspects of physical therapy with sexual violence. During an MA class on sexual relationships, Kunc realizes how much he dislikes being touched and wonders where this preference comes from. As he tells Giangreco, “that’s when I first made the association between sexual assault and my own life. My body carried the memory, and these discussions triggered me to think back to physical therapy” (37). Here, Kunc stresses the orientation-work of physical therapy in terms of prolonged exposure and contact with others. Similarly, he describes his change in perspective as unfolding over time as well as in and through prolonged and persistent experiences of disorientation. As he explains it, Kunc became “absorbed” in and by an orientation towards disability as a social and political issue. Without identifying it as such, Kunc articulates the central question of the social model of disability and simultaneously a “postconventional” ethical approach to impairment/disability and disabled embodiment.

Just as his change in orientation is not an epiphany but rather took time, Kunc argues that there is no quick or easy way to re-orient the practices of therapy. He refuses, despite Giangreco’s persistence, to provide an alternate code of conduct for therapists. Instead he contends “we’ve got to slow down…the temptation of many professionals is to ask, ‘Tell me how to do it differently,’ rather than saying, ‘Help me think about this’” (38-39). Kunc’s insistence that we—all of us—need to take time with meanings and experiences exposed in disorienting encounters is reminiscent of Lobel’s description of “appreciation” as well as Schildrick’s and Mykitiuk’s call to be and stay “in touch” with bodies themselves. Kunc
indicates that “everyone should start with their own experience” (41) as a way of taking a different approach to disorientation or a different way of making sense of disorienting encounters. In contrast, I believe “everyone” should start with the—not necessarily their—experience of others, particularly those others whose bodies or embodiments do not immediately “make sense.” And, importantly, they must take the experience of disorientation as the occasion to think or rethink the orientations in and through which one’s sense of the world and others in it is made. This is, I believe, what Cohen-Rottenberg’s and Kunc’s accounts demonstrate—that the quality or character of openness makes all the difference in appreciating the ethical possibilities and the possibility of ethics within disorienting encounters. Put simply, it is one thing to be open to someone or something when you know or think you know what to expect. Openness towards the unknown or questionable other is quite another, far more dangerous matter. Disorienting encounters are ethical moments because they demand this. Not only do disorienting encounters with disability open up the possibility of relating to (disabled) bodies differently, but they also demand or imply openness towards being disoriented. That is to say, one is not disoriented by an encounter if its disruption is or can be ignored. Likewise, if “I” (can) ignore the disruption of disorienting bodies, then “I” can ignore the questions and questionability they pose to me and, broadly speaking, for orientation. Understanding disorientation as animated in part by the lived experience of a tension between openness in and being open to encounters with disability and experiences of disorientation is central to understanding the ethical dimension and implications of disorienting encounters.

G. **Violence and Disorientation**

Ahmed describes the ethical implications of disorientation in at least two ways. On the one hand, disorienting encounters signal that someone or something encountered is out of the
ordinary. And over time, these encounters articulate (establish and maintain) the limits between who and what is or is not ordinary. That is, as Levinas, Derrida and particularly Leder demonstrate, disorienting encounters simultaneously interrupt and reveal that but (and how) we are absorbed in and involved with the world. These encounters, Ahmed continues, “[show] us how the world itself is more ‘involved’ in some bodies more than in others…it is not just that bodies are directed in specific ways, but that the world is shaped by the direction taken by some bodies more than others” (159). Accounting for moments of disorientation and the “failed” orientation they expose through an ethics of hospitality—and specifically one that "remembers" the conditions that lead to and in turn produce disorienting encounters—open (for us, to us) the possibility of thinking impairment/disability differently. We can do this by thinking first of all about ableism and how it shapes the arrival of everyone—disabled or not—who meets at the crossroads of disability.

In thinking about the ethical implications of disorienting encounters with disability, I am reminded of a story told by author and activist Mike Ervin in the closing scenes of the documentary The Kids Are All Right. The film chronicles Ervin’s work as co-founder of the group Jerry’s Orphans, that protests the annual Muscular Dystrophy Association telethon. Near the end of the film, Ervin, who uses a power wheelchair, tells us that “one time” as he sat waiting to cross the street in downtown Chicago a stranger tried to throw some change into a teacup he was holding. “Fortunately,” he notes, “it had a lid.” The coins bounced off the lid. This moment is crucial. Ervin was disoriented by the sounds of coins hitting his cup; he had not noticed the man until then. This is also, he suggests, the moment that this stranger was disoriented by him. Ervin describes what happened next, saying, “He just looked at me and [jokingly asked], ‘Ah, closed down for the day, huh?’” As Ervin interprets it, this question belies a particular way of
relating to disabled people. “He assumed,” Ervin asserts, “that if I’m sitting on a corner with a cup in my hand I must be begging. It didn’t occur to him that maybe I was waiting to cross the street so I could take the cup of tea home and drink it”. Admittedly, Ervin is only guessing; he does not know with absolute certainty that this is what the man intended, and yet there is very little else he could have had in mind. Ervin recounts this as an instance of his being known and seen as pitiable. This interpretation is informed by a lifetime of similar interactions with people who seem to share a particular orientation towards disability and disabled people.

While pity certainly plays a part in the unfolding of this event, what interests me are the various involvements and ways of being involved in the world that it entails. First, this entire incident takes place within two-thirds of a traffic light cycle. In that time, this man saw Ervin and “knows” the story. The story he “knows” is one in which Ervin is poor, begging on the street and probably homeless. Second, rather than realizing or admitting that his presumption might be wrong when his coins were deflected by the lid of Ervin’s cup, the man makes two decisions: that it was “quitting time” for a disabled beggar and that it was time for a joke. As I understand it, the “joke” is the very notion that there would come a time (of day) in which a disabled person does not need charity. This has to do with how disabled people are thought to be involved in the world. Cohen-Rottenberg indicates this involvement in her rejection of being (seen as or made into) a help object. In and through this orientation, disabled people are understood as not only in need of some help but as living in a constant state of need. The joke is that any other significance or meaning is impossible. Perhaps this person did realize his mistake and was using humor to deflect or diffuse the awkwardness of the situation. Even if this is so, when Ervin tells this story he is not laughing. As Ervin tells it, this encounter produces no ontological disorientation in him. Instead, it is remembered as and is memorable for being a moment of ontic disruption that
gestures toward a conventional meaning of disability that entails poverty, neediness and pity. This is important and relates to the third time-sensitive element of this encounter.

As Ervin tells it, this encounter produces no ontological disorientation in him but instead, as with Lehrer’s and Cohen-Rottenberg’s experiences, reinforces how he knows his place in the world. At the same time, this disorientation opens up the possibility for him to do something—anything—with the moment. By framing this story as “one time,” Ervin suggests that there have been many similar encounters that over time let him know and make him feel that “some people pity me.” But—and this is crucial—this encounter also presents the occasion for him to know and, in telling this story, let others know that he does not understand himself in this way and cannot understand why others do. This does make him laugh. “My main reaction to [these sorts of incidents],” Ervin explains, “is that it makes me laugh. I just can’t imagine why someone would look at me or some of the people I know that way…I laugh too when they see me as real strong or real courageous” (Ibid). In this way, Ervin’s story supports Ahmed’s argument in Strange Encounters that the figure of “the stranger” is fully formed and already “known” prior to the approach or arrival of any person whom we do not know. In these encounters, she argues, the stranger and in turn the encounter loses or is divorced from its strangeness. This, I believe, is part of what makes disorienting encounters disorientating. Rather than being in touch with the strangeness of strangers and the moments in and through which we encounter them, we know or think we know the stranger. We are disoriented, then, when the person encountered is not what we expect.

Ervin’s story illustrates this openness as the ethical dimension of disorienting encounters with disability and as an ethics that emerges at the meeting point of multiple experiences of orientation and disorientation. We could debate whether throwing the coins is “right” or
“wrong,” but neither of these terms quite gets at what is going on here, and labeling this as a “good” or “bad” action/interaction does not help us understand the relations at play in this situation. As I have shown in this chapter, addressing the ethical dimension of disorientation requires thinking about ethics differently: not as leading to moral rules or codes of conduct but rather as a way of thinking and thinking about how bodies, meanings and the world exist in relation with one another and how those relations are accounted for in and through bodies. This ethical approach describes and calls for an ethics of embodiment, hospitality and, ultimately, of disorientation.

H. Conclusion

In this Chapter I demonstrate that disorienting encounters with disability are ethical moments because they expose and sometimes leave us exposed to the strangeness and strange relations that shape and are shaped by the meanings and experiences of disability as and in relation to orientation and disorientation. First, I illustrate the problems and promise inherent in moments of disorientation. In and through Harriet McBryde Johnson's conversation with Peter Singer, we see that orientation makes all the difference not only for meanings of impairment/disability but also for what one thinks of and of doing with disabled bodies. From here, I introduce a different sense of ethics that emphasizes the (point of) contact between real and imagined bodies. According to this formulation of ethics, what matters are those moments when we touch are touched. It is here—in and through each of these moments and encounters—that impairment/disability (in the meaning of any particular body) take on and are given meanings when they are experienced as such. Next, I consider an ethics of embodiment that begins with rather than elides disorientation and can be lived. Through an analysis of Riva Lehrer's “Golem Girl Gets Lucky,” I emphasize a prolonged or persistent sense of being
disoriented through a sense of the body, of home and of the body as home as an always already shared space. From here, I address the ethical implications of disorientation as an interruption of one’s being at home and the possibility of hospitality in and through those moments. Focusing on this sense of openness and of being open, I then illustrate some ways in which openness and being open can be problematic for and in the everyday lives of disabled people. Ultimately, I demonstrate that the ethical thinking that disorientation and disorienting encounters demand is one that takes the proximity and distance between experiences of bodies into account and in turn demands an account of or accounting for embodied experiences of disorientation. This approach to the ethical questions that present themselves in and though disorienting encounters make explicit that we are and must be in touch with bodies themselves and at all times with the ways that bodies (our own and those of others) are encountered and how they take on and take up their meanings.
V. CONCLUSION: TIME TO MAKE SENSE

There are no words to describe the feeling of being told that your cancer has come back. If there were words, or if there was something that I could do to show it to you, I don't think that I would. No one needs to see it. No one needs to experience that. (Lobel 45)

A. **Chapter Summary**

This chapter revisits a number of certainties exposed in and through disorienting encounters with disability and particularly how their assumption and subsequent dismantling help define multiple ways of knowing and not-knowing disability as well as the ontological and ethical implications of disorientation as a lived experience. First, I return to the story of dangerous questions and the question of competing stories about disability raised in the first chapter by reflecting on the disorienting encounter that led me to pursue a degree in disability studies and to write this dissertation. Next, I address the notion of “sense” that I have indirectly referenced throughout this project while examining the variety of ways in which disability “makes sense” and the lived experience of moments when it does not. Then, I discuss the notion and sense of time and timing that reverberates throughout every disorienting encounter I have examined.

B. **Moments That Give Us Pause**

Quite some time ago, I arrived early for a phenomenology seminar to ask a question that had occurred to me while reading a passage from Husserl’s *Ideas*. I could not know it at the time, but the questions I would ask and the responses they received are dangerous and initiate (or perhaps reflect) an ontological disorientation that persists to this day. “Abnormality,” Husserl writes, “must first be *constituted* as such; and the constituting of abnormality is possible only on the basis of an intrinsically antecedent normality” (qtd. in Welton 377). I brought up this passage in class and asked that if Husserl posits or at least describes a differential relation between
normal and abnormal experience(ing), then what would he make of my vision and, for that matter, of disabled people whose bodies and bodily experiences are for them normal? (How) would he understand that the experiences of disabled people characterize the “normal” unfolding of the world? Further, I wondered, what are the theoretical and real world implications of a phenomenological account of non-normative bodies that starts with a sense of them as abnormal? My classmates paused. They sat quietly, perhaps just as disoriented as I had been days earlier when I first encountered this text and through it these questions. On the other hand, perhaps they knew or thought they knew better. The questionability of their silence came to an end when suddenly one and then another spoke up rather emphatically (and a bit dismissively) by saying, “Husserl didn’t mean that.” We sat around the table as I wondered what this all means.

This encounter not only means a great deal, but it also gestures towards the various questions of meaning and experience that animate this project. Here, as in the many examples I have addressed, the meaning of disability unfolds as and in relation to orientation and disorientation as something that is simultaneously known and not-known. In this case, I am the one asking for “the story” of phenomenology and its possible account(ing) of anomalous bodies and non-normative embodiments. If my classmates are correct that Husserl—and as they would later insist, other phenomenologists—do not “mean that,” what exactly is that which they do not mean? There can be no definitive answer to this question because, as I demonstrate in this project, the story of disorienting encounters with disability is always multiple and never finished. That said, there are several interpretations of this statement that make sense or at the very least make sense to me. First, these phenomenologists are articulating the structures of mental, bodily and embodied experience and perception—not commenting on particular kinds of bodies. Second, though these thinkers—especially Merleau-Ponty and, as I have shown, Leder—
repeatedly reference impairments and impaired bodyminds (sometimes by name), they are not writing about disabled people. Third, the phenomenologists are writing about disabled people but not about disablement or disabled embodiment. Fourth, as apparently non-disabled white men, my classmates do not think or cannot imagine non-normative embodiment as a relevant issue within phenomenology. While each of these interpretations have some value, my analysis has been guided by the third interpretation, as it is the story that makes (the most) sense to me and has guided my thinking throughout this project.

Today, and especially at the end of this dissertation, I appreciate this disorienting encounter on many levels as simultaneously an uneasy meeting of multiple orientations and various experiences of disorientation. My disorientation at reading Husserl unfolded alongside a burgeoning sense of disabled embodiment that resulted ultimately in dysorientation. In contrast my classmates, with their apparently able-bodied orientations (to the best of my knowledge), experienced this encounter as ontic disruption and understood my questions as misguided. This encounter, then, unfolded between assorted orientations towards ability and disability that shape and are shaped by meanings and experiences of able-bodiedness and disabled embodiment. Also, as I demonstrate within this project, this is a disorienting encounter between (at least) one sense of disability and another. This moment also illustrated a dangerous question about the horizon of possibility within phenomenology and a movement toward a way of knowing and being in relation to impairment/disability that I would soon find in disability studies. In each of these ways this encounter was and remains disorienting. This dissertation has been an attempt to make sense of the various senses and sensings of impairment/disability that emerge in and through disorienting encounters.
1. **The pause**

In “The Hidden Injuries of ‘a Slight Limp,’” sociologist Devorah Kaliken-Fishman writes that “before every action, there is a pause…and a beginning again” (136). In many ways, the work of this dissertation constitutes a prolonged description of the ontological status and ethical implications of this pause as it plays out within private and political or personal and public encounters. As Kaliken-Fishman explains it, “the pause is for description, for mulling over the requirements of balance, for comparing the proposed action with movements that are familiar, and for explaining to myself why I can or cannot do what is at hand” (Ibid). In this respect, we can recognize the bodily and embodied experience(s) of orientation. Her formulation of “a pause” resonates with my own articulation of impairment/disability at a crossroads that simultaneously touches and puts us in touch with both orientation and disorientation. “In the course of daily living,” she continues, “this thinking is not observable; the behavior just happens, part of what this person does naturally” (Ibid). The disorienting encounters that I have analyzed in this dissertation, my own and those of others, unfold in and through encounters that give each of us pause as questions of impairment/disability are and remain open questions. I pause in response to the store clerk; Linton pauses upon encountering the “sexy” scene on the sidewalk; Jenny and Manning pause when they bump into “something;” Kleege pauses while watching the sunset and when she realizes that she is not watching the sun set; Lobel pauses as he encounters his own reflection and understands that he misunderstood his encounter; finally, Lehrer pauses at the threshold of her home while contemplating what it has and might mean for her to be hospitable. This open question is characterized by orientation and disorientation. The encounters that I describe involve and invoke an awareness of “here and now” that itself emerges in and through an experience of being and of finding oneself already thrown. Disorienting encounters
and dangerous questions, like Kaliken-Fishman’s pause, do not emerge from or interrupt an intrinsically antecedent normality but rather demonstrate the relational nature of any sense of normality or resultant social ordering.

If, as Kaliken-Fishman asserts, “the pause” is for finding one’s place, then this dissertation has shown that one’s place is always a placement. Where we find ourselves when we find ourselves pausing is always already in uncertain relation to the ways of knowing and being that shape and are shaped by our sense of home. In this way, “the pause” also names an experience of not-knowing one’s place or finding oneself out of place. In the encounter described above, for example, I feel—and to an extent am made to feel—different and alienated. Similarly, it seems that my classmates find my questions as well as my perspective a bit strange. Here, my pause while reading Husserl and my classmates’ pauses in response to my questions describe the time it takes to make sense of the interruption(s) of our respective orientations and in doing so getting a sense of them (perhaps for the first time). At the same time, we are disoriented, and this pause accounts for a sense that our embodied and cultural orientations provide little, if any, means of appreciating the space(s) and relation(s) that this disorienting encounter opens between us. We—each of us—pause when (or as) we find ourselves, already within the lost and not-yet home of disorientation, together.

I conclude this dissertation with a remembered story of an open question and the question of ongoing stories not with the hope of having given the final word on disorienting encounters with disability. Rather, I am hopeful that in and through this project impairment/disability and disabled embodiment have become and will remain open questions. There is so much that these encounters do and so much more we can do with them. I end here precisely because “the story” of disorienting encounters is never finished, even and especially when we pause.
2. **Crip time (and space)**

The takeaway message of this dissertation is that disorienting encounters with disability do not occur “out of the blue,” that they are anything but meaningless and that they should be dwelt in rather than avoided. My analysis of disorienting encounters with disability gives an account of them from the perspectives of disabled people. In doing so, I demonstrate the ontological status and ethical implications of these moments. My conclusion, put simply, is this: disorienting encounters with disability are vital, and further, we need them. Disabled and non-disabled people need them to appreciate that (and how) meanings and experiences shape bodies and lives lived in proximity to impairment/disability and through disablement. Similarly, scholars working within and across disability studies, phenomenology and ethics need to appreciate that these encounters are not the occasion for prescription or even explanation but rather for interrogation and wonder. Disorienting encounters put us—all of us—in touch with where we are (here and now) and what might unfold (the future), but they also put us in touch with how these encounters are each time (re)shaping the paths that led “here” just as they shape the paths we follow “there.” Or not. It is entirely possible, for instance, that the store clerk whose demand for “the story” that inspired this project has never, not even once, thought about our encounter. Being open to this possibility—and, more than this, welcoming it—is part of taking the ontological dimension and the ethical demand of disorientation as a starting point.

“What can you see?” asked the travel agent when I called to confirm our plans days before leaving. I mentioned, more as a reminder than as a confession, that I am visually impaired and my soon-to-be-wife has cerebral palsy and uses a collapsible wheelchair on trips like this. There was a pause after which the travel agent said, first of all, that they don’t allow wheelchairs on their buses and, secondly, the tour guides are not responsible if a person has difficulty keeping up
with the rest of the group. I tried to comfort her by explaining how the missus and I operate: she tells me which way to go, and I push. We have successfully navigated Chicago, London and even the jungles of Belize in this fashion. It will not be a problem. Irritated by my determination, the travel agent suggested that we would be happier visiting only one city instead of three and insisted that not only is Italy completely inaccessible but that no one will come forward when we need help.

Nevertheless, here I am: a white man with a white cane standing atop the Ponte di Rialto Bridge in Venice, preparing to descend its steps while carrying a wheelchair. This is the first day of my honeymoon.

It is a fairly indisputable claim that disabled people appear out of place within normative geographies because these spaces were not developed—neither architecturally nor socially—with them in mind. Despite the best efforts of some and the deepest ignorance of others, however, formerly excluded bodies are increasingly entering these spaces. Puwar’s use of the term “space invaders” reminds us that even though these bodies currently take up a position of relative belonging within normalizing institutions, their belonging remains questionable.

Disability is disorienting not only because it appears “out of place” in normative geographies but also because it appears “out of pace” with what Freeman calls chrono-normativity—that is, the “forms of temporal experience that seem natural to those whom they privilege” (3) or what Michalko labels “culture standard time.” This time is linear, continuous and certain. Its normality is bolstered by comparison to what we might call disability time, a time which is thought to be uneventful, jagged, made up in fits and starts, and disoriented. Chrono-normativity marks impaired bodies by the time they need to perform tasks. The pace of mobility impairment, the gate of low vision and the processing speed of learning difficulties are all
implicated in a kind of temporal disablement. But people with disabilities are also keenly aware of their movement through space and time. Attention to whether or not some place is accessible, the location of rest rooms, the delays of public transit and even the time-consuming particularities of dressing are just a few components of how people with disabilities relate to time. This embodied temporality is sometimes referred to as “crip time” and is recognized in part as a time that takes time. But crip time means more than this. It is not, or is not simply, the making or taking of “extra” time associated with accommodation, but it also describes an orientation toward and a way of orienting to time and its relation(s) to experiences and meanings of disability and disabled bodies. According to Kafer, crip time is ”a reorientation to time” (27) that calls us to (dangerously) question how time shapes and is shaped by embodiment generally and by non-normative bodies in particular. Kafer’s discussion of crip time emphasizes its original significance as an open but also a shared (or share-able sense of) time. It is or can be something that is known and more fundamentally sensed between disabled people and across their various relations to the world around them. This is significant for my articulation of disorienting encounters with disability as not simply the time for “making sense” when we are disoriented but further as a time of being exposed to different senses and sensings, alternate orientations and experiences of disorientation. While “culture standard time” can be counted by the rigidity of its rhythms, “crip time” is characterized by openness towards what and whom is to come.

While disorientation disrupts the flow of expectations and the momentum of an orientation, it does not leave us frozen in or out of place. Instead, disorientation is provocative. It is the space (and time) where the possibility of other ways of knowing or being and the
acceptability of not-knowing are introduced as the encounter refuses to let us remain at home by instead demanding that we move forward, perhaps in a new direction.

C. Making Sense

Visuality—seeing and being seen—is the obvious starting point for an account of disability that takes seriously its relation to orientation and disorientation not only because visual perception regularly begins phenomenological discussions of embodiment but also because a politics of appearance remains central to the project of disability studies. Within this discourse, specific meanings and received experiences of impairment/disability are (re)produced in representations of disabled people, and through them certain (ableist) ways of relating to disability dominate. For instance, Garland-Thompson (2002) persuasively argues that, "staring at disability choreographs a visual relation between a spectator and a spectacle" (57). Taking this argument further, Mitchell and Snyder argue that rather than producing meanings of disability, literature traditionally depends on a few very specific meanings such that disability operates as a "narrative prosthesis" used as shorthand for affective content and plot development. It is undeniable that visual encounters shape and are shaped by meanings and experiences of disability, but as I demonstrate, disability is more than something we see. Rather, it is something we encounter (visually and otherwise), something that we sense and something that makes and gives sense in and through various encounters and modes of encountering.

It is also worth noting that the focus on visuality within disability studies scholarship is at least potentially quite ableist. Garland-Thompson's (2009) anatomy of staring encounters and particularly her description of and call for "staring back" (79) as political action presupposes a certainty that one is at this moment an (unwilling) participant in a staring encounter. As a disability studies scholar I am deeply committed to the encounter-based social justice work that
Garland-Thompson describes, and yet as someone with a visual impairment, staring encounters, if they occur in my day-to-day life, often go unnoticed. This is, in part, why my analysis of disorienting encounters with disability has focused on moments of uncertainty that do not or at least do not exclusively involve seeing or being seen. It is no coincidence that my analysis of impairment/disability as and in relation to orientation and disorientation emphasizes touch(ing), being touched and the admittedly uncertain notion of sense.

In *A Finite Thinking*, Jean-Luc Nancy (2003) writes that “if there is anything like thinking, it is only because there is sense, and if there’s anything like sense it’s only in the sense of sense, that sense is always given and gives itself as something to be thought” (3). This is what I have had in mind while writing about disability as making sense. This way of thinking (about) sense opens up the possibility that while we can talk about what disability means to or for “us,” this us is always fragmented. In other words, the sense of disability might differ from person to person without being individualized or personalized. For disabled people, for instance, the sense that disability makes (for them, to them, of the world, for their world) may coincide from one to another in a way that tends toward a sense of identity. But even though a sense of disability can be shared between people, this does not mean that that sense is each time or always the same. Linton’s disorienting encounter discussed in my second chapter offers an excellent illustration of this point. Recall that prior to her encounter outside the grocery store—and for reasons not entirely explained—she understands her impaired body and the impaired bodies of others as sick bodies that may be touched but not caressed and that may be moved around but not danced with. Then, in and through her disorienting encounter, Linton begins to think differently about herself and also about others and the world. For Linton, this encounter momentarily interrupts or pauses her orientation towards disability and thus opens up a space from which to imagine her body and
her place(ment) in the world differently. This does not happen to everyone. Watson and Reeve emphasize that many people with impaired bodies do not consider themselves disabled or at least do not question whether they belong in the same category as people who do. Further, as Kafer notes, some people with non-normative bodies do not (want to) identify as disabled. Instead some disabled people, even some who identify as disabled in the disability studies sense, want a cure. Not everyone is going to orient to disability in the same way, nor should they. This is the epistemic, ontological and ethical demand of appreciating impairment/disability at a crossroads and more generally of conceptualizing impairment/disability in terms of orientation and disorientation.

British comedian Laurence Clark addresses these issues through a series of videos incorporated into his stand-up act. After having coins dropped into his upturned sun hat while sitting at a bus stop on vacation, Clark decides to see how much money he can get if he actually tries. To test this, he takes to the streets of London with a series of progressively inauthentic charity collection buckets. Clark is or appears to be white, has cerebral palsy and uses a wheelchair. He is approximately middle-aged with short brown hair, and depending on the video, he wears a closely trimmed beard or is clean-shaven. He dresses for slightly colder weather in either a sweater or a light jacket. The location of each video appears to be different, though each is shot on a fairly busy public street, on the corner or near the entrance of a store. From a distance he looks like any other disabled man working a charity bucket, and this is the point—to test whether or not the traditional appearance of disability trumps the blatant fakery of each “charity.” His causes are admittedly ludicrous, moving quickly from unusual to unbelievable, and yet each one receives at least one donation. Clark’s experiment and the effect his videos can
have on viewers illustrate the power of orientations toward disability and the promise of disability as orientation.

Clark’s approach is straightforward. His first bucket reads “Pay off my mortgage” in large block letters. He chants this line while shaking the bucket. When he speaks directly to a donor, it is only to suggest that they do not want to give him money. Most people say nothing, but one woman insists, “Yes, I do.” That the self-interested nature of his message utterly contradicts the purpose of charity collection buckets does not seem to bother anyone, if they even notice. He receives a total of nine on-screen donations. Operating a “fake” charity is not only unusual but also illegal in the U.K., and Clark’s second bucket acknowledges this fact, reading: “Please don’t put money in here. I will get a criminal record if you do.” Somehow this is even more successful. Despite the threat of English law and Clark’s repeated requests that people not put money in the bucket, he receives several donations. One person asks what is going on, apparently noticing the incongruity between the sign and its message. Clark explains that his mission is part social experiment and part joke; the point is to see how many people will take the neediness of disabled people for granted and donate money without reading the sign. After listening to Clark’s explanation, the potential donor indicates that he understands and that he “gets” the joke, but then he drops some coins in the bucket and walks away. Clark’s next bucket is even more obvious; it reads, “This is a scam, sucker.” Several people drop coins into this bucket even as Clark tells them: “No, don’t. I’m ripping you off.”

At least two senses of (orientations toward) disability are operating within Clark’s videos. The most glaring is the orientation(s) of donors who we are led to believe are only “seeing” a man in a wheelchair with a charity bucket and explicitly not-seeing the buckets’ messages. Of course, we do not “see” any particular orientation toward disability, but rather we make sense of
it or it makes sense to us. We know or think we know that people are giving Clark money because they know or think they know he needs it. This orientation toward disability is achieved or expressed in and through the simultaneous appearance of “disability” and the disappearance of Clark’s (written and spoken) words. The other orientation towards disability that goes unnoticed or at least, unspoken in these videos is Clark’s own. A disabled man creates fake charity buckets to see how outlandish the “charities” can get before people stop paying him. What’s the story?

Clark’s videos tell us something important about orientation and about disability as orientation that I have not stressed but still remains the source of heated debate between disability studies scholars. That is, not everyone who is or can be identified as disabled identifies as such, and among members of these broad groups disability can and does mean different things. In his stand-up act, Clark posits that the donations he receives are motivated by the charity model of disability—that is, the cultural belief that people with disabilities are victims of their embodiments who require financial assistance and social support. A cultural way of seeing disabled people as necessarily needy may explain the coins dropped in silence, but it complicates the donations made after conversation, especially when that conversation explicitly undermines charity model thinking.

Clark’s fourth bucket reads, “I am not a charity case.” In his stand-up act as well as in on-screen conversation, Clark explains that this fourth sign directly points out the neoliberal paradox that his experiment is trying to test. If a person puts money into the bucket that reads “I am not a charity case,” then, he explains, they must not only agree with but also support his claim of self-sufficiency. However, by giving him money they are demonstrating that they believe he does need help. Clark repeatedly tells donors that he neither needs nor wants their money and discusses the paradox they are bringing about. One donor insists that she “knows” he is not a
“charity case” right before she drops a few coins in his bucket. In this way, Clark demonstrates that disorienting encounters between people do not always result in mutual disorientation.

1. Feeling (at) home

The story in and of Clark’s videos is a story that we have seen throughout this project: a story of disability as and in relation to disorientation. Clark understands disability as a relational sociopolitical issue and in turn appreciates unsolicited charity as oppressive violence. In making and showing these videos, he welcomes the viewer to notice that difference(s) can disappear in the movement of orientation as well as in the wake of disorientation. Certainly the social justice work of Clark’s videos is directed at (and is for) people who do not share his orientation towards disability, but does this work? I have been in the audience for several screenings of these videos (with and without Clark in attendance). While observing the crowds and in conversations afterwards, I have noticed that many apparently disabled people laugh both because they “get it” and because he “gets” them. Others do not. Further, I have seen and heard apparently non-disabled people express that they understand the point of the videos and yet they do not or do not exactly “get it.” They do not laugh.

In contrast to Cohen-Rottenberg’s blog post discussed in Chapter 4, for instance, Clark’s videos are not prescriptive. They are not simply intended for able-bodied (or ableist) audiences as a teaching tool, but rather they are for (making) a community of disabled people who are open to (as well as opened by) the sharing of similar ontologies and lived experiences. They are meant for those who laugh and in laughing recognize themselves in the videos and each other in the audience. In this regard, like Clare’s poems, Clark’s videos invite discussions about staring and other ways of relating to disability from the outside; but they also provide ways for thinking about how disability is experienced and what these experiences mean from the inside—or, more
accurately, from a crossroads. Appreciating disability as and in relation to orientation and disorientation opens up the possibility that impairment/disability will never, at least not definitively, make sense. More than this, this approach presents an ontological and ethical challenge to each of us to welcome different senses and sensings of impairment/disability even and especially when they are not our own. Home—particularly the disabled body as home—is not known like an object, from the outside in. Home, as I demonstrate throughout this project, is felt. Being “at home” describes, before anything else, feeling at home. The same is true of the lost and not-yet home of disabled embodiment. What I have sought with this dissertation is a way to describe and practice a “hospitality that remembers” disorientation and disorienting encounters. Here, remembering is in part admitting—in the sense of being hospitable—the things (bodies, objects and lives) that have helped us find our way as well as the paths (ways of knowing and being) that we have taken and ultimately the homes we have lost, found or toward which we are moving together.

Clark’s videos make me feel “at home” within a particular kind of disability community and with disorientation as a particular kind of disabled embodiment. When I laugh, what I see is others laughing. The sound of our laughter fills up and fleshes out the contours of a (my) home. Clark’s final bucket is more provocative. The fifth bucket reads, “KILL THE PUPPIES.” Here we see a shot of Clark sitting in his wheelchair on a street corner and again wearing a jacket, but this time he alternates between sung verses of “How Much is that Doggy in the Window?” and chants of “Kill the puppies, down with dogs.” The sign affixed to the bucket shows the international symbol for “No” superimposed over the picture of a golden retriever. What makes this bucket particularly interesting is that it receives the clearest display of inattention while also soliciting the most sustained conversation, and for the first time we see “real” uncertainty. An
older man stops in front of Clark, reads the sign and dangerously asks, “Why do you want to do that?” The man immediately interrupts Clark’s response. Barely audible on video, the man mumbles that he “knows” why Clark is out on the street. He has another question that he wonders aloud how to phrase. Before Clark can say anything, the man asks “Some sort of cripple, are you?” Here we can appreciate plainly the tyranny of knowing that robs disabled people of their subjectivity or, more accurately, imposes an alternate subjectivity upon them. From what we can tell, this man thought about asking for “the story,” but the only story he could imagine asking for is one of diagnosis. A disorienting encounter is squandered.

Apparently unfazed by this, Clark manages to say, “Yes, I guess you could say that” before being interrupted yet again, this time for clarification. “Cerebral palsy?” asks the man. This is met with another even-toned “yes.” This interaction is cut short when the man mutters, “Well, there you go,” and drops in some coins before walking away. Next, we see a woman and child pass by. Without appearing to pay any real attention to either Clark or his cause, the woman tosses some money in it without stopping. Clark pleads with her in a markedly louder and more urgent tone than usual. “No, you really don’t want to do that,” he urges. Although we do not see the woman take a second (or, rather, a first) look, we do see the young boy—presumably her child—staring at Clark, disoriented. The video leaves open the question of whether the boy’s reaction is caused by his mother’s action, Clark’s sign or both. Without resolution the video pauses.

Clark’s videos open and leave us—some of us, anyway—living with disorientation by beginning with the familiar narrative of disabled people’s in/visibility and then moving beyond that by inviting us to ask how we feel personally and politically about the issues he raises. Do we, as audience members, feel at home? Do we “get” the joke, or is the joke in fact about us?
Interpreting these videos simply as examples of disabled people’s in/visibility misses the point. What is compelling about them is not that Clark is hyper-visible yet unseen but rather the absent presence of orientations toward disability that they expose and the dysorientation that they initiate. Ableism disappears when the donors in Clark’s videos see him, but they do not see him as someone collecting funds to carry out canine genocide; rather, they see a man in a wheelchair with a charity bucket. Dysappearance and hopefully dysorientation become unavoidable when one asks or is asked about these videos, “What can you see?”

We know from Davis, Michalko, Kumari Campbell and others that disability already occupies a meaningful position in the background of experience such that when it appears disability is already equated with a story of neediness. From this dissertation, we know that orientation is lively; it turns, and we are or can be turned around by disorienting encounters. We also know that the interactions depicted in Clark’s videos are not rare or even out of the ordinary but rather that—and this is disorienting—encounters like this are all too common. Given the sense of disorientation and disorienting encounters that I have articulated here—a moment of ontological and ethical openness to other ways of knowing, being and being in relation to bodies and the world—the question of disorienting encounters that this project asks of us is no longer how we can live in and in relation to disorienting/disoriented bodies but rather how we do.
CITED LITERATURE


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2011  Becoming Professional, Society for Disability Studies Conference,
2013  Constructions of Disability for OT Practitioners, Occupational Therapy History and Philosophy, Rush University College of Health Sciences Occupational Therapy Masters Program, August 13.
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