Introduction

Entering the Field

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I want to express my heartfelt gratitude to all of the people who have fought to construct a campus and community that are physically and socially accessible to people with all types of disabilities, even in the face of statewide budget cuts. My deepest appreciation goes to the [University of California at Berkeley] students who were at the helm of the Disability Rights Movement in the 1960s. They sparked a campus mentality of inclusion and equal rights for all, based on the premise that a university ought to value all of its students.

As this quotation from Chapter I.1, by Alyse Ritvo, reflects, over the last fifty years, people with disabilities have sparked a revolution, fighting for and winning rights to education and access in the United States and around the world. In tandem with the success of disability rights movements and activism, the international academic field of disability studies has grown and flourished. In North America, almost forty postsecondary institutions have formal disability studies undergraduate and graduate programs.[1] These numbers, while impressive, do not adequately represent the increasing importance of disability studies in postsecondary education. The field focuses on social, cultural, and political aspects of disability and contributes to and draws from a wide range of disciplines, including anthropology, social sciences, social work, psychology, international studies, gender studies, cultural theory, ethnic studies, literature, education, law and

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policy studies, and the arts. Despite the breadth of the field, there are few introductory works available. We hope this collection of narratives, many of them from students, will fill some of this gap.

As an umbrella term, **disability** is meant to encompass a broad range of physical, sensory, psychological, and cognitive capacities and variations. Its parameters are fluid, changing, and expanding. Disability has become, for many, a category of personal identity; for others, the term is fraught—identification with disability is partial, contingent, and even contested. In popular usage and through legal, policy, and biomedical definitions, disability links individuals and groups with differing and conflicting ideas about what disability means, both individually and within larger structures. The differences between competing approaches to disability correspond in many ways to the distinctions between deafness and Deaf culture; in this rubric, deafness refers to a hearing impairment and diagnostic category, whereas Deaf culture designates a cultural-linguistic affiliation and identity. Culturally Deaf people often distinguish between their own social position as a linguistic minority and that of other people with disabilities. Notably, in this context, Deaf does not equal disability. While Deaf and deaf activists worked alongside disabled activists in support of the Americans with Disabilities Act in the United States, and while they benefit from its protections, for many in Deaf communities, disability does not describe their collective experience or personal self-concept. At the same time, these are not hard and fast divisions. In recent years, rich scholarship bridging and clarifying distinctions between disability and Deaf studies has emerged (Brueggemann 2009; Burch and Kafer 2010; Krentz 2007). In fact, Deaf culture has provided a powerful context for imagining disability in distinctly cultural frameworks. As Denton Mallas puts it in Chapter V.6, "I've learned to announce my identity as Deaf, not in a pathological way but in a cultural-linguistic way. I am no longer afraid to say, 'Yes, I'm Deaf, and I sign.'"

Disabilities and the Classroom

The twenty-fifth anniversary of the Americans with Disabilities Act (ADA) in the United States was marked in 2015 with celebration and frustration, and the narratives included in this book reflect both the changing landscape of possibility as well as the enduring limited perceptions about disability. These tensions are reflected within college classrooms: while many students begin college with an ethic of respect for people with disabilities and some familiarity with disability rights and inclusion, few have critical tools for understanding the sociopolitical dimensions of disability. As Joshua St. Pierre points out in Chapter III.1, deficit-based medical and rehabilitation approaches prevail and often produce the unintended consequences of

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instilling negative self-perceptions in people: "Studying disability theory was revolutionary for me, as it helped me understand that disability as an individual, biological 'malfunction'—the medical model—is only one reading of disability, and a poor one at that." St. Pierre's disability, stuttering, had been addressed by doctors and speech therapists as a problem to be fixed. In college, however, disability studies perspectives liberated him to think of it as something beyond "malfunction." Many students echo St. Pierre's sentiment—that disability studies provides a revolutionary reorientation to disability that is personally empowering and intellectually invigorating.

In our undergraduate classrooms and others across the United States and Canada, students demonstrate an interesting and fairly consistent range of perspectives about disability. In a representative introductory course, as students begin discussing what they think about disability, a few students may immediately situate disability in a sociocultural context, articulating advocacy or activist perspectives. These students usually have disabilities or have important relationships with disabled people. Other students, many of them preprofessionals planning to work in special education, rehabilitation, or the health or service fields, talk about wanting to "help" people with disabilities—an approach that is advocacy-minded but commonly informed by pity or ableist assumptions that situate disability as dependency or deficit. Many such students, sincere and self-reflective, can be quick to reorient their thinking toward disability, rights, and access. Still another group of students are skeptical of the social context of disability; they expect biomedical "facts" about disability and expert knowledge about treatments, interventions, and cures. While this research is important, disability studies is focused on the personal, cultural, and political context of medical and rehabilitation approaches and encourages students to engage with the relations and tensions across these domains. On occasion, a few students articulate acutely negative perceptions of disability, sometimes grounded in personal experience. Upon further reflection, such individuals often offer painful insights about material hardship, lack of opportunity, and multiple intersectional oppressions. Finally, some students admit that they really do not know much about disability; they do not have a family member or friend with a disability and have not really given the subject much thought. As these students probe more deeply, they often realize that students with disabilities were not actively integrated in their schools—that their lack of familiarity is also a product of able-bodied and able-minded privilege.

We open with this glimpse into the classroom because this book has emerged out of ongoing conversations among the coeditors about pedagogical practices and our collective desire for an introductory narrative collection that would speak to this wide range of experiences. We found that few disability studies anthologies were specifically designed for undergraduates

or introductory courses. While disability studies scholarship is rich, multidisciplinary, and rapidly growing, we wanted a narrative anthology that would include reflections on a range of impairments, material experiences, and sociopolitical perspectives in relation to important issues in the field. One of the tasks we have set to our own students is short **autoethnographic** writing assignments that ask them to apply a critical disability studies lens to self-reflect about specific incidents and contexts of their own lives. The student voices emerging from our own classrooms made us realize that selected essays from our own students, combined with those of other disabled students formally working in the field, would provide a rich array of material—especially for college students new to disability studies. In effect, this collection of narratives features disabled students grappling with disability studies frames—from students newly acquainted with sociocultural dimensions of disability to activists deeply familiar with political issues and theory.

Autoethnography is closely connected to two other forms of writing frequently used within disability studies, **critical self-reflection** and **disability life writing**. New genres of disability life writing focus on the rich insight that emerges from disability experience. Further, as students are exposed to disabled people's unique knowledge as well as discussions of their experiences with environmental and social barriers, they are encouraged to reflect about able-bodied and able-minded privilege. As disability studies scholars in the humanities and social sciences have demonstrated, disability has shaped cultural understandings of personhood, citizenship, gender, sexuality, ethnicity, class, and nation (Baynton 2001; Garland-Thomson 1996; Linton 1998). When students are asked to probe and reflect on their own beliefs and perceptions about disability, they begin to notice and discuss dominant cultural (mis)perceptions about disability. For example, they become aware of how fears proliferate in media representations of mental illness or are engendered by the rhetoric of autism as an "epidemic"; they witness how "inspirational" stories featuring disability erase important social or political inequities. In one exercise, we ask students to reflect on the first time they recall being conscious of disability as a notable difference, an exercise that inevitably reveals internalized beliefs and structures of **ableism**, alive and well. As Fiona Kumari Campbell explains, "'Ableism' refers to the ideological hypervaluation of ableness and the ways in which such norms of abled and disabled identity are given force in law, social policy, and cultural values" (2015, 13). Disability studies endeavors to expose and critique ableist norms, practices, and structures within a larger project of justice and inclusivity.

Disability life writing often provides students with more complex understandings of the social dimensions of disability. In *Signifying Bodies*, G. Thomas Couser identifies the "new disability memoir" (2009, 164) as a distinct genre, one grounded in disability studies, where authors use their

autobiographies to articulate complex sociopolitical dimensions of disability. Memoirs cited by Couser are well known in the field: Stephen Kuusisto's *Planet of the Blind* (1997), Georgina Kleege's *Sight Unseen* (1999), Harriet McBryde Johnson's *Too Late to Die Young* (2005), and Simi Linton's *My Body Politic* (2007), to name a few. All of these writers contextualize disability as personal, familial, social, and political and use narrative to explore their evolution into what Couser calls "disability consciousness" (2009, 165). Linton, whose *Reclaiming Disability* (1998) has been a foundational text in defining the parameters of the field in the United States, invites readers into an intimate political history in *My Body Politic* (2007). In this memoir, she recounts emerging from a spinal-cord injury into a dramatically inaccessible world as well as into the excitement of the burgeoning disability rights movement. Although covering similar analytical territory in both books, Linton's life writing invites readers into an embodied, epistemological journey. Disability memoirs allow readers to inhabit bodies, minds, and histories different from their own and to reorient, through authors' reflections, their critical thinking about disability. Linton's story resonates with readers across diverse backgrounds and disabilities, including several contributors to this book. Mycie Lubin recalls in Chapter II.1:

> Just like Linton, I could not accept my changes at first. I cried, blamed my family for not informing me of medical issues we have, and became angry, depressed, and resigned. . . . I am an immigrant with a very thick accent. English is my fourth language. I am black and a woman. I thought, *No way am I going to add disability to the list.* I already had too many obstacles in a country as racialized as America. . . . [B]ut I found out soon that I was using the wrong method to fight the disease. The best approach was to face it, accept it, and keep going.

Another disability-conscious memoir, *The Shape of the Eye* (2011), written by George Estreich, whose daughter Laura has Down syndrome, positions narrative as a necessary humanizing force in relation to the potentially reductive qualities of science. Thinking of his daughter's future in a world both *accepting of* and *correcting for* Down syndrome, he offers this reflection:

> We live in a world where Down syndrome is described both as an element of a diverse humanity and as a defect to be eliminated. . . . If our technologies are to benefit people with Down syndrome, then their lives need to become more real to us. Science can illuminate one part of that reality, and technology can affect it. But only story can convey it. (207–208)

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Complex disability narratives work against reductive ideas about abilities and future potential; in addition, such stories challenge hollow stereotypes and presumed limitations attached to diagnostic labels. The narratives in this book resonate strongly with the ideas expressed in new disability memoirs. Some writers are deeply engaged with disability theory, while others powerfully recount processes of discovery; across this range, all these writers actively make meaning and produce knowledge from personal experiences of disability.

Barriers and Belonging

> All . . . changed when I found disability studies. I began to see myself in the mirror. I didn't have to be a lone "sick kid" trapped in his room; I could be a member of a community—a community of those who had been excluded and overlooked due to their various physical and mental disabilities but who still had something important to contribute to the world.

As this quotation from Adam P. Newman's chapter (VI.4) illustrates, the title for this book emerged organically from the included narratives and reflects intrinsic political goals of disability studies: to expose and dismantle attitudinal and structural **barriers** and to promote and create meaningful sociopolitical **belonging** for disabled people. From the beginning of modern disability rights movements, activists have articulated their concerns and demands around identifying physical and attitudinal barriers. While many architectural barriers in public spaces have been removed, as these narratives demonstrate, disabled people continue to face significant obstacles, many of which are exacerbated by ableist attitudes that situate disability as an individual issue. As Newman also mentions, experiences of exclusion and isolation among people with disabilities are far too common, and finding community can be a transformative experience. These narratives promote complex knowledge of disability as a valued element of human diversity, and they provide glimpses into spaces of what we call **radical belonging**—within families and communities, and across the lifespan. By radical belonging, we wish to underscore the idea that integrating people with disabilities into the broad social fabric—from family units to social networks, communities, employment, and larger institutional structures— is a shared responsibility.

The chapters in *Barriers and Belonging* speak to this communal labor and conceptual shift. Central to actively engaging in this shared perspective is adopting a critical and relational approach to **access**. Tanya Titchkosky provides indispensable tools for this process in *The Question of Access* (2011).

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Titchkosky sees access as a form of perception and invites disabled and nondisabled people alike to engage in a "politics of wonder," an open-ended questioning, and a "restless reflexive return" (15) to what access means and how it shapes relationships:

> Exploring the meanings of access is, fundamentally, the exploration of the meaning of our lives together—who is together with whom, how, where, when, and why? Once we recognize this, we can begin to regard disability as a valuable interpretive space for denaturalizing our existence and complicating singular or totalizing ways of making meaning as bodied beings. Denaturalizing existence does not require us to deny the materiality of the body, nor that of social space, but it certainly does make the relation between people and places a significant, historical, material fact, worthy of concerted critical reflection. (6)

Many of the narratives in this book address access from this perspective of relationship, reflexivity, and wonder. All the chapters engage with disability as a significant "interpretive space," and many contributors recount experiencing a personal paradigm shift when they first considered disability as valuable or as a source of insight worth sharing. Zachary A. Richter, for example, describes in Chapter I.6 how the concept of ableism utterly transformed his internalized shame about disability into pride and activism. Garrett R. Cruzan, in Chapter IV.4, grapples more with how disability reshapes the meaning of our lives together. He traces an intellectual journey of embracing his spinal-cord injury as liberating him into newfound knowledge while also reframing his personal relationships with family and activist networks. He also articulates a larger responsibility: "I am learning to embrace my place in spreading awareness, and I know how important that is."

Like the new disability memoirs described by Couser, the autoethnographic narratives in this collection focus (to varying degrees) on the complex interactions between an individual's physical, mental, and sensory experience of impairment and the person's social context. As Carolyn Ellis, a pioneer in autoethnographic theory, methodology, and writing, explains, autoethnography begins with one's personal life and requires "attention to . . . physical feelings, thoughts, and emotions" (2004, xvii). Further, it involves what Ellis refers to as "'systematic sociological introspection' and 'emotional recall' to try to understand an experience" (xvii); in her case, she has used autoethnography to explore a variety of issues such as marriage, aging, teaching, and her experience with cancer. This approach, reflected by the narratives included here, invites readers to engage with the writer's experiences and gain sociocultural understanding on a profoundly personal, empathic level.

In line with the field's foundational practice of focusing on the perspectives of disabled people, this collection brings together a wide range of disability experiences from contemporary students in the United States and Canada. The contributors provide insight into distinct disability experiences, from sensory impairments, chronic pain, cognitive and learning disabilities, mental illness diagnoses, and autism, to stuttering, spinal-cord injuries, memory loss, and post-traumatic stress. The narratives also reflect diverse ethnic, religious, class, cultural, and regional backgrounds as the authors reflect on experiences from childhood, from adolescence, and into adulthood.

As contributors grapple with barriers and belonging, they are also negotiating the interplay between the biological and the cultural. As disability studies scholars Lennard Davis and David Morris have pointed out, "The biological without the cultural, or the cultural without the biological, is doomed to be reductionist at best and inaccurate at worst" (2007, 411). While Davis and Morris focus largely on bridging humanities and science scholarship, their **biocultural** model provides a useful framework for situating the narratives in this collection. Biomedical conditions—whether sensory, physical, emotional, or cognitive—are constantly shaped by the cultural, and the writers of the chapters in this book capture crucial elements in the self-knowledge that results from this interaction.

This collection is designed to capture this process of disability knowledge formation. Through an autoethnographic lens, these chapters address a number of questions, including:

- How do people currently contextualize their experience of disability?
- How does disability studies matter—especially to disabled students? How does it shape or transform students' understanding of able-bodied and able-minded privilege and material relations of power?
- What work does disability theory perform to enhance biocultural understandings of disability?
- How can nondisabled peers better understand and critically analyze disablement as well as engage in confronting barriers and cocreating environments of belonging?

Social Approaches

Social approaches to disability are foundational to disability studies. Disability rights movements in many nations, in which groups demanded greater access to education, employment, housing, public spaces and

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services, and the support necessary to live independently, also articulated new frameworks for understanding disability. In coalition with disability activists, academic advocates—primarily from the social sciences—challenged the dominance of medical and rehabilitation fields as the key producers of disability knowledge. The **social model**, first introduced in the United Kingdom by physically disabled activists and scholars in the 1970s, has powerfully influenced disability studies (Oliver 1990; Shakespeare 2006). The model strictly distinguishes between **impairment** (the biological embodied difference) and **disability** (the social, structural, and attitudinal barriers that limit a person's participation and access to opportunities available to nondisabled citizens). The simplicity of this early model, often referred to as the **strong social model**, has been the source of its success but also of its weaknesses (Shakespeare 2006). The impact of the social model has been profound. Tom Shakespeare distills the strengths into three key areas: political effectiveness of building a social movement, instrumental effectiveness in supporting the passage of rights legislation, and psychological effectiveness in supporting positive self-esteem and a sense of collective identity for disabled people (2006, 30). At the same time, as feminist scholars pointed out early on (Crow 1996; Wendell 1996), the artificial separation of impairment and its disabling effects prevented discussions of the complications of illness, pain, chronic conditions, dependency, and care relations, as well as of the interconnected issues of gender, sexuality, ethnicity, and other social positions.

In the United States, social frameworks have been more aligned with a **minority group model** and coalitional rights approach. Activists in the 1960s and 1970s, such as Judith Heumann and Ed Roberts, worked in collaboration with people with a wide range of impairments, and disabled people came together to demand changes in built environments, social attitudes, and policy (Shapiro 1994). Disability rights leaders also learned strategies from civil rights activists, war protesters, and women's rights leaders, among other social justice groups. These social and theoretical histories are important to the field, but recent disability studies scholarship has integrated more interactional approaches that are mindful of the complex interconnectedness and contextual nature of impairment and disability. This is reflected in *Keywords for Disability Studies* (2015), in the editors' description of disability: "Although the social model predominates, in much recent scholarship, disability refers to a subjective state, the condition not only of identifying as disabled but also of perceiving a world through a particular kind of lens" (Adams, Reiss, and Serlin 2015, 8). In other words, disability experience, in relation to contextual and larger structural forces, functions as a core site of theoretical knowledge. As Michael T. Salter puts

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it in Chapter IV.5, "I changed my view of my PTSD [post-traumatic stress disorder]. . . . I refuse to be the victim, and I embrace this change."

Sharon Snyder and David Mitchell have powerfully formulated the interactional nature of impairment and disability through a **cultural model** framework, which insists that the meaning and experience of impairment and disability are intensely contextual and bound by social and cultural beliefs. In the cultural model, impairment is not simply a biological reality but a site of critical engagement: "Impairment is both human variation encountering environmental obstacles and socially mediated difference that lends group identity and phenomenological perspective." They suggest, further, that this more complex understanding of impairment is encompassed in the "*politicized* term disability" (Snyder and Mitchell 2006, 10; emphasis in original). This broader cultural definition allows disability to operate "both as a referent for a process of social exposé and as a productive locus for identification" (10). Individual experiences of impairment and disability produce important knowledge, which is always mediated by social meanings, personal context, and multiple other factors such as class, gender, sexuality, ethnicity, and citizenship.

Interactional social frameworks of disability, those informed by a combination of elements described above, are now well established and have shaped national and global approaches. In the United States, the passage in 1990 of the Americans with Disabilities Act (ADA), which codified a social dimension of disability by protecting people "regarded as" having an impairment, was seen as landmark legislation for acknowledging social biases against disability within the definitional prongs (it was amended in 2008; see Americans with Disabilities Act of 1990 2009). International definitions of disability, such as that of the World Health Organization (WHO), are even more specific in highlighting interactional social dimensions of disability:

> Disability is not an attribute of an individual, but rather a complex collection of conditions, many of which are created by the social environment. Hence, the management of the problem requires social action, and it is the collective responsibility of society at large to make the changes necessary for full participation of people with disabilities in all areas of social life. (2001, 20)

As this brief history demonstrates, social approaches to disability have shaped laws, policy, and international definitions. Notably, the shift in thinking from the individual and medical to the sociopolitical remains counterintuitive to people outside disability fields, but as many contributors make clear, it is also deeply transformational.

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Prevailing Themes

Across this collection, several key terms and themes in disability studies recur. We note these here to provide context, and we encourage readers to consider tensions and interconnections between these concepts. Because cultural meanings of disability are deeply bound up with medicine, rehabilitation, psychiatry, special education, and other professions, diagnostic categories have exerted a great deal of influence not only on medical and rehabilitation understandings of disability but also on individual and social perceptions. Disability studies has called attention to the power dynamics of this **naming process** and takes seriously activist and advocacy efforts to articulate, name, and "reassign meaning" (Linton 1998, 9) from personal and collective experiences. Within current health-care, education, and economic systems, diagnostic categories are crucial to claim coverage, gain access to appropriate services, and qualify for financial support. At the same time, individuals and subgroups often experience varying forms of **stigma** associated with specific disability diagnoses. Erving Goffman (1963) defined "stigma" as a socially discrediting attribute, one that results in a form of **spoiled identity**, which he saw as a process of being classified, stereotyped, and socially excluded based on one negative attribute. Tracing the enduring relevance of stigma in relation to disability, Lerita Coleman Brown (2013) sees the unequal relationship between the **stigmatized as inferior** and the **nonstigmatized as superior** as crucial to understanding how stigma continues to function. In this power dynamic, nonstigmatized people assert their privilege by conveying the social inferiority of stigmatized individuals and groups through "social rejection," especially "social isolation and lowered expectations" (Brown 2013, 154).

Several contributors address personal experiences of stigma, describing feelings of inferiority, social rejection, internalized shame, or fears of social isolation. For example, Megan L. Coggins, who lives with schizoaffective disorder, shares in Chapter V.3, "I still struggle with prejudices and issues of stigma. I often hear, when I share my story, that I do not 'look sick.'" Each response to stigma is unique, and every narrative reframes disability on its own terms; part of this process is critical engagement with naming. Some people resist stigma by proudly self-disclosing or claiming a diagnosis, while others resist labels or assert the power to rename, reclaim, or resignify their condition.

The social rejection of disabled people and the use of disability rhetoric to mark specific groups as inferior have long histories. Documenting and resisting historical and contemporary stigmatizing uses of disability, as well as rescripting disability as positive, integral, or generative—or further,

as transgressive, edgy, or sexy—is at the heart of disability studies. New terms, introduced by disability activists and scholars, have been central to resisting the stigma that is still associated with disability. The term **non-disabled**, for example, is used in disability studies to decenter and mark the social privilege embedded in the terms "able-bodied" or "able-minded" (Linton 1998). Contrasting **disabled people** with **nondisabled people** calls attention to the constructed nature of both positions. Similarly, Rosemarie Garland-Thomson (1996) introduced the term **normate** to signify a category of multiple privileged positions, in which able-bodied privilege becomes interlinked with white privilege and heterosexual, gender, class, religious, and other forms of privilege. As Rodney B. Hume-Dawson, in Chapter VI.3, keenly recalls of his childhood in Sierra Leone, "Most of the people who loved me wanted me to walk the 'normal' way. For some of them, the implications of what that meant did not matter. As long as I walked like them, that was what was important." Blake Culley (Chapter III.3) embraced such normative pressures as well; as a deaf child, she wanted to be "normal" and worked to convince her hearing classmates that she was not like the other deaf students, who were seen as being "behind in their education."

Even with tools to expose such privilege, **normative pressures** on disabled people are often intense. Indeed, in order to resist internally damaging emotions or internalized shame, many disabled people assert some form of positive **disability identity**, which, while its meaning varies for different people, has come to reflect political orientation with disability rights and justice; to many, it has become an assertion that disability is integral to, not separate from, one's sense of self and understanding of the world—that disability shapes and informs one's membership and participation in communities and groups. Identity claims also work to gain recognition for an impairment that, while unseen, shapes one's political affiliation and activism. Allegra Heath-Stout cites such a moment in Chapter V.1:

> "But you're not disabled!"
>   I stare at my friend from just inside his front door on our college campus, watching as he takes in the sight of my bright purple T-shirt emblazoned with "Disabled and Proud." I am taken aback by his declaration. Finally I respond, "Yes, I am. I have learning disabilities."

While some writers assert strong disability-pride identities, others resist identity claims as political strategy toward social change. Building on Robert McRuer's influential *Crip Theory*, many disability studies scholars have reclaimed the term "crip" to signal an orientation toward disability and a resistance to compulsory able-bodied and able-mindedness, as well as to challenge the stability and coherence of identity (McRuer 2006; Kafer

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2013). The narratives in this book engage with these tensions—with the importance of identity to an affirmative self-concept as well as to its fluidity and instability.

Connected to this, in addressing the unique and heightened **stigma of psychiatric disability**, some contributors with mental illness diagnoses reclaim the term **madness** to openly reject assumptions of incompetence and to challenge false binaries between sanity and insanity. Shayda Kafai explains in Chapter I.2, "I became aware of the power inherent in claiming this aspect of my identity, of reframing it in a context distinct from the stereotypes that had for so long dominated my understanding of madness." Further, Rebekah Moras explicitly traces important overlaps between madness and disability studies. As Moras describes in Chapter VI.5:

> Through disability studies, I am accepted and nurtured, as much in times of active madness as in those of relative balance. . . . I have been able to work with feminist and disability-positive practitioners who have supported me in framing my experiences within social and institutional contexts and who have not solely individualized my madness.

Historically, one of the gaps in disability studies has been a predominance of focus on physical disability. In recent years, however, there has been a surge of scholarship in the field focused on disabilities of the mind—from cognitive, intellectual, and developmental disabilities to trauma, autism, and psychiatric disabilities. Margaret Price coined the term "**mental disability**" (2011, 9) to link these broad categories and to analyze their sociocultural connections. However, while this proves useful in some instances, it runs the danger of drawing too sharp a line between the physical and the mental. Price has grappled with this issue herself and has recently suggested the term "**bodymind**" (2015, 269) to signal the impossible separation between bodies and minds, and as a more accurate container for the complex interaction between mental and physical processes. This term is a useful placeholder in a field that has been more focused on corporeal and visible markers of difference than on cognitive impairments and mental diversity.

In fact, the complicated difference between **visible** and **invisible disability** is another recurring theme, and the boundaries between them, like those between mental and physical disabilities, are often porous. Having an invisible disability—like chronic pain, migraines, illnesses, and, for some, autism—brings up questions of **self-disclosure**, **passing** as able-bodied or able-minded, or having to assert one's disability status against others' visual assumptions. Strictly speaking, most disabilities encompass a range of (in)visibility, much of which is situational. People with chronic pain, for

example, may be perceived as more or less disabled depending on whether they are using a cane or a scooter, but their experience of pain may be much the same. As Catherine Graves writes in Chapter III.2, "The natural tendency is to associate disability with physical appearance. If you don't look sick, you must not be sick. I often wish I changed colors to reflect my pain and fatigue levels, so I could say, 'See, I told you I don't feel well.'" Price suggests that many disabilities are neither visible nor invisible "but *intermittently* apparent." Further, she suggests, "A better metaphor than vision for some kinds of disability might be *apparition*. Consider the act of stimming, a repetitive behavior such as snapping a rubber band against one's wrist, or tapping one's fingers" (2015, 272; emphasis in original). Indeed, many disabilities might be better described as **apparent** and **nonapparent**, depending on the context of the encounter. These terms push against sight as perceptual norm; moreover, they are meant to call attention to the transitory and situational nature of individual disability experience and expression.

Overview of Parts

> Gone are the days when the focus of telling one's disability story was about overcoming one's challenge. For me and many others whose work I have been privileged to read, our focus is not so much on the triumphant aspects of our lives but on telling the story from a social perspective.
> —Rodney B. Hume-Dawson, Chapter VI.3

In an effort to revisit key concerns and highlight commonalities across disability experience, we have organized the chapters in this book into six parts, often grouping together work by authors with quite different **impairment effects**—the individual complications and adaptations to specific conditions—but united by similar sociocultural concerns and perspectives. This structure is meant to circle back to foundational concepts and themes, deepening complexity and insight for readers as they move through the collection. At the opening of each part, we provide brief introductions to the chapters included as well as questions to frame readings and promote discussion. In these introductions, we have made key terms and phrases boldface. Most of these concepts are defined explicitly, but others are meant to serve as critical reflection prompts for readers to investigate on their own. We encourage students to use the boldface terms as themes to focus on while reading and as elements for discussion. At the end of each part, we offer suggestions for additional pairings and linkages across the collection as an invitation to broader conversations about the diverse perspectives included.

The chapters in Part I, "Laying the Groundwork," introduce foundational themes in disability studies—themes that echo throughout the collection.

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Authors explore key sociocultural issues that shape what disability has come to mean in their lives. These issues include the personal impact of (in)accessible environments, the complexity of mental illness diagnosis and its relationship to disability rights, and the distinctions between apparent and nonapparent disability. Most importantly, these chapters provide a glimpse into the range of experience—from ableist discrimination and cross-cultural diversity to internalized shame and the creative adaptations of everyday living.

Part II, "Families, Adaptive Living, and Reorienting Expectations," is grounded in the ways family systems shape and transform ideas about disability. Children come to understand their impairments and develop a sense of self through their parents' and family members' orientation toward—or away from—disability. In addition, as a few narratives demonstrate, parents who have disabilities often develop adaptive strategies centered on physical, sensory, or cognitive differences; inevitably, children and partners participate in these processes. In the best situations, families are involved in fostering inclusion and promoting environments of radical belonging, but family dynamics are often complicated by normative pressures and dominant negative assumptions about disability.

The chapters in Part III, "Disability and Communication," consider multiple layers of interpersonal exchange, including hearing and speech acts, artificial but persistent social demands for disclosure, and the (im)possibility of accurately communicating hidden and variable disabilities. This section links the following broad questions: What are the complications of communicating about disability? What constitutes "aberrant" communication, and how do disabled people navigate normative expectations and pressures to conform? Building on the potential embedded in difficult conversations, Part IV, "Mapping Complex Relations," explores aspects by which disability informs, challenges, and enlivens relationships and mutual communication. Authors disclose vulnerabilities and adjustments to disability, focusing on how disability has affected or changed friendships, families, and broader social relations, including (dis)connections with civilian and military contexts. Further, these narratives encourage readers to reexamine their own relations to disability, to disabled people, and to the beliefs and practices that shape their personal perceptions of diverse bodyminds.

Part V, "Identity, Resistance, and Community," explores myriad ways in which disability informs personal identity, social relationships, community affiliations, and political commitments. Several contributors describe how disability studies has contributed to personal empowerment and philosophical reorientation toward disability. These chapters reveal intricate connections among integrating disability into a positive self-concept, resistance to ableism, and participating in communities that are both sustaining and

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sustainable. Finally, in Part VI, "Theories and Lives," narratives focus on ways in which disability studies theories have both influenced and transformed authors' self-perceptions, political concerns, and professional goals. Included are chapters by student activists and graduate students pursuing scholarly research in disability studies. These narratives critically examine the enduring effects of structural ableism, the ongoing necessity of expanding sociocultural knowledge of disability, and the ever-present need for disability activism.

While themes reverberate and overlap across the book as a whole, these narratives underscore the incredible diversity of **bodymind experience**. In disability studies, the blurring boundaries of disability are constantly in motion, and the field opens itself to a capacious understanding of the term itself—in which anxiety speaks to blindness, Deaf identity opens to mad pride, neurodiversity bumps up against PTSD, and acquired impairments are juxtaposed with congenital conditions. As the narratives in this collection demonstrate, students welcome the critical lens of disability studies; at the same time, many, through their own experiences, engage in a process of stretching their own understanding—and in some cases of nudging the field—to make room for new, yet resonant, insights. These narratives, these stories, weave new threads into a vibrant, colorful, and diverse tapestry that celebrates—and struggles with—the messy richness of disability experience.

Orienting toward Relations

As these contributors critically reflect on experiences of disability, they capture over and over the relational nature of disability. At times, they describe how disability may complicate, trouble, or foreclose relationships, but just as often, and more importantly, these narratives illustrate new relational formations. Rosemarie Garland-Thomson's (2011) articulation of **fitting** and **misfitting** provides a useful framework for a relational reading. These terms provide theoretical flexibility for looking at interactions between bodyminds and environments. Garland-Thomson explains, "When we fit harmoniously and properly into the world, we forget the truth of contingency because the world sustains us. When we experience misfitting and recognize that disjuncture for its political potential, we expose the relational component and the fragility of fitting" (597). This dynamic process corresponds to this book's overarching framework of barriers and belonging. While much can be learned through identifying barriers and contexts that produce misfitting, new models for relationships and communities are brought to life as contributors recount fitting spaces—environments of belonging. Zachary A. Richter captures this juxtaposition in Chapter I.6: "In the case of my most dominant pathology, the symptoms at first separated me from other

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people . . . but they now unite me in solidarity with a wider community through my new self-identification as autistic."

Ultimately, as these autoethnographic narratives shed light on the nuances of environmental, attitudinal, and systemic barriers, they invite readers to think more expansively about relations of access, to consider privilege and subordination, and to work toward creating locations of belonging for everyone. Many writers reflect on family systems, mapping out what Rayna Rapp and Faye Ginsburg call a new "kinship imaginary," in which the presence of disability in a family "catalyzes new forms of activism that are reshaping . . . communities" (2011, 381). Parent advocates such as Joanne De Simone (Chapter II.3) and Tricia Black (Chapter II.4) participate in such kinship reframing, as do many family members and partners of the contributors. Beyond family systems, many narratives map out participation in politically active disability communities. Like Zachary A. Richter, other contributors, such as Allegra Heath-Stout (Chapter V.1), Denton Mallas (Chapter V.6), Adam P. Newman (Chapter VI.4), and Lydia X. Z. Brown (Chapter VI.6), experience belonging in activist, cultural, and academically rich disability communities. In such groups, they are engaged in what Alison Kafer calls the "political/relational model" (2013, 6) of disability, in which people come together through affinity and political affiliation. Through a relational orientation, everyone invested in integrating disability into the fabric of human variation has a role to play in the creation and establishment of new models of collaborative living. This collection invites readers to self-reflect upon and expand their own relationships to disability—to break down barriers and make possible a sense of radical belonging—not through blurring, diminishing, or transcending diversity in bodies and minds but through critical engagement across difference.

NOTE

1. The most accurate and up-to-date list of disability studies programs in the United States and Canada is maintained by the Disability Studies program at Syracuse University; see the list at http://disabilitystudies.syr.edu/programs-list.

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