

BODIES IN CULTURE, CULTURE IN BODIES:
DISABILITY NARRATIVES AND A RHETORIC OF RESISTANCE

by

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DEDICATION

For Jason: I think of you and I am not afraid.

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CHAPTER ONE: INTRODUCTION—BODIES IN CULTURE, CULTURE IN BODIES: CONNECTING DISABILITY STUDIES AND RHETORIC

In the following dissertation I historicize dominant discourses of disability and place my analysis of five published disability narratives in dialogue with those discourses in order to show how the authors of these narratives craft alternative rhetorics to resist representation that casts them as unsuited to public space. Critical to my dissertation is my belief that personal narratives by rhetoricians with disabilities are invaluable sites of rhetorical inquiry, especially in light of the marginalized subject position of people with disabilities in the larger culture. Because my dissertation connects rhetoric and disability studies, my purpose is two-fold. For rhetorical theorists, I argue that attention to dominant discourses of disability and the alternative rhetorics in disability narratives can expand our present understanding of rhetorics of the body to interrogate: (1) who has the authority to speak and who doesn't; (2) who the dominant culture grants the position of subject and who the dominant culture sees as inherently "Other" or object; and (3) how differing intersections of identity as configured by the actual appearance of the body can often determine whether or not the body "speaks" or is "spoken of" and, in conjunction, whether or not that body is heard, ignored, or silenced. For disability studies scholars, I hope to rediscover the disability narrative as a genre that provides people with disabilities an opportunity to make meaning of their embodied experiences and their material circumstances while simultaneously addressing the ways in which disability itself is also a social construction similar to race, class, and gender. In order to situate my project, I utilize my introductory chapter to: (1) define key terms such as disability, narrative, and a rhetorics of resistance; (2) provide a literature review of work on rhetorics of the body

and scholarship in disability studies in order to show how my work both intersects with and extends lines of inquiry in each of these areas; and (3) provide an outline of my chapters and their purposes.

Defining Disability: Expanding the Social Model

As disability studies theorist Simi Linton points out, the medical model and the overcoming model of disability dominate popular conceptions of the disabled experience. The “medical model” of disability casts disability as an individual “pathology” and sets as its goal the “normalization” of the individual through intervention or cure, while the “overcoming model” constructs disability as a personal loss or tragedy and therefore the responsibility of the individual to conquer through determination and will (11). As a scholar and as a person with a disability, I eschew these models and take as a starting point for my definition the “social model” first developed by the Union of the Physically Impaired Against Segregation in Great Britain in the early 1970s (Shakespeare 197). The social model conceives of disability as a socially constructed difference such as race, class, and gender. While supporters of the social model acknowledge that physical and mental impairments do indeed exist, they argue that disability itself is primarily a product of society’s unwillingness to accept or accommodate differing configurations of both the body and mind.

I also support the “civil rights model” of disability embraced by disability rights activists in the United States as a means of claiming that people with disabilities make up a “discrete and insular minority” that has experienced a long history of discrimination on the basis of physical difference (Johnson, *Make Them Go Away* xv). As legal scholar

Matthew Diller notes, the Americans with Disabilities Act of 1990 relies on the civil rights model by: (1) “identify[ing] discrimination, and a resulting inequality, as the central social issues people with disabilities face” and (2) “establishing a framework of relationships in which employers and public institutions have a responsibility to facilitate the social integration of people with disabilities” through the application of principles of access and accommodations (65).¹

However, I also note how the social and civil rights models (in an understandable and justifiable attempt to move away from the assumptions embedded in the medical and overcoming models that essentialize impairment as individual pathology or personal tragedy) neglect the ways in which the embodied experience of impairment shapes the lives of people with disabilities. Feminist disability theorist Liz Crow argues that in an effort to concentrate on the ways in which disability is a social construction that leads to the oppression of people with disabilities, many disability studies scholars and disability rights activists have fallen silent on the subject of embodied experiences of impairment for fear of reifying the medical and overcoming models of disability (209). Crow asserts that such a silence belies the exigencies of living with a disability when she states:

Most of us simply cannot pretend with any conviction that our impairments are irrelevant because they influence every aspect of our lives. We must find a way to integrate them into our whole experience and identity for the sake of our physical and emotional well-being, and, subsequently, for our capacity to work against Disability

¹ Matthew Diller—along with many other legal scholars—notes the failure of the ADA to be interpreted by the courts as civil rights legislation, a phenomenon Linda Hamilton Krieger describes as a “backlash” in the introduction to her collection *Backlash Against the ADA: Reinterpreting Disability Rights*. I will discuss the implications of my work in relation to this scholarship further in my conclusion to this dissertation.

[as a social construction and a site of oppression] . . . (227)

In this sense Crow argues for a more holistic model of disability that acknowledges the particularity of bodily impairment as a major factor in the material, lived, and embodied experiences of people with disabilities. Feminist philosopher Susan Wendell similarly posits a more holistic model when she urges disability theorists and disability rights activists to consider the particular challenges of impairments associated with chronic illness. Wendell explains:

chronic illness frequently involves pain, fatigue, dizziness, nausea, weakness, and depression, and/or other impairments that are difficult to ignore. Everything one does, including politics, must be done within the limitations they present. The need to accommodate them is just as great . . . as the need to accommodate blindness or hemiplegia, but they cannot be accommodated unless they are acknowledged and discussed openly. (23)

Both Crow and Wendell argue that incorporating the specific embodied experience of impairment into our models of disability will prove liberatory for people with disabilities: Wendell observes that people with chronic illnesses will better be able to work toward social change for all people with disabilities if their particular experiences of impairment are addressed and accommodated, while Crow argues that enabling people with disabilities to make meaning of their specific experiences of impairment on a lived, embodied, material level will allow them to attend to the exigencies of pain and limitation that accompany certain impairments and, at the same time, more fully

participate in the process of deconstructing mythologies of disability that exclude them from public life.

The work of Crow and Wendell has thus allowed me to consider the embodied experience of impairment critical to a more comprehensive and inclusive understanding of disability. Therefore, when I speak of disability in this dissertation, I will be considering the category as the nexus of: (1) the embodied experience of impairment as felt and lived by people with disabilities and (2) the social construction of impairment that has served as justification for discrimination based on physical difference. In this sense, my use of the phrase “bodies in culture, culture in bodies” as the beginning of the title of my dissertation attempts to locate disability as both the lived experience of particular bodies in culture and as a cultural construction that has weighted these particular bodies with the ideological freight of deviance and lack, thereby contributing to their marginalization as “objects” or “Others.”

Toward an Inclusive Theory of Rhetorics of the Body

As Jack Selzer notes in his introduction to the collection *Rhetorical Bodies*, it is only recently that rhetorical scholars have begun to uncover “material, nonliterate practices and realities—most notably the body, flesh, blood, and bones” as “legitimate areas of rhetorical scrutiny” (10). As justification for this project, Selzer presents four scenarios in which bodily forms and experiences are made expressly rhetorical. First, he offers the case of the Baroness Elsa von Freytag-Loringhoven, who, as part of New York’s post World War I artistic community, shaved and painted her head, wore hats trimmed with vegetables instead of flowers and feathers, and literally “inscribed” her

own verses of poetry on her torso for other to read (4). Next, he provides a poem by John Donne in which the author “imagines” his body a text read by his doctors after his death (4-5). Selzer argues that Loringhoven’s and Donne’s acts are “rhetorics of the body” in that each rhetorician utilizes his or her own body symbolically to make a statement to a particular audience about the nature of life and art (as in Loringhoven’s case), and death and a supreme deity (as in Donne’s case) (8).

The next two cases Selzer discusses are ones in which the dominant culture co-opts bodies that are considered “less-than human” based on ethnicity, sex, or ability, and represents these bodies as spectacles meant to shock or entertain. Selzer introduces Saartjie Baartman (also known as the “Hottentot Venus”) whose body, living and dead, was displayed in London and Paris as a main attraction in the freak shows of the nineteenth century.² Baartman’s body was framed as a curiosity—even a monstrosity—because of her voluptuousness, particularly in relation to body parts seen as sexual, such as lips, breasts, and buttocks. Often Baartman’s body was placed alongside the living body of a white European woman, young, slender, demure, and fully clothed, to mark the physical contrast between the two. Selzer points out that freak show advertisers, writers, and scientists represented Baartman’s body as proof of the African woman’s primitivism and sexual promiscuity, as opposed to the white European woman’s refined and modest nature (5). Finally, Selzer discusses the “living mascots” of baseball teams at the turn of the twentieth century, a number of which were hunchbacks or African-American (otherwise know as “coon”) mascots (6). These bodies were framed by the dominant culture as good luck charms and team pets as they served the players, performed

² In Chapter Five of this dissertation, I work further with the concept of the disabled body as “freak” by utilizing Rosemarie Garland Thomson’s theory of the freak show detailed in her 1997 book *Extraordinary Bodies: Figuring Disability in American Culture and Literature*.

comedically for crowds, and offered up their heads (in the case of the “coon” mascots) or humps (in the case of the hunchbacks) to be rubbed before the players went up to bat. In these ways, the bodies of the African-American and disabled mascots were dehumanized, reproduced as spectacles, and commodified as living advertisements for baseball teams. In making his case for the study of rhetorics of the body, Selzer claims that “the real-life Hottentot Venus and the real-life mascots were living bodies that came to bear ideological freight which writers then translated into text for social purposes” (8). In the end, he collapses all of the instances he describes (the cases of Loringhoven, Donne, Baartman and the mascots) into what he calls a group of “vignettes” that reveal the ways in which these “material, embodied events” are all “rhetorical events in one way or another” (8).

I take as a starting point for this dissertation Selzer’s claim that bodies come to bear “ideological freight” in a culture that assigns values to a variety of physical and physiological traits and experiences (8). However, I also hope to provide a corrective to his discussion of these “material, embodied events” broadly construed as simply a “series” of instances so similar to one another that taken together they prove that “rhetoric has a specific material aspect that demands acknowledgement” (8). I argue that these events in fact reveal much more about rhetorics of the body than Selzer indicates, primarily because he fails in his analysis to examine the subject positions of Loringhoven, Donne, Baartman, and the mascots. I believe it is certainly not a coincidence that Loringhoven and Donne, who made their own decisions about how to represent their bodies, were members of privileged ethnic and class groups—white and elite—and, in Donne’s case, granted the knowledge-making authority of the male. In this

sense, the cultural meanings these two bodies had already accrued as visible members of privileged groups assisted in empowering them to use rhetoric to create their own meanings of their bodies. Conversely, Baartman and the mascots, already visibly marked as “inferior” by differing configurations of race, sex, class, and ability, were represented in contexts that depended on their objectification and therefore deprived them of the agency necessary to take control of one’s representation. In fact, one can assume that their very livelihood depended on allowing those in power to do it for them.

For this reason, I believe that a thorough conceptualization of the body as a site of rhetorical study cannot only interrogate: (1) how privileged bodies choose to represent their own bodies through language and symbols and (2) how privileged bodies choose to represent “other” people’s bodies through language and symbols. If rhetorical scholars adhere to such a theoretical frame, every rhetorical act related to the body would be analyzed in light of the dominant culture’s ability to make meaning—and the voices of those who are marginalized or “other”ed would be lost. My study of dominant discourses of disability and of disability narratives as a rhetoric of resistance works to recover those voices by extending Selzer’s definition of “rhetorics of the body” to include the examination of: (1) how the ideological freight the disabled body carries may actually preclude the creation of rhetoric in particular situations; (2) how people with disabilities find opportunities to be “rhetors of the body” in a culture that largely denies them voice; and (3) how the disability narrative can serve as a means for people with disabilities to take control of their representation in order to resist objectification.

Rediscovering Disability Narratives in the Field of Disability Studies

In their introduction to the 2008 collection *Disability and the Teaching of Writing: A Critical Sourcebook*, Cynthia Lewieki-Wilson and Brenda Jo Brueggeman define disability studies thusly:

Rather than viewing disability solely as an individual-based deficiency or pathology, or through the lens of medical or therapeutic discourses, disability studies . . . draws on critical, social and constructivist theories in order to understand disability in the contexts of history, culture, and society. Among the issues disability studies looks at are the way disability has been interpreted historically and within varying cultural contexts; . . . political and material circumstances resulting from the assignment of value to certain kinds of bodies; . . . how language and rhetoric shape attitudes toward disabled people . . . the list could go on and on. (1-2)

In Lewieki-Wilson and Brueggeman's definition, there is a clear intersection between work in the area of rhetorics of the body and disability studies as a field of inquiry. In the following dissertation, I consider "how disability has been interpreted historically and in varying cultural contexts" in chapter two and in chapter four. In chapter two I discuss the use of the war metaphor to characterize disease, and in chapter four I discuss the ways in which people who use wheelchairs have been framed as either invalid in body and in character or as imprisoned, literally and figuratively, by their chairs. In chapters three and five, I examine the ways people with disabilities use the personal narrative to contest the "value assigned to their bodies" when I argue in chapter three that Rik Carlson and

Dorothy Wall craft alternative metaphors of disease to respond to a cultural erasure of their embodied experiences with ME/CFS,³ and again in chapter five, when I argue that Harriet McBryde Johnson, John Hockenberry, and Dean Kramer embark on a process I term “defreaking the disabled body” to challenge dominant discourses that frame their bodies as deviant and thereby inferior.

Yet in Lewieki-Wilson and Brueggemann’s overview of disability studies a discussion of disability narratives is conspicuously absent. They point to “how language and rhetoric shape attitudes toward disabled people,” but they do not mention how disabled people are using language and rhetoric to shape *themselves*. Perhaps one could imagine this is implicit. However, I believe Lewieki-Wilson and Brueggeman most likely omit mention of disability narratives as a means through which disabled people “use language and rhetoric” to reconsider the “value assigned their bodies” because there has been a long history of dismissal of the personal disability narrative in the field of disability studies.

In his influential book *Enforcing Normalcy: Disability, Deafness, and the Body*, Lennard Davis makes the claim that “in narrativizing an impairment, one tends to sentimentalize it and link it to the bourgeois sensibility of the individualism and the drama of the individual story. . .” (4). In the first edition to *The Disability Studies Reader*, published in 1997, Davis extends his critique of disability narratives when he contends that narratives written “from the perspective of having a disability . . . tend to be written so that normal people might know what it is like to be blind, crippled, deaf, and so on . . . the

³ ME/CFS, or Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, is most commonly known in the United States, at present, as Chronic Fatigue Syndrome (CFS) or Chronic Fatigue Immune Dysfunction Syndrome (CFIDS). In chapters two and three I more thoroughly discuss both the nature of the disease and the variety of names it has been assigned.

danger of that kind of project is that it is embarked on with the aim of evoking “sympathy” or “understanding” (4). Disability studies scholarship, he argues, “shuns this unequal power transaction in favor of advocacy, investigation, inquiry...and deconstruction” (5). Here Davis assumes that writers of disability narratives do not engage in the activities of “advocacy, investigation, inquiry...and deconstruction”; in fact, he seems to argue that the two categories of work—disability narrative and disability studies scholarship—are mutually exclusive. He implies that a person who would write a disability narrative could not possibly possess the critical facility to do disability studies scholarship—and therefore that it would be impossible for a disability narrative writer to use the means and achieve the ends of disability studies scholarship at the same time. I believe it is important to note as well that in the second edition of *The Disability Studies Reader*, published in 2008, the year I finished this dissertation, Davis reprints the same introduction. Ten years later, disability narratives are cast in the same way.

Other disability studies scholars have followed Davis’ lead. In their 2004 book *The Body and Physical Difference: Discourses of Disability*, David T. Mitchell and Sharon L. Snyder argue:

First-person narratives of disability have historically fed a public appetite for confessional writing that promises the revelation of personal catastrophe as the evidence of a more truthful access to secreted lives. The confessional mode places physical and cognitive limitation on display to be consumed, and the mainstream parading of personal misfortune inevitably assures the reader/viewer of his or her comparative good fortune or assuages a shared societal sense of guilty and insensitivity.

Disability falls readily into conventional scenarios of triumph over tragedy or stories of saintly suffering where the afflicted fades away (physically and intellectually) into private martyrdom. (10)

When they allude to “personal misfortune” and “triumph over tragedy,” Mitchell and Snyder are referencing two dominant cultural mythologies of the disability—the medical model and the overcoming model—that I discuss at the beginning of this chapter in my definition of disability and develop more thoroughly in relation to my argument in chapters one and three. Mitchell and Snyder seem, then, to be arguing that no disability narrative author has been or ever will be able to challenge those models or construct new ways of understanding disability. They point to Nancy Mairs, the author of several widely anthologized personal essays on her experiences with multiple sclerosis, as a particular example of a disability narrative writer whose concerns are private and individual; they contend that by focusing on “her interior life” and the “hassles” of “being crippled,” Mairs directs attention to her personal history of “limitation” in a way that casts disability as a means for herself—and her readers—to “use disability to burrow down into the psychic and physical depths of human affairs” rather than as a means to look outward and engage in cultural critique (10).

In Mairs’ introduction to her 1996 book *Waist High in the World: Life Among the Nondisabled*, she includes a passage that characterizes her project as:

a Baedeker for a country to which no one travels willingly: the observations and responses of a single way-farer who hopes, in sketching her own experiences, to make the terrain seem less alien, less perilous, and far more amusing than the myths and legends about it would suggest. (6)

Mairs' description of her purpose seems at once to uphold and contradict the assertions made by Davis, Mitchell, and Snyder that dismiss disability narratives as valuable sites inquiry for disability studies scholarship. When she describes her work as a "Baedeker," she invokes the genre of the travel guide, which one can assume is used by people who need one—that is, people who are just visiting. Mairs, then, implies that she is writing to an audience of people who identify as nondisabled. Thus, one could easily characterize her book as, in Davis' words, "written for the normal," and, imagined through the eyes of Mitchell and Snyder, designed to feed nondisabled people's seemingly insatiable appetite for hearing about how tragic it is to live "in a wheelchair."⁴ By describing herself as "a single way-farer," one could assume that she is posing disability as an individual problem, and casting herself as a solitary figure divorced from a community of people with disabilities or from cultural constructions of disability. Yet she also references "the myths and legends" of disability, which reveals that she is conscious of the ways disability has been socially constructed and how her body may have been ideologically freighted as a result of those constructions. And she makes clear that part of her hope is to change preconceptions about what it means to be disabled—by narrating her experiences as a person with a disability (which, according to Davis, is synonymous with sentimentalizing it). In essence Mairs claims to set out to do in her personal narrative of the experience of disability almost everything Davis, Mitchell, and Snyder say a disability narrative writer always does, and everything Davis, Mitchell, and Snyder say a disability narrative writer never does.

⁴ I use the phrase "in a wheelchair" advisedly—as a means to make a point about how dominant discourse characterizes people who use wheelchairs as essentially passive. See chapter three.

Curiously, in a 2002 collection on disability studies and the humanities, Snyder (along with co-editors Brenda Jo Brueggemann and Rosemarie Garland Thomson) includes an essay by Nancy Mairs as an exemplar of “how disability autobiography can contest current ideologies about disability” (8). One can only imagine how and why Snyder came to change her position on disability autobiography in particular or Mairs in general so abruptly and without explanation. However, I would like to note here that Mairs’ work within the field of disability studies scholarship is often regarded as the exception that proves the rule in relation to people with disabilities writing about their embodied experiences as disabled subjects. In this dissertation I argue that there are many other authors of disability narratives, both inside and outside of the academy, whose body of work can be considered as a whole to be a rule that proves the exception. I do not analyze Mairs’ work in this study because I believe her visibility in the academy⁵—while enormously important for the project of re-envisioning disability and incorporating disability narratives into disability studies—points to the relative invisibility of other disability narrative authors whose work is equally valuable to the project of disability studies.

In addition I hope that my dissertation will make a larger point that disability narrative authors who do not are not members of the academy also engage in the work of cultural critique. None of the authors whose work I analyze in depth in chapters three and

⁵ I used portions of this dissertation as part of my research presentation during my campus visits while I was on the job market. At each university I visited, an audience member would ask me why I had not included Nancy Mairs. In a similar vein, when people in the academy learn I have multiple sclerosis, many do the verbal and visual equivalent of snapping their fingers, pointing at me, and exclaiming: Nancy Mairs! This is completely understandable, and it is a privilege to be associated with Mairs and an honor that my work is seen as speaking to her work, but I also hope that Mairs’ work, my work, and the work of others in the academy who incorporate their subject positions as people with disabilities into their scholarship will open up possibilities for the inclusion of a greater diversity of perspectives on the embodied experience of disability.

five claim to write from a disability studies perspective, but all of them demonstrate an acute awareness of how dominant cultural constructions of disability have shaped their experiences as disabled bodies in culture. Rik Carlson and Dorothy Wall consider how their embodied experiences of ME/CFS have been rendered invisible by a culture that views disease primarily in terms of whether or not it can be cured, while Hockenberry, Johnson, and Kramer discuss the ways in which their physical differences have been cast as abnormal in a culture that views disability through the lens of deviance. None of these writers come out of the academy: Hockenberry writes from the perspective of a reporter and cultural commentator on disability rights issues; Harriet McBryde Johnson is a lawyer who concentrates on disability rights and a lead organizer of the ongoing campaign to protest the annual Jerry Lewis Muscular Dystrophy Association Telethon; Kramer serves as a speaker and writer for the National Multiple Sclerosis Society; Wall works as an editor and publisher and self-identifies as an activist in the movement to create a new name for the embodied experience of ME/CFS; and Carlson is a self-described ex-waterbed salesman who now runs the Vermont ME/CFS Association. Far from fading into obscurity at the close of their narratives, as Mitchell and Snyder claim disability narrative authors are wont to do, each of these writers end their narratives continuing to work in their chosen professions and engage in advocacy on behalf of the disabled community. In this sense, their narratives can be seen as part and parcel of a body of activist work.

Defining Narrative as Rhetoric and Disability Narratives as a Rhetoric of Resistance

I believe that the use of the term “autobiography” to describe personal narratives of disability may inhibit the recuperation of the disability narrative work that can operate simultaneously as a means to: (1) bring the embodied experience of disability into public space and (2) critique dominant cultural constructions of disability. As Georgina Kleege notes in an essay on teaching disability autobiography in the college classroom:

The standard charge scholars make against disability autobiographies is that they reinforce cultural stereotypes and hinder social change. These texts, such critics argue, perpetuate the notion that disability is a personal tragedy that happens to an individual rather than a set of cultural structures and practices that affect many disability narratives. As a writer and reader of disability autobiography, I believe it is possible to use one’s personal experiences to comment on the culture one inhabits. (206)

Here Kleege and I are in complete agreement. Yet I am disinclined to use the term “autobiography” to characterize personal writing by people with disabilities because, as women’s studies scholar Sidonie Smith argues, the genre itself has historically served as a means to reproduce the domination of a “universal subject [with] a hard nut of normative . . . individuality” (3). Sidonie Smith theorizes the “I” in autobiography as a “self . . . founded on exclusionary practices . . . position[ed] on the border . . . of that which becomes identified culturally as other, exotic, unruly, unrational, uncivilized, regional, or paradoxically unnatural” (11). Ultimately, Smith argues that autobiographies by women writers and theorists such as Virginia Woolf, Gertrude Stein, and Zora Neale Hurston are able to rewrite the “I” to include the subjectivity of bodies marginalized by

the identity configurations of gender, race, and class. However, I believe it is important to consider that disability studies theorists may dismiss disability autobiography as a site of resistance to dominant discourses because they view the genre in the context of Smith's review of its history: as part of a Western tradition that centralizes a "universal man . . . [on] a romantic journey toward the core of his being" (15).

Literary and disability studies scholar G. Thomas Couser, for instance, examines autobiographies by people with disabilities in terms of the ways the pressures to conform to the conventions of the genre and the cultural expectations of the audience may constrain these authors' ability to make new meaning of the disabled experience. For instance, he explains that autobiographies traditionally involve a comic plot and theorizes three primary stories writers of disability autobiography tell in order to achieve that end, including: (1) the story of "triumph over adversity," (2) the story of "recovery and correction," and (3) the story of "spiritual compensation" (79-81). Each of these ways of framing disability, he argues, makes meaning in precisely the ways dominant culture already conceives of it—as a condition to be overcome, to be cured, or to be accepted as part of a divine plan.

Because personal writing on the subject of disability—when viewed through the lens of autobiography—has often been theorized by disability studies scholars as reifying cultural mythologies of disability such as those Couser describes, I have chosen to utilize the term "disability narratives" to characterize the work of Carlson, Wall, Hockenberry, Johnson, and Kramer, with a specific focus on the definition of narrative⁶ as rhetoric.

⁶ Because as a rhetorician I am invested in viewing narrative rhetorically, I do not in this dissertation use theories of narratology, which I understand as a formalist/structuralist account of literature.

I employ three diverse definitions of narrative as rhetoric from a long history of narrative as theorized in the rhetorical tradition. While each of these definitions come out of very different time periods and very different paradigms, I believe each has much to offer as a specific application to the consideration of disability narratives as site of liberatory discourse for people with disabilities.

First, I invoke Aristotle's *On Rhetoric*, in which he defines narrative as "an account of a course of events" that is "indicative of character." Aristotle argues that a persuasive narrative will make the "deliberate choice[s] [of the character] clear: what the character is on the basis of what sort of deliberate choice has been made" (*Rhetoric* 3.16.8). Next, I employ Walter Fisher's work with the narrative paradigm, in which he theorizes narrative as "symbolic actions—words and/or deeds—that have sequence and meaning for those who live, create, and interpret them" (375). Last, I consider bell hooks' discussion of personal "testimony" as a means of narrating for an audience a "passion of experience" with oppression (91). If disability is considered a deviance that cancels out all other possibilities for personhood, and if, as a result of that view, people with disabilities have been systematically dehumanized to the extent that they remain an oppressed minority well into the twenty-first century, then narrative as a rhetorical act as defined variously by Aristotle, Fisher, and hooks opens up opportunities for people with disabilities to use language in ways their marginalized subject position might otherwise preclude.⁷ Narrative as conceived by Aristotle allows them to build an ethos that revalues the embodied experience of disability as they characterize their actions in terms of "deliberate choices." Narrative as defined by Fisher makes space for people with

⁷ See Rosemarie Garland Thomson's *Extraordinary Bodies* and James I. Charlton's essay "The Dimensions of Disability Oppression: An Overview" in the second edition of *The Disability Studies Reader*.

disabilities to reclaim their subjectivity as they create meaning from their lives as bodies and as bodies in culture. And hooks' theory of testimony of lived experience as a means to counteract oppression points to the ways in which people with disabilities use narrative in order to contest the ways they have culturally devalued and socially marginalized.

In this way I utilize this dissertation to argue that disability narrative can be a vehicle for a "rhetoric of resistance" that I posit allows people with disabilities to:

- (1) move their bodies and their voices from the margins to the center of public space;
- (2) revalue the embodied experiences of disability as a site for knowledge and meaning making; and
- (3) challenge dominant discourses of disability that cast the disabled body as inferior and thereby serve as justification for the cultural devaluation and social marginalization of people with disabilities.

The following chapter breakdown demonstrates that I have structured this dissertation in order to place the "rhetorics of resistance" I locate in disability narratives in dialogue with the histories of dominant rhetorics that have erased, excluded, or denigrated the embodied experiences of people with disabilities. In this way, I hope to draw attention to the ways in which the disabled body has traditionally been relegated to the margins of public space while at the same time highlighting how disability narrative works to place the disabled body squarely in the center.

Outline of Chapters to Follow

The second chapter of my dissertation is entitled “To Kill or to Cure?: The War Metaphor, Othering, and Cultural Erasure in Discourses of Disease.” In this chapter I contend that the war metaphor controls the ways in which we perceive, name, and respond to disease, with dire consequences for the people who live with it, the scientists who research it, the physicians who treat it, and the members of the public who commit their time and money to “cure” it. Ultimately I argue that the war metaphor has directly contributed to the creation of the two dominant mythologies of illness and disability that pervade U.S. culture today—that of curing and that of overcoming—thereby effectively erasing those whose bodies and stories do not match the myths.

Chapter Three, “Illness as Invisibility: Metaphors of Mystery as Resistance in Narratives of ME/CFS by Rik Carlson and Dorothy Wall,” utilizes theory on illness and metaphor and on illness and narrative to show how the construction of alternative metaphors in narratives representing the illness experience can be an act of cultural resistance. I argue that disability narrative authors Rik Carlson and Dorothy Wall each present an overarching metaphor of mystery that operates as a challenge to the either/or paradigm inherent in the war metaphor of disease (either a disease exists or it doesn’t; either a disease is cured or it is not) by serving as an invitation to readers to become their co-collaborators in assigning meaning to mystery rather than attempting to draft them to fight in a murky battle that can never really be lost or won.

In Chapter Four, “From ‘Invalids’ to ‘Prisoners’ and Back Again?: Historicizing the Material Rhetoric of the Wheelchair and the Wheelchair-User as a Rhetorical Body Throughout the Nineteenth and Early- to Mid-Twentieth Centuries,” I utilize Carole

Blair's theory of material rhetoric and Simi Linton's theory of ableism to embark on an investigation of the history of the wheelchair as a material object, of wheelchair-users in public space, and of the dominant rhetorics used to characterize the two. I suggest that although the Disability Rights Movement of the last fifty years has indeed motivated major shifts in public policy mandating provisions of access and accommodations for wheelchair-users—including the Americans with Disabilities Act of 1990—the long legacies of a *rhetoric of invalidity* and a *rhetoric of containment* as yet still shadow the material object of the wheelchair and the bodies of wheelchair-users by upholding a dominant ableist ideology that serves as justification for their cultural devaluation and marginalization in public space—even into the first decade of the twenty-first century.

My fifth and last chapter is titled “Defreaking the Disabled Body: Reclaiming Subjectivity and Resisting Otherness in Disability Narratives by Harriet McBryde Johnson, John Hockenberry, and Dean Kramer.” In it I utilize feminist disability theory—including Rosemarie Garland Thomson's concept of the freak show and Susan Wendell's work with the disabled body as “Other”—in order to demonstrate the ways in which disability narrative authors and wheelchair-users Harriet McBryde Johnson, John Hockenberry, and Dean Kramer consistently reverse the mechanisms of the freak show in ways that reclaim their subjectivity, resist the category of “Other,” and thereby explode what I term “the normal/nondisabled-abnormal/disabled binary.” I suggest that by defreaking the disabled body and reclaiming it as a site of personhood and agency, Johnson, Hockenberry, and Kramer shift the spectacle of freakdom to the ableist ideology represented by the spectator, whose assumption of a normal body is exposed as a fiction

that exists only by virtue of an equally fictive construction of the disabled body as an abnormal “Other.”

In the end I conclude this dissertation with a summary that situates my project within areas of inquiry in the field of rhetoric and composition, including: (1) the process of writing work by rhetoricians who have been marginalized into the rhetorical tradition and (2) the practice of integrating disability into the writing classroom. To that end, I provide a brief review of the tradition of recovery work in the area of feminist historiography and point to its implications for including the rhetoric of people with disabilities in our studies of rhetorics of the body. I also position my study in relation to recent discussions of disability and the teaching of writing, ultimately arguing that my re-envisioning of disability as a nexus of embodiment and social construction will prove useful as we strive to create more inclusive classrooms. Ultimately, I articulate my hopes that my project will inspire others in the field of rhetoric and composition to write the rhetoric of people with disabilities into the rhetorical tradition as well as incorporate concepts of disability into their composition pedagogies.

CHAPTER TWO: TO KILL OR TO CURE?: THE WAR METAPHOR, OTHERING, AND CULTURAL ERASURE IN THE DISCOURSE OF DISEASE

The National Multiple Sclerosis Society hurt my feelings the other day. I received in the mail a decal for my car window that featured the NMSS's new logo: the letters *MS*, in orange, with a black slash over them. My stomach flipped when I saw it, but I couldn't immediately determine why. I set the decal on my desk and, throughout the day, kept picking it up and looking at it again. Finally, I realized that it was the black slash that disturbed me, the thick dark line meant to represent the Society's effort to eradicate MS. Mulling over that line for the fourth, fifth, sixth time, I felt myself suffocating under its weight. I felt it signaling my own erasure.



New York City based advertising agency *Wieden + Kennedy*, whose corporate clients include Nike, Coca-Cola, and Starbucks, collaborated with the design firm *Open* to create this logo for the launch of the Society's new "Join the Movement" campaign, meant to "help make MS more relevant to busy people in a busy world." In a press release announcing its contribution to the building of the NMSS' new "corporate identity," *Wieden + Kennedy* ask:

What color is MS?

When you think breast cancer, it's pink; heart disease or AIDS you think red; and testicular cancer you think yellow; but how do you create a public identity for a disease whose symptoms come and go and range from numbness and tingling to complete paralysis? Well, now when you think multiple sclerosis and the National MS Society, who address the challenges of each person whose life is affected by MS, you will see Orange! ("NMSS Launches a New Movement")

This exuberant passage is lacking depth in three important ways. First, the advertising agency assumes that the relationship between the color orange and the nature of the neurological symptoms of MS is somehow self-evident. Second, the agency does not address the choice to place a black slash *over* the orange letters. Last, the limited content of the passage seems to imply that the color selection is the only element of the new design worthy of commentary. If this were indeed the case, one might imagine that *Wieden + Kennedy* would also find it necessary to speak to why the color combination—black and orange—is suggestive of nothing so much as Halloween.

Ironically enough, this association, however accidental, is something that people with MS are able to get behind. Essayist Nancy Mairs, who has had multiple sclerosis for over thirty years, likens the experience of the disease to being “haunted by a capricious and mean-spirited ghost, unseen except for its footprints, which trips you even when you're watching where you're going, knocks glassware out of your hand, squeezes the urine out of your bladder before you reach the bathroom, and weights your whole body with a weariness no amount of rest can relieve” (84). The members of my Internet

support group for women with multiple sclerosis refer to the disease as “the MyStery,” most often when we are trying to comfort each other in the face of baffling symptoms, the progression of disability, and the fact that as of yet physicians have no idea what causes this disease, much less what will possibly treat or cure it.

National MS Society President and CEO Joyce P. Nelson explains that the “black slash” feature of the logo is meant to encourage people to “‘make their mark’ to end MS,” while the NMSS society’s website asks visitors to “‘make their mark’ *against* MS” (italics mine) and provides a virtual sharpie and canvas with the orange letters “MS” to be written upon (“Make Your Mark”). In this configuration, MS is cast as the enemy, and the black sharpie is the weapon to be utilized to blacken it, to cross it out.

The National MS Society has a long history of utilizing the war metaphor to frame the disease. Dr. T. Jock Murray, a medical historian and MS specialist, explains that since the NMSS’s founding in 1945, it has worked actively to “develop a military metaphor for the battle against the disease” (515). At the same time, the Society has emphasized “the idea of individual struggle and achievement: the patient overcoming the disease by personal willpower and determination” (515). In this sense, the National MS Society utilizes the war metaphor to encourage both the general public and the individual with MS to “battle” the disease, and to make their goal the disease’s “defeat.”

Unfortunately, the nature of MS as a disease makes representing it as an enemy and the processes of living with it, researching it, or treating it as war particularly problematic. MS is an autoimmune disease, meaning that for whatever reason, one’s own immune system somehow begins to see healthy tissue (in the case of MS, the myelin coating that insulates the nerves) as diseased and systematically sets about removing it.

This process produces numerous (*multiple*) plaques (*sclerosis*, or scar tissue) on the brain and spinal cord, and it is these plaques that disrupt neurological functioning and produce the symptoms and disability that are the hallmarks of MS.

In a process as complex as this, what is to be erased, fought against, done battle with? Who is the enemy? Is it the plaques? One's own misguided immune system? Whatever mysterious trigger—genetics, the environment, a virus, or some combination of all of the above are the current guesses—that led the immune system to misunderstand the function of myelin in the first place? In her book *Waist-High in the World: A Life Among the Nondisabled*, Nancy Mairs muses:

Who would I be if I didn't have MS? Literally, no body. Physiologically, lesions . . . are integrated into my central nervous system. Since they can be located with Magnetic Resonance Imaging, I suppose they might be cut away, but what remained would be an even less serviceable version of a "Nancy" than the one MS has fabricated. (8-9)

In this sense, the war metaphor in relationship to MS and as exemplified in the black slash logo leads to my feelings of erasure. My body *is* MS—as in, what has happened and is happening to my brain and spinal cord in the course of the disease cannot ever be separated, or eliminated, from my body. Therefore, in the model provided by the Society, my body inevitably becomes the enemy to be fought against, defeated, and Xed out by the black sharpie.

I realize this is a very narrow interpretation of a broad sentiment—the desire to make those with MS well and to prevent anyone else from ever having to experience MS. And these are goals that I support wholeheartedly. Rather, my concern lies with the

language and symbols being used to frame these goals. Medical historian Charles Rosenberg theorizes that “a disease does not exist until society decides that it does—by perceiving, naming, and responding to it” (2). In this chapter I contend that the war metaphor controls the ways in which we perceive, name, and respond to disease, with dire consequences for the people who live with it, the scientists who research it, the physicians who treat it, and the members of the public who commit their time and money to “cure” it. First, I review the medical history and social construction of Post-Polio Syndrome (PPS), breast cancer, and autoimmunity in multiple sclerosis to show how the war metaphor has constrained efforts to effectively diagnose, research, and treat these diseases. Second, I elaborate on Susan Sontag’s theory of illness as metaphor to illustrate how the war metaphor can lead to the damaging conception of people who have diseases as “Others” whose bodies at best harbor an enemy or at worst *are* the enemy, particularly in the case of the disease Myalgic Encephalomyelitis or Chronic Fatigue Syndrome (ME/CFS⁸). In the end, I argue that the war metaphor has directly contributed to the creation of the two dominant mythologies of illness and disability that pervade American culture today—that of curing and that of overcoming—thereby effectively erasing those whose bodies and stories do not match the myths.

⁸ I utilize the name ME/CFS in this chapter—rather than the more commonly used names Chronic Fatigue Syndrome (CFS) or Chronic Fatigue Immune Dysfunction Syndrome (CFIDS)—because in my interviews with ME/CFS activists Rik Carlson and Dorothy Wall I became aware that the ME/CFS patient community is working on a grassroots campaign to change the name to ME/CFS, a name they believe better reflects the severity of the condition and at the same time emphasizes ties to patient communities in Canada and Europe, where the disease is known solely as ME. In the future, I hope to conduct a thorough scholarly investigation into the controversy surrounding the name of the disease.

“It’s a Little Hard to Explain”: The Constraints of the War Metaphor in Discourses of Polio, Breast Cancer, and Multiple Sclerosis

In our society, the war metaphor is ubiquitous in its application to disease. Susan Sontag’s famous book *Illness as Metaphor* grew out of her experiences as a person with cancer when she first became ill with the disease in the 1970s. She refers to the book as an “exhortation” to the public to rethink the discourse we use when we talk about illness, asserting that the “military metaphor of disease” is the one she is “most eager to see retired” (182). According to Sontag, “the military metaphor in medicine first came into use in the 1880s, with the identification of bacteria as agents of disease. Bacteria were said to ‘invade,’ or ‘infiltrate’” (66). However, over time the metaphor came to apply to diseases in general, from polio to cancer to MS, casting them as “evil predators” (7), “demonic enemies” (57), and “alien others” (99). I argue that in such a schema there is only one possibility for addressing disease, and that is to accomplish the following: (1) identify the enemy; (2) declare war; and (3) win. And at a time at which the medical profession is dominated by the biomedical model of disease, the central goal of which is the discovery of a cure (Rosser 249), then “winning” becomes synonymous with “curing.”

It is widely accepted in American culture that polio as a disease was “cured” by the implementation of the Salk vaccine in 1955. Literary scholar Mark Shell, who himself had polio, notes the omnipresence of the war metaphor in the discourse surrounding the disease, explaining that when the Salk vaccine succeeded in preventing new cases of polio “a total victory was declared—along the lines of Truman’s declaration of total

military victory against the Axis powers” (2). However, Shell points out a central problem with this language and what it implies—that polio as a disease was “over” because the “active and destructive” virus had been isolated and inoculated against (22). It is this “view of polio” Shell tells us, that is simply “wrong” (22); that in fact, of the 1.6 million people who experienced infection with the polio virus, sixty-five percent will go on to develop Post-Polio Syndrome (PPS), a condition that in essence causes the person to re-experience the virus, causing further progressive neurological impairment (National Institutes of Health). As Shell puts it: “[polio] returns, boomerang-style” decades after the person’s first encounter with disease (22).

Not only are the physical symptoms and disability of Post-Polio Syndrome devastating, but so are the psychological effects. In his book *Living with Polio*, historian Daniel J. Wilson attributes the majority of psychological trauma those with PPS experience to the fact that “survivors were convinced they had beaten the disease” and that at its unexpected and unwelcome return they (justifiably) felt “a profound sense of failure and defeat” (228-29). In Wilson’s analysis the war metaphor continues to do its insidious work—people who did not die of polio, who went on to “live successfully in the world of the able-bodied” are “survivors” who have “beaten” the disease (229). Cast in this light, no wonder a sense of “defeat” arises at the disease’s resurfacing.

Nowhere in his book does Wilson take special note of the militaristic language he uses to describe polio, but he does mention that people with Post-Polio Syndrome are often told by medical professionals that what they are experiencing is “all in their heads” and are misdiagnosed with psychiatric disorders (228, 238). Wilson discusses the challenge polio survivors face as a result: the quest to “find doctors who listen to their

concerns, take them seriously, and seek to find out more about the late effects of polio before pronouncing an uninformed diagnosis” (239).

What is interesting in Wilson’s history of Post-Polio Syndrome is that a feeling of “defeat” is described as being of consequence only in the people with the disease. It seems to me that physicians, when faced with patients exhibiting the symptoms of PPS, may also feel “defeated,” particularly because in the narrative of “total victory” over polio, the biomedical model of disease they subscribe to had prevailed. The bodies and stories of those with PPS were living testimony that this belief was mistaken. It is no wonder that physicians have had conscious or unconscious difficulty recognizing the condition—because doing so means forever changing a story of unmitigated triumph to one of partial defeat, at least in a schema of the disease constrained by the war metaphor.

Mark Shell calls the narrative of polio’s conquering “a fiction that obscures the fact that many more people still suffer from polio than is generally understood” (205). Further, he remarks that with the “premature declaration of a cure” the “search to understand what polio had been and research into the ongoing effects . . . was abruptly ended,” leaving many questions unanswered (2). Shell even goes so far as to assert that if these areas of inquiry had remained open, we might have been able to create new knowledge that would have helped us to “deal with similar viruses and several diseases” (209). It seems, then, that the desire to remain true to the war metaphor of disease in the case of polio contributed to a shortsightedness in terms of knowledge seeking that has radically effected not just those with PPS but also those who live with similar disorders. People with PPS have been marginalized in the sense that their experiences with the disease have been consistently denied by the medical profession and silenced in larger

culture in order to keep the narrative of triumph over polio intact. Meanwhile, people with other diseases, particularly neurological disorders such as MS, Parkinson's disease, amyotrophic lateral sclerosis (ALS), and ME/CFS, retroactively experience the negative consequences of the war metaphor in relationship to polio because opportunities for further research into the virus's effect on the central nervous system were lost when the virus itself was initially "conquered."

This view of the effects of the war metaphor on polio's history, then, is a story not of triumph but of bodies marginalized and lines of inquiry closed. Similar themes occur in the histories of breast cancer, autoimmune disorders, and ME/CFS, and I believe that these problems are due more to the discourse of war in disease than may initially appear obvious. In the case of breast cancer, for example, the disease was long ignored "in research labs and medical conferences" and by "policymakers and regulators," and the National Cancer Institute diverted funds allocated for breast cancer to research on other diseases (Kasper and Ferguson 4). Scientist Anne S. Kasper and sociologist Susan J. Ferguson attribute the "silence" surrounding breast cancer to "social norms" that made it a "private matter" (4, 6), while sociologist Jane S. Zanes elaborates on this theory by arguing that it was the breast as a "value-laden body part" and the fact that breast cancer was primarily a woman's disease that led to the condition's "invisibility" (155). Kasper and Ferguson believe that the major turning point in the public's reception of breast cancer occurred when the photographer Matuschka's self-portrait of her mastectomy made the cover of *The New York Times Magazine* in 1993, accompanied by the headline 'You Can't Look Away Anymore' (6). Not coincidentally, a search of LexisNexis reveals that the phrase "the war on breast cancer" was utilized over ten times more in the popular

presses in the decade following the appearance of Matuschka's photo than in the decade before the cover was run. It seems, then, that the concept of a war against the disease, and the mobilization of the public behind that war, could not gain real cultural currency until the enemy could be publicly identified and made visible, until it was permissible to "look," rather than "look away."

Although the rise of this discourse may be seen as a positive step—and certainly was indicative of a real and important shift in cultural attitudes toward breast cancer itself—breast cancer expert and medical historian Dr. Barron H. Lerner believes that the "routine" use of "military metaphors" in breast cancer discourse has led to a consistent focus on finding a cure at the expense of examining other aspects of the disease in terms of research and advocacy. The collection *Breast Cancer: Society Creates an Epidemic*, addresses many such issues in desperate need of attention, including evaluating the effectiveness of early detection (Lerner 44), addressing the horrifying disparity in access to medical care and treatment between middle-class women and poor women and minorities (Kasper 183), and designing studies that take into account the environmental link to breast cancer (Steingraber 271). All of these pressing issues are now obscured by what Ferguson and Kasper call the "growth industry" that is the "Race for the Cure" (5). In this sense, the war metaphor has been a double-edged sword for women with breast cancer. On the one hand, it has served to help make their disease visible and raise funds for research. On the other, it has arguably constricted the scope of that research while at the same time limiting efforts to improve the lives and material circumstances of women with the disease.

The war metaphor also plays a critical role in discourse relating to autoimmune diseases, such as MS, lupus, and rheumatoid arthritis (RA). As anthropologist Emily Martin points out, the immune system has been consistently framed both scientifically and popularly as an ever-vigilant protector against non-self entities, a model that has been extended to construct the body as a battleground, the immune system as a valiant soldier, and everything from household germs to cancerous tumors as the enemy. In what Martin refers to as the “military account of the immune system,” the body is a “scene of total war between ruthless invaders and determined defenders” (53).

So thoroughly has the war metaphor been integrated into the clinical definition of multiple sclerosis that I have not been able to find one that does not use it. The National Institutes of Health, for example, explains that MS occurs “when the immune system seems to wrongly identify self as non-self and *declares war* on the part of the body (myelin) it no longer recognizes” (“MS Information Page,” italics mine). The National MS Society characterizes the “normal” immune system as one that “*defends the body against foreign invaders* such as viruses or bacteria. In the case of MS, the body *attacks* its own tissue” (“About MS,” italics mine). WebMD describes MS as a condition in which “the body’s *defenses . . . attack* the central nervous system—the brain and spinal cord” (“What Is Multiple Sclerosis,” italics mine). When people ask me to explain what MS is, I cast about for non-military language and nearly always slip by using the words “attack” and “destroy.” When that happens, I grow petulant. The war metaphor makes sense, I whine to myself. My immune system *does* attack the myelin in my brain and spinal cord. It *has* destroyed it. I’ve seen the pictures.

But however apt the war metaphor may seem, viewing the processes of MS—or disease in general—through this lens necessarily takes our attention away from other possibilities. As George Lakoff and Mark Johnson theorize, “The essence of metaphor is understanding and experiencing one kind of thing in terms of another” and thus, “the very systematicity that allows us [to do so] will necessarily hide other aspects of the concept” (5, 10). Emily Martin, whose book on the war metaphor as it operates in relation to the immune system was influenced by her personal experience with her brother’s death from polio during her childhood, argues that the military metaphor:

preserves and gives emphasis to certain sorts of events: the equivalent of a traditional history of generals, battles, and their dates. Most of the time, the immune system (as well as any society in the history books) goes about carrying on daily life, the mundane business of feeding and clothing and cleaning its members. (98)

In making this claim, Martin suggests that a hierarchy of knowledge emerges as a result of the war metaphor, wherein researchers focus primarily on what happens when the immune system is in crisis rather than investigating what occurs when it is carrying out its quotidian functions. Scientists have also commented on the inadequacy of the war metaphor to encapsulate the work of the immune system, particularly in relationship to disease. As senior immunologist Dr. Aaron Hunter testifies, ““If you think just in terms of warfare, it is a little hard to explain autoimmunity”” (109).

Dr. Hunter’s phrase “a little hard to explain” is key in an examination of why the war metaphor serves as the dominant means of constructing disease in our culture. In an investigation of the metaphor of “inflation as adversary,” Lakoff and Johnson argue that

the personification of a phenomenon as an enemy allows us to “make sense of the world in human terms—terms we can understand on the basis of our own motivations” (34). Thus the “inflation as adversary metaphor... at least gives us a coherent account of why we’re suffering losses” (34). In other words, if a thing is difficult to understand, and therefore seems to be beyond our control, it helps us to personify it through metaphor—and personifying it as an enemy allows us to distance ourselves from it (it is bad—we are good), and gives us a means through which to seize control by making our central goal its destruction. In this sense, the war metaphor is a seemingly logical response to “a disease thought to be intractable and capricious—that is, a disease not understood—in an era in which medicine’s central premise is that all diseases can be cured (Sontag 5). It also serves as a road map for thought, speech, and action in an otherwise confusing and frightening situation: the enemy is identified, war is declared, forces are united, and the march into battle begins. The black slash over the letters MS in the NMSS’s logo, then, serves to mark the enemy, signify the war, and ask the audience of “the busy public,” as introduced in *Wieden + Kennedy*’s press release, to donate time and money to the war effort. Unfortunately, this conceptualization of the disease also marks the body of the person who has MS. At best, the mark casts the body with MS as a battleground. At worst, the mark casts the body as the enemy itself.

Unconquerable Bodies: People with ME/CFS as the Enemy

In the case of polio, the enemy was identified, a war was fought, and victory was declared, leaving those who became ill with Post-Polio Syndrome years later in the midst of a type of cultural erasure in which medical professionals denied their bodily

experiences and the fact of the disease received little public attention. In the cases of breast cancer and MS, the enemy has been identified, war has been declared, and battles are being fought, allowing those with breast cancer and MS to receive cultural validation as “ill,” but at the same time constricting the parameters of the illness experience as well as efforts in research, treatment, and advocacy. In the case of ME/CFS, however, there is a different consequence to the dominance of the war metaphor in discourses of disease. Because for years an enemy was never identified, those with the illness have been constructed as the enemy themselves in a type of “blame the victim” or “scapegoating” scenario that has had disastrous consequences for a seriously ill population.

For nearly thirty years, there were no “specific biomarkers” for ME/CFS: no virus, as in polio; no cancerous cells or tumors, as in breast cancer; no lesions rendered visible by the technology of the MRI, as in MS. It was only in July of 2007 that *The New York Times* ran an article titled “Chronic Fatigue No Longer Seen as Yuppie Flu,” which coincided with the announcement of the results of a study by the Centers for Disease Control revealing that researchers have finally been able to link the disease to genetic mutations and abnormalities (Tuller). It is worth noting that before the discovery of plaques in the central nervous system through autopsy in 1868, MS was known as “hysterical paralysis,” and throughout the mid-nineteenth century, those with the disease—primarily women—were given a series of treatments designed to “snap them out of it,” including being stripped naked and sprayed with cold water and strapped on racks and hung suspended (Murray 397-99).

Obviously, people with ME/CFS have not been subjected to this kind of treatment. But as DePaul University sociologists Leonard Jason and Renee Taylor argue,

“one of the most devastating issues facing individuals with CFIDS is public, familial, and professional skepticism about the reality of invisible symptoms and impairments” (xvii). Chronic Fatigue Syndrome was first isolated as a “distinct entity” in the United States in 1988, following a series of outbreaks of an illness of unknown etiology that caused overwhelming fatigue, cognitive dysfunction, persistent muscle and joint pain, sore throat, and headache, among others (Tuller). The disease first presented as a terrible bout with the flu, but the trouble was that this flu did not go away, even after months, then years, with the illness.

The most widely publicized initial accounts of the disease occurred in San Francisco, California, and Lake Tahoe, Nevada. When University of California medical professor Carol Jessop first began to see female patients who were experiencing the symptoms of ME/CFS, “male colleagues scoffed, calling the tests ‘million dollar workups on neurotic women’” (Spurgin). Meanwhile, Dr. Gary Holmes, lead researcher of Centers for Disease Control’s investigation of the Lake Tahoe outbreak, stated that “a lot more [was] being made of [the disease] than it probably deserve[d]” and that “almost every person in the United States has symptoms that are compatible with the symptoms of the syndrome”: the implication being that those who claimed to be devastatingly ill were at best hypochondriacs and at worst malingerers (Boffey).

It is not hard to understand Holmes’s skepticism in the absence of specific biomarkers revealed by laboratory findings or signs of visible disability in the patients he saw. The people he examined in Lake Tahoe, he explained to *The New York Times* in July 1987⁹, “had undistinguished symptoms. They were walking in. They really did not have

⁹ *The New York Times* July 1987 article by Philip Boffey discussing experts’ skepticism regarding the existence of ME/CFS was published almost twenty years to the day before this year’s article by David

any major signs of illness” (Boffey). The fact that the outbreaks occurred in affluent areas led the media to dub the illness “the yuppie flu” or “Shirker’s Syndrome,” while the fact that it was most often identified in women led many physicians to maintain it was a new manifestation of female hysteria (Tuller). As feminist critic Susan Griffin explains, “the medical establishment drew a profile of the person most likely to come down with the disease. A mature woman, professional, upper middle class, white, overly ambitious, she did not know how to rest, and this is why she was fatigued” (31). Dr. Eliot Kieff, head of infectious diseases at the Brigham and Women’s Hospital, explained Chronic Fatigue Syndrome as “ordinary neuroses manifested as tiredness,” occurring primarily in women who were “very unhappy” (Boffey).

Throughout the 1980s and 1990s, the majority of physicians did not believe ME/CFS was an organic disorder but rather a psychiatric problem, largely due to the fact that The National Institutes of Health relied upon a study led by Dr. Stephen Strauss, the head of medical virology, which found that the majority of patients with ME/CFS had a history of mental disturbances (Bell 111; Griffin 32). Straus went on to become the leading expert on ME/CFS at the NIH, serving as a peer reviewer for journal articles, disseminating informational pamphlets to physicians, and making recommendations as to the allocation of research money. Journalist Hilary Johnson argues that from this position of power, Straus “set the parameters for professional and lay discourse, insuring that it would only be conducted in terms of psychopathology” (Spurigin). As in the case of Post-Polio Syndrome, people with ME/CFS were being told the disease was “all in their heads.”

Tuller announcing the experts’ consensus that the disease indeed is an organic disorder rather than a psychosomatic condition.

In her 1997 book *Hystories: Hysterical Epidemics and Modern Culture*, Elaine Showalter claims that ME/CFS, along with Multiple Personality Disorder, satanic rituals, and alien abduction, is a product of sensationalistic media narratives that reflect a nation in the midst of fin de siècle panic. Hysteria, Showalter argues, “is a mimetic disorder: it mimics culturally permissible expressions of distress” (15). Used by marginalized populations, it provides a “body language for people who might otherwise not be able to speak or even admit what they feel” (7). To bolster her claim that ME/CFS is a modern epidemic of hysteria, Showalter points out that a Harvard medical study found that more than eighty percent of people with the disease are women (9). In addition, she reminds her readers that ME/CFS is a “syndrome, not a disease,” explaining that the distinction lies in the fact that syndromes are disorders for which no cause can be found (118). She makes clear that she does not dispute the “reality” of the symptoms of CFS, but that she finds it regrettable that people with the disease “spurn the idea that they can be helped by psychotherapy or antidepressants” (129).

As I read Showalter’s book, I kept remembering my first visit to the emergency room a little over two years ago, when I was experiencing my first definitive attack of multiple sclerosis, which included tingling, numbness, trouble walking, loss of balance, and fractured vision. The doctors there provided me with a massive dose of anti-anxiety medication via an IV, told me a brief clinical exam had ruled out multiple sclerosis, and gave me a prescription for a sedative to take home. Later, when I read my own medical records, I saw that the attending physician had written: “Patient reports experiencing anxiety, although she appears to be in no acute distress.” After enduring the same symptoms for a month and a half, I reappeared in the same emergency room and

demanded an MRI, having done some research of my own. The next day I was diagnosed with multiple sclerosis, a disease that affects two-thirds more women than men and for which there is no known cause. Had the MRI not been developed in 1981, multiple sclerosis might well have been included in Showalter's list of hysterical epidemics, and I might well have been one of her stubborn hysterics, overly suggestible and manifesting physical symptoms in order to express my despair at my own oppression.

A great deal is at stake when people experiencing unusual physical symptoms are prematurely labeled as having psychiatric disorders in the absence of any visible bodily abnormality. Not only do they go through what Susan Griffin calls the emotionally painful "disjuncture between private experience and public image" (32), but they also find themselves facing very real material consequences of larger culture's denial of their disease (32). People with ME/CFS, according to DePaul University sociologists Leonard Jason and Renee Taylor, are the most "underserved of all those with chronic illness" by "medical and community-based service programs" (xix). They are frequently refused Social Security and disability benefits; they often are unable to receive the accommodations they need at work; they are denied access to programs designed for people with culturally validated disabilities, such as low-cost accessible transportation (xix).

But perhaps the most catastrophic material consequence for those with ME/CFS has been Centers for Disease Control's misallocation of funds specifically designated by Congress for further research on the disease. In 1999 the CDC acknowledged that it had diverted millions of these dollars into research on other diseases from 1988 to 1998 (Tuller) after an audit by the Department of Health and Human Services revealed that 39

percent, or 8.8 million dollars, of funds for ME/CFS had been “incurred for non-related activities” (“Audit”). Inspector General June Gibbs Brown stated in her audit that the Centers for Disease Control knowingly made “inappropriate charges” with ME/CFS monies and provided “inaccurate information” to Congress about their use of these funds (“Audit”). When this information was made public, the CDC issued an apology, restructured its policies and its personnel, and renewed its commitment to ME/CFS. Since then, the CDC has sponsored a six million dollar public awareness campaign and conducted comprehensive studies of prevalence as well as possible causes, diagnostic markers, and treatments. Dr. William Reeves, the Centers’ new expert on ME/CFS and a key figure in uncovering the organization’s misuse of funds, validates the bodily experiences and stories of those with ME/CFS, stating that ““People with [the disease] are as sick and as functionally impaired as someone with AIDS, with breast cancer, with chronic obstructive pulmonary disease”” (Tuller). But most significantly, as the July 2007 *New York Times* article states, “now nearly everyone agrees the syndrome is real” (Tuller).

In her article for *The Nation*, journalist Maryann Spurgin remarks that what is missing from the history of the denial of ME/CFS as a “real” disease is “motive.” Why did doctors say patients were suffering from psychiatric disorders? Why did the media dub the disease “the yuppie flu?” Why were those with the disease ignored, shunned, and mocked? Why such resistance, Spurgin asks? I argue that when the ubiquity of the war metaphor in the discourse of disease is taken into account, the motive is quite clear. People with ME/CFS posed a very real threat to the notion that diseases can be conquered, that bodies can be cured. Because the discourse of war was not applied in a

way that allowed it to seemingly neatly and compactly encapsulate the story of ME/CFS, those with the disease were cast as a sort of “enemy of the state,” their insistence on their illness a treachery that had to be stopped. In short, because they could not be literally cured, they were figuratively “killed.”

In *Illness as Metaphor*, Susan Sontag theorizes that the “move from the demonization of illness to the attribution of fault to the patient is an inevitable one, no matter if patients are thought of as victims. Victims suggest innocence. And innocence, by the inexorable logic that governs all relational terms, suggests guilt (99). Yet it seems that the guilt the larger culture associated with people with ME/CFS occurred not because the illness was demonized but because it *was not*. Because the existence of the illness was denied, the people with the illness became the enemy. The names they were given—yuppies with the flu, shirkers, hysterics—each signify what Sontag contends diseases themselves come to signify through metaphor: “social and moral wrongs,” “laxity, weakness, disorder, and corruption” (61, 168). In this sense, the war metaphor tells us much more about the healthy than it does about the sick. For although the war metaphor ostensibly seems to work on behalf of those who have diseases, it in actuality serves as a means for those who are “well” to distance themselves from the enemy, whether it is the disease itself or the person who has it.

According to cultural critic Sander Gilman, it is important to examine “how the ill are perceived” because “it is the perception of the patient that structures the patient’s treatment, the patient’s status, and the patient’s self-understanding” (7). But here even Gilman creates an artificial divide—a divide the war metaphor supports—between “the patient” and the “perceiver,” implying that one is one and the other is the “Other,” and

that the perceiver ought to become more cognizant of the labels she affixes to the patient for the patient's sake. Here it is worth referring to Sontag again by invoking her famous passage:

Everyone who is born holds dual citizenship, in the kingdom of the well and the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place. (3)

The war metaphor, then, with its emphasis on eradicating disease and conquering disability, works to obscure the fact that everyone will experience these states. It provides those who use it with a sense of safety because it seems to serve as a means to control the uncontrollable, to assert that when the war is won, no one will become the "Other" who is ill. If polio, breast cancer, MS, and ME/CFS can be destroyed, either through biomedical cure or cultural erasure, no one will ever have to say: "we have seen the enemy, and it is us."

Conclusion

As a person with MS, I write this chapter from a place of privilege. My disease is only rarely fatal, unlike breast cancer. There are treatments for my disease, whereas people with Post-Polio Syndrome and ME/CFS have as of yet no place to turn for relief. There is no Post-Polio Syndrome Society, and the CFIDS Association of America does not have an official corporate identity or a logo to accompany it. Yet I begin and end with the National MS Society's logo because it is the most recent manifestation of the rhetoric of war in relationship to disease. The war metaphor remains our primary means of

constructing disease—a sort of default rhetoric—despite Sontag’s optimistic prediction in the conclusion of her 1977 book that the “militaristic hyperbole” surrounding disease “would evolve in the coming years”—that it indeed “must change,” particularly in regard to cancer, when “the disease is finally understood and the rate of cure becomes much higher” (86). Deeply unfortunately, this has not been the case, perhaps in part because Sontag here falls into the assumption that the circumstances of disease—whether or not it is understood, whether or not it is curable—construct the language rather than that the language, too, constructs the circumstances of disease. Militaristic hyperbole continues to abound, with little attention to the damage it causes, much less cognizance that if the manner in which we talk about disease were to radically change, so might our actions toward it, and so might disease itself.

The CFIDS Association of America website announces that the mission of the organization is to “conquer” CFS, and here the discourse of war begins. As I access it today, the home page foregrounds the July 2007 article in *The New York Times*, stating that it is “the first science article affirming the reality and severity of CFS” to be published in “the nation’s most respected daily newspaper,” and offering visitors the opportunity to thank the editors through the completion of an e-mail form (CFIDS Association). The tone of relief is palpable as the Association celebrates the newfound credibility of people with ME/CFS. As of now, there are no telethons, bike-a-thons, walks, or runs advertised by the site with the goal of a cure (Munson 8). But like Sontag, I will end with a prediction: that with the advent of its credibility as a real illness, the discourse of war around ME/CFS will grow. Instead of operating as an underground war on unconquerable bodies, the war will serve as a public battle against the disease. And

while it will initially seem incalculably liberating for those with ME/CFS to fit the existing model—what a joy to fit in after being ostracized for all these years!—the metaphor will continue to constrain efforts toward effective research, treatment, and advocacy, while at the same time insidiously contributing to the “Othering” of the bodies of those who have the disease.

Disability studies scholars argue that disability discourse is dominated by two prevailing mythologies: the “medical model,” which casts disability as individual pathology and sets as its goal the “normalization” of the individual through intervention or cure; and the “overcoming model,” which constructs disability as a personal deficit that is located entirely in the individual and therefore as the responsibility of the individual to conquer through determination and will.¹⁰ Even in the language used to explain these models, military language is present with the words “intervention” and “conquer.” Attention to the rhetorics of disability, then, necessarily requires attention to both dominant metaphors and alternative metaphors in discourses of disease. In the next chapter, I focus on the use of alternative metaphors in two ME/CFS narratives and the ways in which they challenge mythologies of disability.

¹⁰ See Introduction for further information on these models.

**CHAPTER THREE: ILLNESS AS INVISIBILITY: THE METAPHOR OF
MYSTERY AS RESISTANCE IN NARRATIVES OF ME/CFS BY RIK CARLSON
AND DOROTHY WALL**

My time spent analyzing the source of my discomfort with the National Multiple Sclerosis Society's new logo led me to research the history and the effects of the war metaphor in relationship to disease, and to begin an investigation of what other metaphors have been used to frame the experiences of diseases that do not fit the existing model, diseases that, in the words of Susan Sontag, are "the subjects of deepest dread," diseases whose "causality is murky, and for which treatment is ineffectual," such as Post-Polio Syndrome, MS, and ME/CFS (58). I have chosen to concentrate in this chapter on the use of alternatives to the war metaphor in ME/CFS narratives because ME/CFS is a disease that since it was first recognized as Chronic Fatigue Syndrome by the Centers for Disease Control and Prevention in the 1988, has been routinely dismissed by medical professionals and the popular media as "the Yuppie Flu," "Shirker's Syndrome," or, in the case of women with the disease, a new manifestation of female hysteria.¹¹ As a result of this dismissal, one can argue that people with ME/CFS experience a unique exigency to create new metaphors to frame their experiences of disease.

As a woman with MS, I feel a kinship with those who have ME/CFS for two reasons. First, MS and ME/CFS are both chronic, disabling conditions whose etiology is unknown; and second, in the period¹² between the discovery of *sclerose en plaque*

¹¹ See David Tuller. "Chronic Fatigue No Longer Seen As Yuppie Flu." *The New York Times*. 7 July 2007. 8 October 2007 <http://www.nytimes.com/2007/07/17/science/17fatigue.html?_r=2&ref=science&oref=slogin&oref=slogin>.

¹² This period in the history of MS is consistently played down in the medical literature and is never mentioned in the literature of the National MS Society. This silence may contribute to the fact that women with MS today continue more frequently to be initially diagnosed with conversion disorder or other psychiatric conditions than do men with MS (Holland; Hill; Register).

disseminee in 1868 and the advent of the MRI¹³ in 1981, women with MS were frequently diagnosed with hysteria while men with MS were accurately diagnosed with the disease itself. This gender differential in terms of diagnosis occurred so frequently that MS was for years actually believed to be more prevalent in men than in women when in reality MS is at least “twice as common” in women than in men (Murray 2006). Had I experienced MS in the late nineteenth century, then, it is highly probable that I would have been labeled an hysteric and subsequently confined (even more dramatically than women generally were at that time)—if a wealthy woman, then most likely by the “rest cure,” and if a poor woman, then most likely by the walls of an institution.

Today, people with ME/CFS face a similar silencing that has far-reaching ramifications for their lives. Rik Carlson, an activist who has had ME/CFS since 1995 and whose ME/CFS narrative I will explore here, explains:

You hear about people being mistreated, and then you hear it again, and then you hear it again. Especially for women, because it’s primarily a chick thing.¹⁴ Their doctors don’t believe them, and so their husbands don’t believe them, and their employers don’t believe them, and the government doesn’t believe them. Their marriages are destroyed, they lose their jobs, and they don’t qualify for disability benefits. They end up in public housing or on the streets. And their spirits are fractured. (Personal Interview)

¹³ The MRI made visible the lesions, or plaques, on the brains and spinal cords of people with multiple sclerosis. The appearance of these plaques, disseminated in space and time, are the clinical diagnostic marker for MS today.

¹⁴ According to the Centers for Disease Control and Prevention website on ME/CFS, “CFS occurs four times more frequently in women than in men, although people of either gender can develop the disease.” <www.cdc.gov/cfs/cfsbasicfacts.htm>.

In this chapter I utilize theory on illness and metaphor and on illness and narrative to show how the construction of alternative metaphors in narratives representing the illness experience can be an act of cultural resistance. First, I apply I.A. Richards' theory of metaphor and Jack Selzer's concept of material rhetoric to the ways in which writers Dorothy Wall and Rik Carlson employ their lived experiences of ME/CFS as the foundation upon which they build their metaphors. Second, I consider theories of embodied writing by feminist theorist Susan Griffin and sociologist Arthur Frank to analyze Wall's and Carlson's use of the metaphor of the "invisible" to describe both the immediate physical/sensual life of their bodies as well as their positionality as ill bodies in culture. In the end, I argue that Wall and Carlson present an overarching metaphor of mystery that operates as a challenge to the either/or paradigm inherent in the war metaphor of disease (either a disease exists or it doesn't; either a disease is cured or it is not) by serving as an invitation to readers to become their co-collaborators in assigning meaning to mystery rather than attempting to draft them to fight in a murky battle that can never really be lost or won.

Alternative Metaphors as A Challenge to the Restitution Narrative of Illness

In *Illness as Metaphor*, Susan Sontag argues that [cancer] should be "regarded as if it were just a disease—a very serious one, but just a disease. Not a curse, not a punishment, not an embarrassment" (102). Here Sontag is critiquing the use of metaphors that liken diseases to "evil, invincible predator[s]" and the ways in which such metaphors "demoralize" people who have diseases (7). The "solution" to this problem, she asserts, is "to rectify [our] conception of the disease, to de-mythicize it" (7). Yet, if disease is, as

Sander Gilman argues, “a complex interaction of social and biological forces” wherein the person with the disease “is never value neutral, that is, solely a person exhibiting specific pathological signs or symptoms,” then it is virtually impossible for us to conceive of any disease as “just a disease”—as much as it is impossible for us to conceive of gender as simply biological sex (7). As Jack Selzer explains in his introduction to the anthology *Rhetorical Bodies*, “living bodies” in culture necessarily bear “ideological freight,” and thus our conceptions of bodies are inextricably entangled with the language and symbol systems used to frame them (8).

Linguists George Lakoff and Mark Johnson theorize metaphor as integral to our experience of the world and integral to an examination of power and discourse, for “metaphorical concept[s] . . . structure what we do and how we understand what we are doing” and it is the “people in power” whose metaphors dominate our perceptions (5, 157). So if the dominant metaphors used to frame disease in the medical profession and in the media have been militaristic in nature, as I argue in chapter one, then alternative metaphors utilized by people with diseases to describe their bodily experiences and material circumstances are essential to examine in order to further our understanding of rhetorics of the body. In his introduction to his book-length study of representations of disease, Sander Gilman explains that “like any complex text, illness is read within conventions of an interpretive community that comprehends [it] in light of earlier, powerful readings of what are understood to be similar or parallel texts” (7). The use of alternative metaphors in disability narratives, then, can be seen as a means of challenging the conventions of an interpretive community that has consistently framed people with

diseases as either hapless victims whose bodies harbor an enemy or as enemies themselves.

In his book *The Wounded Storyteller: Body, Illness, and Ethics*, sociologist Arthur Frank asserts that writers of disability narratives often rely on the conventions of what he terms “the restitution” model of illness, which he defines as “a powerful narrative of what medicine expects from the ill person and what other social institutions expect from medicine. At the core of these expectations is the assumption of restitution: returning the sick person to the status quo ante” (83). Such narratives, Frank explains, follow a “basic storyline: ‘Yesterday I was healthy, today I’m sick, but tomorrow I’ll be healthy again,’” taking as their natural resolution a return to normalcy or a “restoration of health” (77). This storyline reflects the biomedical model of disease and the medical model of disability in that it supports the notion that diseases and disabilities are physiological “defects” that can—and should—be isolated, identified, treated, and cured.

The dominant narrative of restitution, then, is inextricably linked with the dominance of the war metaphor of disease in that the “restoration of health” is inevitably associated with a victory over the enemy that is the ill, disabled, or diseased body. Therefore, when writers of disability narratives create new metaphors to represent their experiences of disease, they begin the process of revising the “restitution narrative,” insofar as “the meanings of metaphors themselves depend on a larger narrative context, functioning as . . . reminders of a story that is already authoritative” (Kirmayer 155). In the disability narratives explored in this chapter, rhetoricians Rik Carlson and Dorothy Wall both reference and resist the culturally authoritative narrative of restitution—and the

war metaphor embedded in that narrative—by creating new metaphors to represent their experiences of disease.

Materiality, Lived Experience, and The *Tenor* of ME/CFS

I. A. Richards, in theorizing metaphor, utilizes the term *tenor* to denote the subject and the term *vehicle* for the object. As discussed in *The Philosophy of Rhetoric*, in the metaphorical statement “men are wolves,” “men” serves as the *tenor*, “wolves” serves as the *vehicle*, and what links the two is *ground* or “the commonplaces associated with the second term (wolves) and how they might apply to the principal subject (men)” (Richards 96; Enos 73). In examining the tenor, vehicle, and ground of a metaphor, then, the audience must be familiar with both the *tenor* and the *vehicle* in order to determine the *ground*.

I argue that there is an overarching metaphor of mystery in the two disability narratives *Encounters with the Invisible: Unseen Illness, Controversy, and Chronic Fatigue Syndrome* (2005), by Dorothy Wall, and “*We’re Not in Kansas Anymore*”: *Chronic Fatigue Syndrome and the Politics of Disease* (2004), by Rik Carlson. In this metaphor ME/CFS as a lived experience of disease is the *tenor* and invisibility is the *vehicle*, and mystery serves as the associative link, or the ground, between the two. Usually, it is assumed that the *tenors* and the *vehicles* of metaphors are discursive terms around which there is some kind of linguistic consensus. Yet as I illustrate in chapter one, the dominance of the war metaphor in relationship to disease has precluded the creation of a general consensus in the public’s mind as to what the term *ME/CFS* denotes. Thus, in order to construct alternative metaphors, Wall and Carlson must first do the work of

establishing ME/CFS as a *tenor*—as a disease and as an exigency for activism—by connecting it concretely to the material and to lived experience.

Both Wall and Carlson begin that project by discussing how their writing is grounded in their understanding of themselves as severely ill and in their identification as disabled. In a personal interview with me, Wall explained that her book began with a series of essays she wrote as she was recovering from a major relapse of ME/CFS in 1995. She had been ill since 1980, when she was in her early thirties, a single mother working on her degree and piecing together “a pastiche of part-time teaching positions into a full-time job that paid less than cleaning motels” (xix). As is typical with ME/CFS, the disease first presented as a “massive flu” that rendered her “bedridden,” then evolved over the years into a chronic illness with persistent symptoms of overwhelming fatigue, muscle pain, and cognitive difficulties that varied in levels of severity but never completely resolved (xxiv). When she became “housebound” during her 1995 relapse, Wall began what she terms a “coming out” process; “after fifteen years of passing as a healthy person,” she started to identify herself as “seriously ill, and disabled by that illness” (Personal Interview). During that time, she began composing essays meant to “pull back the veil from the sick room...and make clear the severity of this illness and its impact on daily life,” which for Wall included the inability to see clients in her work as a writing consultant or to participate in family life with her husband and daughter (xxiv; Johnson). In fact, Wall’s ME/CFS was so debilitating she did not have the physical or mental stamina to “talk on the phone...or make breakfast in the morning” (Personal Interview).

Like Wall, Carlson describes what he has lost in his illness not by lamenting his symptoms but by detailing the daily activities that he no longer is able to participate in as a result. In his personal interview with me and in his book, Carlson identifies January 2nd of 1995 as a turning point in his life; it was the day he was “hit with the worst flu [he’d] ever experienced . . . like getting smashed in the head with a cast iron frying pan” (Personal Interview). In his book, he writes: “There isn’t anyone who owns a business who doesn’t work sick” (27) and describes his efforts to continue running his waterbed store despite the consuming fatigue, cognitive difficulty, and severe pain that allowed him to do little but “crawl to [his] recliner and slump” (*Kansas* 27, 28). Carlson connects disability not just to bodily experience but also to material circumstance when he explains that he did not identify as disabled until the flu persisted for all of 1995 and into 1996, when he finally understood that he was “too sick to keep working” (Personal Interview). As he states in his book:

I was just always so sick. Fear had a grip on me too. Fear of the future because the damage to my business was irreversible and fear of more disease. I was continually ravaged by the flu. Barbara [his wife] did it all: [the cleaning, the shopping, caring for their son]. She [kept heating] leftovers. I cowered. This was no fun. (*Kansas* 48)

The material consequences of ME/CFS are clear in this passage: like Wall, Carlson can no longer effectively run his business, contribute to his household, or raise his child. In this way, both Carlson and Wall make the experience of ME/CFS accessible as the reader begins to imagine what it must mean to lose as the result of an illness all these elements of a life at once.

Once they have laid bare their process of identifying as ill and as disabled by that illness in their daily lives, Wall and Carlson then describe the (equally devastating) realization that their particular illness is not recognized institutionally or communally. Of her experiences with medical practitioners, Wall writes:

I have an enduring image of one doctor after another peering at me with that poker face that means they're madly trying to compute the subtext: Was I a malingerer? Did I evidence emotional imbalance? Was I having family problems? (xxi)

Additionally, Wall reports that the “level of misunderstanding” she faced in colleagues, friends, neighbors, and in her immediate family was “astonishing” and that although she was “too weak and in too much physical pain to walk around the block” or “sustain more than a brief conversation;” even the people closest to her believed that she was most likely experiencing depression or “having a rough time with menopause” (Johnson; Personal Interview). In her personal interview with me, Wall explains that “it took [her] awhile to realize that [what she was confronting was] the notion that if an illness doesn’t fit the existing paradigm, it can’t be real.” In this sense, Wall uses her lived experiences of the denial of her disease to confound the cultural expectation—created in part by the war metaphor—that all those who are ill can be cured, and the attendant belief (somewhat circular in nature) that if one cannot be cured, then one cannot truly be ill.

Like Wall, Carlson also describes the disparity between his bodily experiences and the larger culture’s conception of those experiences by detailing for his audience the very real material consequences the cultural dismissal of ME/CFS has had for his life and for the life of his wife and young son. His most effective example is that of being denied

disability benefits by the Social Security Administration because “ME/CFS did not fit their mold of being disabled” (*Kansas* 48). Carlson explains to his readers that his efforts to appeal the decision led to his realization that “not only was [his] struggle with overwhelming sickness, but it was also with all those who thought everything [he] experienced was a fabrication. If [he] didn’t qualify for disability . . . , [he] would find [him]self and [his] family unable to pay the rent” (53). In his book he frames his dilemma thusly: “It’s one thing to be really sick, but what do you do if [people] in authority say it ain’t true?” (51). Here Carlson reveals for his audience the practical and psychic costs of what DePaul University sociologists Leonard Jason and Renee Taylor term the “societal iatrogenesis”—or the damaging physiological and emotional effects of institutionalized mistreatment of a seriously ill person—that arises from the cultural dismissal of ME/CFS as a disease (xix).

Both Wall and Carlson explain in their talk and in their writing that it was this iatrogenesis that led to their urgent need to use writing to express what feminist theorist Susan Griffin refers to as the “disjuncture” between their experiences of their bodies as ill and the larger culture’s denial of that illness (32). As Wall explains in her introduction to *Encounters*, “ME/CFS [ruptures] individual lives [and] family lives [as well as] our culture’s concepts of illness and its faith in medical solutions” (xxvi). For Wall her lived experience of this rupture became an occasion ripe for rhetoric tailored toward an audience made up of “those who live with the confusion, obscurity, and distortion that is ME/CFS” (xxvii; Personal Interview). In the end Wall’s overarching purpose in writing a disability narrative was to produce a book people with ME/CFS could “hand to their friends, family, employer or physician and say: ‘Read this and you’ll understand’”

(Johnson). Wall thus envisions her narrative serving both as a pragmatic and theoretical tool for readers to use as a means to strengthen personal and professional connections as well as to better understand the culture in which they live in relationship to the topics of illness, disease, and disability.

Although Carlson did not initially “set out to write a book,” he makes clear that his narrative was created for pragmatic and theoretical purposes similar to Wall’s. Carlson’s initial audience was one person: the administrative law judge who was to preside over his hearing appealing the Social Security Administration’s decision to refuse him disability benefits. At the time of the hearing, Carlson handed the judge “eighty pages” of what he termed “hideously boring reading” that he hoped would serve as evidence that “[his] disease was real” so that he could convince her he met the official criteria for disability (Personal Interview). In her ruling the judge acknowledged that Carlson’s written portrayal of his day-to-day experiences with ME/CFS served as the crux of her decision to define his disease as disabling and thus render him eligible for disability benefits. Carlson reports that at the close of the hearing, the judge turned to him and said, “‘Mr. Carlson, you should write a book,’ to which Carlson replied: “‘I don’t think so. I don’t really like the topic’” (Personal Interview).

In this sense the first version of Carlson’s disability narrative of ME/CFS operated as both a pragmatic and theoretical tool in circumstances firmly rooted in the material. His work helped his audience—the judge—formulate a new definition of what it means to have ME/CFS and as a consequence paved the way for him to receive the financial relief he needed to support his family. It also directly led to the second version of his narrative—the published book—in that the judge “planted a seed. [Carlson] started

thinking that if he could change [the judge’s mind] maybe [he] could change [the minds] of others” (Personal Interview). Through “manning the 800 number” of the Vermont CFIDS Association—an organization he launched in 1997—Carlson began “collecting stories. [He] heard about people being mistreated, and then [he] heard it again, and [he] heard it again” (Personal Interview). Using these stories and his original eighty pages “as a framework,” he began a book that he hoped would operate as a “defense mechanism” for people with ME/CFS. He wanted to convince “all the skeptics out there” that ME/CFS is “a true infirmity that destroys lives” and that “terribly ill people are made far worse by the politics [of disease]” (*Kansas* iii; Personal Interview). In this declaration of purpose and audience, Carlson echoes Wall’s description of the multiple ruptures—bodily, quotidian, institutional, and cultural—that also serve as her impetus for telling her story.

Because *ME/CFS* is such a hotly contested term, utilizing it as *tenor* for a metaphor is a rhetorical challenge in and of itself. Wall and Carlson rise to this challenge by using materiality in two critical ways: first, by describing the effect of the disease on their bodies and day-to-day lives, and second, by explaining how these material circumstances influenced the creation of their rhetoric. Jack Selzer calls for rhetorical scholars to explore “the relationship of rhetorical events to the material world that sustains and produces them” as a means of theorizing the “situatedness of literate acts” (9). I believe that the “situatedness” of Wall’s and Carlson’s work is doubly important for scholars of rhetoric, not only because it helps us to understand the context that shaped these rhetors’ writing but also because the embodied and material nature of this “situatedness” is the foundation upon which their metaphors are built. Carlson and Wall

are only able to construct an effective counter discourse of metaphors once they have linked the elusive concept of *ME/CFS* concretely and convincingly to material, lived experience for an audience otherwise bombarded by conflicting explanations of the term.¹⁵ It is this rhetorical move that allows both Carlson and Wall to create an implicit agreement with their readers as to how *ME/CFS* operates as a *tenor* within their specific narratives—as a serious disease that firmly denotes the chasm between the bodily suffering it causes and the cultural dismissal it has received.

Embodying Symptoms and Signs: The *Vehicle* of the Invisible

In both *Kansas* and *Encounters*, Carlson and Wall make the *tenor* of *ME/CFS* accessible to the audience by framing it as a disease that is simultaneously an embodied experience and a social construction. They then use the *vehicle* of the *invisible* to signify for their audience both the corporeal pain and cultural isolation that are at the core of the lived experience of *ME/CFS*. The *ground* between the *tenor* of *ME/CFS* and the *vehicle* of the invisible is the peculiar, surreal nature of a thing that exists but cannot be seen. The metaphor of *ME/CFS* as invisible operates in Wall's and Carlson's narratives in two important ways. Not only do they use it to describe their physical symptoms of pain and the absence of clinical signs that that pain exists,¹⁶ but they also use it to characterize the

¹⁵ As I point out in chapter two, *ME/CFS* has been framed variously as an epidemic disease, a psychosomatic disorder, a fabrication of a sensationalistic media, an expression of privileged ennui, an expression of the desperation that accompanies oppression, a vogue diagnosis, and as a convenient excuse not to work.

¹⁶ According to the American Cancer Society, *symptoms* are “indications of disease that are felt or noticed by the individual” with the illness but may not be “easily noticed” or “quantified” by others. *Signs* are “also indications of disease,” but they are “defined as observations made by a doctor, nurse, or other health care professional.” It is a “symptom” to have the chills, while it is a “sign” to have a fever. “Shortness of breath” is a symptom, and the “sound of abnormal breathing as heard through a stethoscope” is a sign.

alienation they feel as a result of the lack of support for and recognition of ME/CFS in larger culture. In this way they collapse both the bodily and cultural experience of ME/CFS into the same *vehicle* of “invisibility,” thereby demonstrating through metaphor that the two phenomena—the lived experience of the body and the lived experience of the body in culture—are in fact integrally connected and inherently intradependent.

In his interview with me, Rik Carlson explained that “people with ME/CFS are constantly searching for new words to express what [their bodies] are experiencing.” This quest for “new words” to construct the physical experience of illness can be directly linked to feminist theorist Susan Griffin’s claim that “European languages lack the vocabulary needed to describe physical sensations with any precision, especially symptoms that are painful and uncomfortable” (33). The pain and fatigue that are hallmarks of ME/CFS cannot be seen by others; they are not “written” on the bodies of those who have the disease. As Dorothy Wall stated in her interview: “with ME/CFS, there’s no limp, no scars or bruises, no wheelchairs.” Neither is there any laboratory test that can identify ME/CFS as a distinct entity or even confirm the physical sensations people with ME/CFS are experiencing. In this way the physical experience of ME/CFS is doubly invisible, especially in a medical profession that relies primarily on the clinical observation or laboratory measurement of signs to diagnose disease (Kleinman 9).

Carlson’s first use of the term *invisible* as a *vehicle* for the symptoms and signs of ME/CFS occurs during his description of his initial series of visits to skeptical doctor after skeptical doctor, when he began to realize that “[his] terrible infirmity” was “for the most part invisible” for two reasons: (1) nothing appeared to be wrong with him other than the fact that he was “a fat guy who was a little slow” and (2) there was no clinical or

scientific “marker” to quantify or qualify his illness, no laboratory result a doctor could point to and say “ah, here’s your problem” (*Kansas* 83). As Carlson commented in his interview with me: “If you break your arm, you hold up an X-ray and it’s a done deal. If you say you feel sick and there’s no sign of it, you’re a cheat. You start to feel jealous of people who have cancer. That’s when you *know* you have a problem” (Personal Interview).

To experience jealousy of people with cancer may initially seem petty, but when Dorothy Wall uses the *vehicle* of the invisible to describe “an entire community, struggling to maintain lives without the benefit of diagnosis, validation, or treatment,” what is at the root of Carlson’s sentiment is more understandable (11). First, the “signs” of cancer are observable through laboratory testing: cancerous cells and tumors can be isolated and identified by a medical professional who can then diagnose the disease. Second, as I discuss in chapter one, the dominant war metaphor of disease has been consistently applied to cancer in such a way that the discourse of “disease as enemy” and of treatment and advocacy as “war” has helped garner support for people who have cancer, even as it has also constrained those efforts. As Wall remarks at the opening of her narrative, “if someone has cancer, we know what the word means: surgery, chemotherapy, radiation, hair loss, weakness, nausea. The name sinks in with sharp, terrifying recognition” (11). In this way cancer is a culturally “visible” illness even if tumors or cancerous cells do not mark the body on the outside; the name alone evokes the interior, scientifically recognized—and therefore culturally legitimate—markers of the disease.

Because ME/CFS has of yet no objective markers—located either “inside” or “outside” the body—the only way those with ME/CFS can convince others of their bodily suffering is to “find a language for this illness, words to convey the ‘otherness’ of their bodies and lives” (Wall 11). In *Kansas* and *Encounters*, Carlson and Wall repeatedly link their own vivid—also highly metaphoric—descriptions of their bodily experiences with the cerebral concept of invisibility, thereby issuing a challenge to what Arthur Frank argues is the “caricature Cartesianism [that is Western thought] . . . a head, compartmentalized away from disease, talking about the sick body beneath it” (2). Wall, for example, describes her body as “florid with pain, aches flaming through every muscle . . . a flat-iron press[ing] the right side of [her] face, veins of pressure gripping [her] cranium . . . thoughts mov[ing] through with resistance, like sound through water” as she “wades through [her] day behind a filmy screen of exhaustion” (12, 15). In the meantime, she knows that she “appears to [the outside world] to be a busy person [with] appointments, lunches, family, work,” her physical pain concealed behind a “mask of ordinariness, the illusion of health” (13). Here the metaphor of the invisible resurfaces as Wall uses the words *mask* and *illusion* to describe the ways in which her bodily knowledge remains hidden from others’ view, obfuscated by her appearance of normalcy. As Wall links what her body knows with her understanding of the “invisibility” of that bodily knowledge in culture, she insists upon a voice that continually fuses mind and body, that in Arthur Frank’s words, makes clear to the reader that “the mind does not rest above the body but is in fact diffused throughout it” (2).

Carlson utilizes a similar strategy of “diffusing” the mind through the body with language as he describes what his body feels during a Christmas party while at the same

time narrating the proceedings and analyzing his own sense of isolation from everyone at the gathering:

We ate, sat by the fire, watched some football with the sound off and listened to good music. Smokers went to the garage. I wore shoes. I announced nothing. The anvil was on my chest. My brain was packed with gauze . . . I sat and smiled but slipped into my hole . . . I couldn't keep up with the talk. Maybe they noticed. It had been a year. I had the flu. I always had the flu. (39-40)

The form of Carlson's passage mirrors the content in a way that is specifically embodied. The rhythm of the prose is choppy, demonstrating that his thoughts are interrupted by pain and confusion. The sentences are simple and the syntax is repetitive, reflecting his slowed cognition. Bit by bit he takes in his surroundings and evaluates his perceptions. He sees his guests having a good time; he wonders if they notice that he isn't joining them, that he isn't feeling well, even though he also knows he appears perfectly healthy—"sitting, smiling, wearing shoes." The fact that he mentions these seemingly unimportant details—elements we would all take for granted in a social setting—shows how monumental it is for Carlson to have achieved even that small level of social propriety and engagement. These details also suggest what he is *not* doing—lying down, expressionless, barefoot or in slippers—in such a way that he is able to imply that these are the ways of being that have become normal for him.

At the same time, Carlson indicates how wearied he is by the constancy of his illness in his quiet recital of the facts: "It had been a year. I had the flu. I always had the flu." His lack of critical commentary implies a state of resignation aside from the

insertion of the evaluative word *always* in the final sentence, which lets readers know how frustrated—even appalled—he is to have a flu that has lasted a year—and still shows no signs of ending. Some of the subjects that Carlson discusses at times seem irrelevant (what does it matter that “smokers went to the garage”?) or unrelated (“I announced nothing.” “The anvil was on my chest”), but in fact this series of apparent fragments artfully fuses observations of the mind, the body, and culture. The smokers going to the garage are having fun, circulating, enjoying sensual pleasures, while Carlson’s illness precludes his participation in these activities. Carlson “announces nothing”—does not speak, does not speak with authority, does not have anything to say—*because* “the anvil [is] on his chest”—because he is short of breath, because he feels pain in his lungs. The reader can infer that these symptoms make the physical act of speaking difficult and the art of thinking of something interesting to say virtually impossible.

The *vehicle* of the invisible is implicit in Carlson’s Christmas party passage in two important ways. The first occurs in Carlson’s declaration that he “slipped into [his] hole.” If used in the literal sense, the word *slipped* denotes an accidental fall; if used in the figurative sense, it signifies an inadvertent remark or action. A *hole* in its most literal sense is an empty space or a gap in something formerly solid, like earth, or all of a piece, like cloth. In nature, a *hole* is a kind of shelter—even a home—but it is a dimly lit and cramped place, not conducive to company or activity. In this way, a *hole* connotes loneliness and gloom. Thus to *slip into a hole* can be seen as accidentally or inadvertently descending into either a literal dark and confined space out of view, or into a more figurative position of isolation and passivity. But whether the phrase *slipping into a hole*

is used in a literal or a figurative sense, it does the work of moving its object from a state of visibility to a state of invisibility.

Second, the *vehicle* of the invisible is at work when Carlson states that “maybe [the party guests] noticed” he was ill. The use of the word *maybe* serves to emphasize the irony of the situation insofar as an illness this unrelenting and incapacitating—one that has gone on for a year, that makes it noteworthy to wear shoes—has possibly, even most likely, gone unnoticed by close friends and family. The doubt in the word *maybe* lets the reader know that none of the party guests indicated—either before, during, or after the gathering—that they perceived anything amiss in Carlson’s appearance or behavior. In this way the audience understands that Carlson’s disease indeed remains invisible even in his most intimate social circle. Even if anyone at the party did pick up on Carlson’s physical pain and attendant social isolation, the fact that neither one was publicly acknowledged reveals that it was considered the most socially acceptable or graceful course of action to pretend the situation did not exist.

Wall and Carlson each use the *vehicle* of the invisible in their narratives to articulate the particular and peculiar subjectivity of appearing well and feeling sick, of looking “able” and experiencing disability, of having a disease and living in a culture that denies that disease’s existence. At the same time, the use of invisibility as a *vehicle* in a metaphor ironically—and artfully—does just the opposite of what it means. In the process of circling back to the *tenor* of ME/CFS, the *vehicle* of the invisible, in fact, renders the *tenor* visible by drawing the audience’s attention to the *ground* between the two: that of mystery. Yet the *vehicle* of invisibility as utilized in the disability narratives of Carlson and Wall goes further than to merely emphasize the mystery inherent in a

disease with no known cause or cure and no specific biomarkers with which it can be identified. Carlson and Wall firmly locate the invisibility of ME/CFS not just in the body but also in culture. The invisibility they speak of permeates the fabric of society; it is a presence at Christmas parties, in doctors' offices, in workplaces, in legal proceedings, in homes and families.

Thus the mystery of ME/CFS as framed by Carlson and Wall does not belong just to the body with the disease but to the culture that constructs it. As this mystery is brought into public space, it is reconfigured as a phenomenon that shapes the lives of both the sick and the well, thereby challenging a metaphorical system that implies a battlefield exists between the two. Mysteries are at once fascinating and frightening, intriguing and baffling. The endless possibilities a mystery presents make it a trope that invites an audience to work with the rhetorician to, in the words of feminist theorist Susan Griffin, "achieve perception through collaboration" (36). As the mystery unfolds through their use of metaphor, Carlson and Wall resist the cultural role of "enemy" implicit in the war metaphor, not by Sontag's process of "*de-mythicizing* disease" but rather by a process of "*re-mythicizing*" it. The writer and reader, the sick and the well, are united in their efforts to create meaning from mystery, and together they bring new narratives about the illness experience into being.

Re-Mythicizing Disease

Although Wall's and Carlson's use of the *ground* of mystery can imply a desire for their readers to take on the role of detective and begin a search for a solution—or, in biomedical terms, a cure—Wall and Carlson never emphasize a hope for a cure in their

narratives. They do not end their books with calls to action—with requests for the reader to donate money for research, or even to “spread the word” about ME/CFS. Carlson instead asks his readers simply to “imagine” what it means to have an illness that is so “invisible” they “disappear” (“Invisible”), while Wall calls to her readers in her epilogue to “listen” to the “voice of the body” in a story without a “conclusion or an end” (*Encounters* 244). In this sense Carlson’s and Wall’s lack of formal conclusions to their narratives reflects what Arthur Frank refers to as the “primary condition” of the illness narrative: that the “teller’s diseased body shapes the illness story” (2).

Just as Carlson “always” has the flu, just as Wall is “never able to forget she lives in the land of the chronically ill,” the two rhetoricians construct the metaphor of mystery to resist solution the way the disease of ME/CFS itself resists resolution (*Kansas* 40; 244). Wall instead refers to life with ME/CFS as “an ongoing improvisation” while Carlson calls it a “slow process of personal growth” (244; *Kansas* 155). Thus each rhetorician embraces process over product, the open-ended nature of possibility rather than the closure of definitive ending. The object of the mystery posited in these narratives is for both writer and reader to explore, learn, and discover, rather than to conquer, triumph, or overcome. The goal, then, is not one of “restitution” or “restoration of health,” but a revaluing of what Susan Griffin refers to as “bodily knowledge,” of “testimony” that gives “full witness to the life of the body” (38). Cultural anthropologists Linda Garro and Cheryl Mattingly argue that the genre of the illness narrative “provides a vehicle for confronting contradictions between an individual’s experience and [cultural] expectations about illness and its care, divergences between what [is] expected and what transpired” (28). Through the metaphor of mystery, Carlson and Wall locate their bodies,

their experiences, and their cultural situatedness *in* these contradictions and divergences, opening them up as opportunities for meaning-making rather than positing them as gaps in knowledge that must be forever closed.

CHAPTER FOUR: FROM “INVALIDS” TO “PRISONERS” AND BACK AGAIN?: HISTORICIZING THE MATERIAL RHETORIC OF THE WHEELCHAIR-USER AS A RHETORICAL BODY THROUGHOUT THE NINETEENTH AND EARLY- TO MID-TWENTIETH CENTURIES



For the past four decades, the blue and white symbol of the wheelchair-user depicted above has served as the official International Symbol of Access (ISA) for people with disabilities. Designed by Danish student Susanne Kofoed in 1968, the symbol was selected, copyrighted, and disseminated by the International Commission for Technology and Accessibility (ICTA), an organization founded in the 1960s by the Swedish Handicapped Institute and created for the purpose of promoting and implementing global standards of accessibility for people with disabilities. In 1969 the International Organization for Standardization (ISO) and the United Nations (UN) each endorsed and adopted the symbol with the goal of providing “a consistent international designation of accessible entrances, information, facilities, transportation and amenities” (ICTA website). In the United States, the ISA marks ramped entrances, elevators, automatic doors, parking spaces reserved for people with disabilities, and public restrooms designed for wheelchair-users—in short, the symbol distinguishes spaces, designs, and technologies that provide people with disabilities access in the public sphere. In the August 2007 issue of *Disability and Society*, sociologists Liat Ben-Moshe and Justin J.

W. Powell call the ISA one of the “most widely recognized representations of disability”; they also commend the ways in which it provides the public with “daily interactions with issues of accessibility” (489).¹⁷

Yet despite the ubiquity of the ISA and the important ways in which it has symbolized efforts to provide public accommodations to people with disabilities, I argue in this chapter that the act of representing the body of the wheelchair-user as a denotation of access belies the long history of exclusionary practices—and material, embodied, and symbolic rhetorics—that have relegated the material object of the wheelchair and the actual body of the wheelchair-user to the margins of public space, beginning in the nineteenth century—with the advent of the first known wheelchair—and up until the present day. In chapter two of this dissertation, I traced a dominant rhetoric of war used to characterize disease and argued that this language has resulted in the cultural erasure of the bodies of those with chronic illnesses that resist cure. In chapter three I examined the use of alternative metaphors in disability narratives by Rik Carlson and Dorothy Wall and argued that in recasting illness as mystery, these writers challenge the dominance of the war metaphor in discourses of disease. In chapter four I utilize Carole Blair’s theory of material rhetoric and Simi Linton’s theory of ableism to embark on an investigation of the history of the wheelchair as a material object, of wheelchair-users in public space, and of the dominant rhetorics used to characterize the two. I believe the resulting study has important implications for rhetorical scholars who work with concepts of embodiment

¹⁷ However, Ben-Moshe and Powell ultimately make the purpose of their article a reconsideration of how well the ISA represents issues of accessibility for all people with disabilities. For example, many people with invisible mobility impairments (such as trouble with balance or fatigue that prevents them from walking distances) need to use disability parking spaces, yet in body they do not match the symbol that grants them access.

and materiality as well as for disability studies scholars who examine the connections between language and the cultural construction of disability.

Current work with material rhetoric and rhetorics of the body tends to assume that one must focus primarily on *either* the rhetoric of material objects (buildings, antidepressants, quilts) *or* the rhetoric of bodies (the pregnant woman, the factory worker, the “beard”); it also seems to imply that if one engages in either form of rhetorical study, one does not also assiduously incorporate work with rhetoric in the more traditional sense, what Sonja Foss, Karen Foss, and Robert Trapp call “the uniquely human ability to use symbols to communicate with one another” (11).¹⁸ Yet as exemplified in the discussion that follows, it is virtually impossible to consider the rhetorical implications of the wheelchair as a material object without also considering the rhetorical implications of bodies that use wheelchairs—and it is just as impossible to adequately consider the cultural impact of each/both without also analyzing the evolution of the language use surrounding each/both. Thus, at least in this case, the material object, the particular body, and the language that frames each/both are inextricably intertwined, and furthermore—at least in my own estimation—a rhetorical study of any of these aspects of wheelchair use on its own would not adequately convey the ideological freight this particular intersection of object, body, and language carries in our culture. In this way, my chapter is inspired by Carole Blair’s work with United States memorial sites as “material rhetoric . . . that acts upon the whole person—the body as well as the mind,” and her call to rhetorical scholars to consider how “the material, symbolic, and purposeful dimensions of rhetoric may interact, interfere, or intersect with one another” (46, 50).

¹⁸ See “Habeas Corpus,” Jack Selzer’s introduction to the collection *Rhetorical Bodies*, and the contents of the collection itself.

In this chapter I begin by providing an overview of the historical marginalization of people with mobility problems¹⁹ from biblical times up until the introduction of the material object of the wheelchair at the turn of the nineteenth century. In so doing, I trace the roots of what I term a *rhetoric of invalidity* that I argue became the dominant means of defining those who used wheeled mobility and of justifying their exclusion from public life. Next, I pinpoint the emergence of a *rhetoric of containment* that began to surround wheelchairs and wheelchair-users in the early twentieth century, and, using a case study of Franklin Delano Roosevelt as a rhetorician as evidence, I argue that this *rhetoric of containment* only allowed wheelchair-users public voice if they found opportunities to (somehow—and seemingly miraculously) rhetorically embody traits traditionally associated with the able-bodied (agency, efficacy, perspicacity). In conclusion, I suggest that although the Disability Rights Movement of the last fifty years has indeed motivated major shifts in public policy mandating provisions of access and accommodations for wheelchair-users—including the Americans with Disabilities Act of 1990—the long legacies of the *rhetoric of invalidity* and the *rhetoric of containment* as yet still shadow the material object of the wheelchair and the bodies of wheelchair-users by upholding a dominant ableist ideology that serves as justification²⁰ for their cultural

¹⁹ Harvard medical professor Lisa Iezzoni, a woman with MS and herself a wheelchair user, defines “mobility problems” as existing on a continuum, “ranging from persons who walk independently but more slowly or less surely than before to those who require complete assistance with all mobility tasks, such as turning in bed” (3). Her 2003 public health study of people with mobility problems focuses principally on people with chronic conditions, such as arthritis, cerebrovascular disease, or multiple sclerosis. However, in her discussion of the cultural construction of walking, standing, and wheelchair use, she also includes people born with conditions that cause mobility problems, such as spina bifida and cerebral palsy, as well as people who become mobility-impaired as a result of accident or injury, such as people with spinal cord injuries.

²⁰ Albeit much more insidiously than in the nineteenth and early-to-mid twentieth centuries, as I will show in the following sections.

devaluation and marginalization in public space—even into the first decade of the twenty-first century.

Exclusion from History and a History of Exclusion: In Search of the Wheelchair-User as Subject

The most recent—and as far as I am aware, only—effort to trace the history of the material object of the wheelchair occurred in 1969, when Dr. Herman Kamenetz, a rehabilitation specialist and the winner of the American Medical Association’s Physician’s Award, published “A Brief History of the Wheelchair” in a 1969 issue of the *Journal of the History of Medicine and Allied Sciences*. Kamenetz’s piece focuses primarily on four modes of transport for people with mobility problems: the litter²¹ of ancient times; the wheelbarrow,²² which came to Europe from China in the twelfth century; the wood and wicker “invalid-chair” of late eighteenth- and early nineteenth-century England; and the metal, four-wheeled model that originated in the United States in the 1930s and was still the standard for wheeled mobility when Kamenetz published his article in 1969 (205-10). The conclusion of the article is self-congratulatory as Kamenetz celebrates the United States as the acknowledged world leader in wheelchair production and design; in the end he suggests that with the “hospital chair of today” the work of wheelchair developers is finished (210).

²¹ The litter was, in its most basic form, comprised of a wooden plank with handles and carried by slaves, paid servants or family members. The more wealthy the family, the more luxurious the litter: some were canopied and curtained—and these were often used by men and women of means without disabilities for transportation as well as by those who were mobility impaired.

²² It is not known whether the wheelbarrow was invented for the purpose of transporting people with mobility problems or if it was simply created as a means for carrying heavy loads. However, as Kamenetz documents, famous drawings and paintings from the sixteenth and seventeenth centuries show “the old,” “the ill,” and the “disabled” traveling in wheelbarrows.

Unfortunately, Kamenetz discusses the evolution of these mobility devices only from the perspective of the nondisabled: those who designed the devices, those who carried and pushed the devices, and, later, those who prescribed the devices as part of medical treatment. Never does Kamenetz make an effort to imagine,²³ find documentation of, or include the perspectives of people with mobility difficulties on these devices and how these devices may have shaped their lives in public space. Kamenetz's piece is illustrative of the ways in which the work of the academy, before the rise of disability studies, "supported and defended" what disability theorist Simi Linton calls "the dominant cultural narrative of disability" (1). Linton defines this dominant narrative as an "ableist narrative," one that casts disability as an "innate biological inferiority" which inevitably—if regrettably—justifies the social inequities and subordinate status experienced by people with physical and mental impairments (Linton 9; Hahn 43). Kamenetz's article is one such example of the naturalizing narrative embedded in an ableist viewpoint in that he constructs people with disabilities primarily as objects the nondisabled needed to transport from one place to another; in short, they presented a problem that needed to be solved. However, from a rhetorical perspective, Kamenetz does indeed (however inadvertently) manage to historicize for the contemporary reader the ideological freight the dominant culture assigned to the body of the wheelchair-user—from the times of the litter to the year of the article's publication—by the very nature of their absence from his history as meaning-making subjects. In the only extant article we have on the history of the wheelchair, the voices, embodied experiences, and material and cultural circumstances of wheelchair-users are completely excluded.

²³ Admittedly a difficult task.

In this sense, what is implicit in Kamenetz's work is confirmed by the recent work by historians conducting scholarship from a disability studies perspective. As Paul Longmore²⁴ and Lauri Umansky explain in their introduction to their 2001 collection *The New Disability History*, major fields of historical inquiry have long “rendered people with disabilities invisible and have neglected disability themes that were of central concern to their subjects” (3). As a result, our histories have ironically reflected a “truth” central to the lives of people with disabilities; just as they have been excluded from our histories, they have also been excluded from public space and full citizenship—and repeatedly denied opportunities for “self-definition and self-determination” (4). In the section that follows, I make an effort to fill in what Longmore and Umansky call the “historiographical gaps” in the existing scholarship on the lives of people with mobility problems in order to contextualize the rise of the wheelchair as a material object in the late nineteenth century and the attendant evolution of a *rhetoric of invalidity* to characterize both wheelchairs and wheelchair-users.

²⁴ Longmore is a disability rights activist, an Associate Professor of History at San Francisco State University, and a wheelchair user. He has written extensively on disability history and theory. He has also written disability narrative, most notably his essay “Why I Burned My Book,” which chronicles his experiences as an academic who uses a wheelchair and a ventilator. When Longmore's first book was accepted for publication in 1988, he learned from the Social Security Administration that if the book saw print, what small amount of money he made from the royalties would disqualify him from receiving the benefits he needed for healthcare and attendants. In short, if he achieved a public life as a scholar, he would no longer qualify for the assistance he needed to live.

From “Broken-Down Human Beings” to the “Invalid-Chair”: The Long History of People with Mobility Problems and a *Rhetoric of Invalidity*

People with disabilities, including problems with walking or standing²⁵, have since biblical times lived on the margins of public space (Linton 3; Mitchell and Snyder 6). In the Old Testament, Leviticus declared persons who were “lame,” “injured” or “too long of limb” unsuited to participate in religious ceremonies, a pronouncement that recalls the Apostle Paul’s injunction in the New Testament prohibiting women from speaking in church. During colonial times in the United States, immigration inspectors were charged with examining potential citizens for mobility impairments and denying them entrance to the country if they proved to have “irregularities of movement or posture” or any other evidence that they were “defectives” or “broken-down human beings” (Baynton 48). In England fifteenth-century Elizabethan law granted poor people with mobility difficulties the status of “honest beggars,” thereby permitting them to spend their days panhandling in the streets and their nights in poorhouses or hospitals (Iezzoni 50). Eighteenth- and nineteenth-century United States policymakers followed England’s lead by “sheltering” the poor and the mentally and physically disabled in almshouses, the deplorable conditions of which were most famously exposed by social reformer Dorothea Dix in 1854 (Shapiro 59). And although people with visible mobility difficulties from the upper classes were traditionally cared for and financially supported by their families—rather than thrust out onto the street or placed in institutions—they were considered to be

²⁵ Longmore and Umansky point out that “similar experiences of cultural devaluation and socially imposed restriction recur across various disability groups and throughout their particular histories,” but because of the nature of my study, I focus only on those with mobility impairments. From a disability rights perspective, however, I believe it is important to keep in mind that the historical practices of exclusion and discrimination I discuss here applied also to those with mental impairments, visible physical impairments other than mobility difficulties, people with chronic illnesses, the blind, and the D/deaf.

sources of “shame and embarrassment,” unfit for public view, and as such spent much, if not all, of their lives cloistered in their homes as “invalids” (Gallagher 29; Linton 3).

This admittedly brief overview of the historical marginalization of people with mobility difficulties reveals the ways in which the inability to walk and/or stand has long served as a “physical marker” that has “accumulated cultural associations of limitation and deviance” to a point that these particular bodies have been constructed as “inherently inferior and parasitic” (Mitchell and Snyder 5, 24). It is worthy of note, too, that their material circumstances—as deportees, as beggars, as “homebound”—have reflected their cultural devaluation. Even the language historically used to describe them—as “defectives,” as “broken-down human beings,” and as “invalids”—confirms Mitchell and Snyder’s assertion in their introduction to the collection *The Body and Physical Difference: Discourses of Disability* that dominant discourses of “limitation, incapacity, and monstrosity” continually render the disabled subject “unsalvageable, and thus, somehow stubbornly inhuman” (24).

If, in the spirit of new scholarship on rhetorics of the body, we consider the body rhetorical in the sense that as a result of its ideological freight, it becomes a “legible” or “readable” text, then the new disability history reveals the mobility-impaired body read by the dominant culture as “less than” or “in-” human (Blair 17). And if we consider the mobility-impaired body to be a rhetorical text, we can then apply to the material object of the wheelchair—as a device meant for use by the mobility-impaired—the central question that drives Carole Blair’s inquiry into the nature of material rhetoric. Blair argues that to consider a material object a rhetorical text—that is, “partisan, meaningful, and consequential”—we must ask not just “what the text means, but . . . what it does”;

and when we ask what it does, we must also consider what it does “to (or with, or against) other texts” (17, 23, 39).

I argue that if the culturally devalued and socially marginalized mobility-impaired body is a rhetorical text that symbolizes for the nondisabled what it means to be “defective, broken-down, and an invalid,” then the first known wheelchair at the turn of the nineteenth century, most commonly known as the “invalid-chair,” serves also as a rhetorical text in that its design and construction as a material object supported and confirmed the wheelchair-user’s physically “invalid” state, and, perhaps more importantly, cultural state of “invalidity.” Though Kamenetz remarks upon the ways in which the first incarnation of the wheelchair, which came into popular use at the turn of the nineteenth century, “indeed served patients well,” contemporary disability historians such as Fred Pelka, Hugh Gregory Gallagher, and Joseph Shapiro each note the ways in which the original invalid-chair imposed limitations on its users (Kamenetz 209; Gallagher²⁶, *Splendid*; Pelka, *Disability*; Shapiro, *No Pity*). Made of wicker and wood, the chair itself was “bulky” and “cumbersome,” with wheels so large they customarily reached shoulder-height of the user (Gallagher 31, 91). Taken together, the chair and the wheels weighed upwards of ninety pounds (Shapiro 214). Even if the user had the strength to propel his or her own weight plus the weight of the chair, the height of the wheels alone made it logistically impossible for the user to grasp them in order to move herself forward. In short, the chair needed to be pushed by someone else; the wheelchair-

²⁶ The late Hugh Gregory Gallagher (1932-2004) was a disability rights activist, Capitol Hill lobbyist, wheelchair-user, Franklin Delano Roosevelt scholar, and writer. He lobbied for the passage of the Architectural Barriers Act of 1968 and the Americans with Disabilities Act of 1990; he also led the movement to represent FDR as a wheelchair user in the design and creation of the FDR memorial in Washington, DC, which was dedicated in 1997. In addition, he is the author of the 1998 disability narrative *Blackbird Fly Away: Disabled in an Able-Bodied World*, about his experiences with polio, clinical depression, and life as a wheelchair-user.

user was thus consistently reliant on a nondisabled body to achieve forward movement. According to Gallagher, “it was virtually impossible to live an independent life [in such a chair]” (91). Fred Pelka, in his discussion of wheelchair patents and production, argues that the earliest wheelchairs were constructed in such a way because nondisabled designers built them specifically “for use by invalids” who were expected to be dependent on others and stay close to home (320). Thus, the wheelchair as an object of material rhetoric seemed purposefully designed to respond to and corroborate the dominant culture’s reading of mobility-impaired bodies as unsuited for independent life and public space.

It is through this analysis of the mobility-impaired body as rhetorically “invalid” and of the wheelchair as an object of material rhetoric created for “invalids” that I amass material and embodied evidence for a dominant *rhetoric of invalidity* used to characterize wheelchairs and the bodies of wheelchair-users. I base my characterization of this rhetoric as one of *invalidity* on the frequency with which the word *invalid* has historically defined the bodies of people with mobility impairments and on the fact that it served as the primary descriptor for the earliest known wheelchair. To further characterize this *rhetoric of invalidity*, it is important to examine the etymology of the word *invalid*. *The Oxford English Dictionary* defines the adjective *invalid* as (1) “of no power or strength,” and (2) “of no force, efficacy, or cogency, especially without legal force, void,” and lists the first usage of the word in this sense as “The beames of the Moone are too weake and invalid to ripen a tender grape” from a 1638 sermon by John Gore (“invalid, *a*”). The use of the word *invalid* as a noun to mean “an infirm or sickly person” followed a mere four years later in 1642; the *OED* traces the first usage to a letter by lawyer Jeremy Taylor that

pronounces “The Narcissus Bishop of Jerusalem . . . an invalide and unfit for government by his extreame age” (“invalid *a.2* and *n*”). Two centuries later, in 1847, the term *invalid-chair* first appeared in William Makepeace Thackeray’s *Vanity Fair* as “Sir Pitt’s invalid-chair was wheeled away into a tool-house in the garden” (*OED*), and, according to disability historian Fred Pelka, the first official patent for the invalid-chair was registered twenty-two years later, in 1869 (“invalid”, *a.2.* and *n*”; 320).

In her groundbreaking book on disability theory, *Claiming Disability*, Simi Linton²⁷ includes a chapter on “reassigning meaning” to popular terminology used to characterize people with disabilities, including the word *invalid*. There she points out that “both *invalids* [the adjective and the noun] share the Latin root *invalidus*, which means weak” (28). While she acknowledges that some disabilities do indeed “result in the weakening of the body, or, more likely, parts of the body . . . the totalizing noun, *invalid*, does not confine the weakness to specific bodily functions; it is more encompassing” (29). Although Linton does not go on to say *how* it is “more encompassing,” I believe that the ways in which the definitions and applications of the term have evolved over time clearly reveal that the use of the word *invalid* to describe a person with a mobility impairment—and the use of the word *invalid-chair* to name a mobility device used by a person with such an impairment—carries with it the connotations of its original usage as an adjective, thereby implying that the person with the impairment or the person using the chair is incapable of “power, strength, force, efficacy, or cogency.” Thus, *the rhetoric of invalidity* surrounding the wheelchair and the bodies of wheelchair-users is

²⁷ Simi Linton is a disability studies scholar, disability rights activist, consultant, public speaker, wheelchair user, and the author of the disability narrative *My Body Politic: A Memoir*. She is currently touring the United States with a multimedia adaptation of the book and developing a documentary film version. She has served as Associate Professor of Psychology at Hunter College and is at present Co-Director of Columbia University’s Seminar on Disability Studies.

“encompassing” in that it does not merely serve as a means of describing the bodily condition of illness or impairment that prevents a person from standing or walking. Instead, it assumes a person with such a condition cannot possibly possess the character traits necessary to achieve a sense of self and accompanying sense of agency. Thus a person who uses an *invalid-chair* is effectively rendered *in-valid*—not just ill, not just physically impaired, but also not quite human—mentally, emotionally, morally—and certainly not suited for the public sphere, civic participation, or community life.

The Early to Mid-Twentieth Century Wheelchair, the Medical Model of Disability, and the *Rhetoric of Containment*

The India-reed Chair and the E&J Model

The basic design of the “invalid-chair” remained essentially the same until the second decade of the nineteenth century, when gradually it began to be replaced between 1914 and 1918 by an updated version of what was previously known as the “Bath Chair,” utilized in the nineteenth century as a means of transportation for “invalids” who visited Bath, England, for the healing benefits of its waters (“Bath, *n.*”). Because it was “made entirely of India reed,” this incarnation of the “Bath Chair” was lighter than the original “invalid-chair” and could be pushed more easily—and thus, for greater lengths of time and for greater distances—by an attendant (Cooper 2). This India-reed chair became the standard for wheeled mobility for fifteen years, when it was followed by a folding model made of tubular steel. Created by Herbert Everest, a mining engineer who became a paraplegic as a result of a 1918 mine collapse, it was patented in 1932 by Everest and fellow mining engineer Harry Jennings and marketed as a solution for the problem of

travel—because it folded, an attendant could fit it into the trunk of a car (Cooper 3; Pelka 320). The company that resulted, Everest and Jennings, or E&J, had what Pelka refers to as a “virtual monopoly” on the wheelchair market for the next thirty-five years (321).²⁸

The two chairs described above—the lighter India-reed chair and the folding “E&J” model—were definitive improvements upon “the invalid chair” in that one was easier to push and the other could more easily be transported from one location to the other. However, as wheelchair bioengineer Rory A. Cooper²⁹ indicates, both models were “impractical for [sustained] mobility” (2). Though the India-reed chair weighed nearly half as much as the original “invalid-chair,” it had many of the same design flaws: its size made it difficult to fit through doors; its wheels were still hard to manage; and it was too inflexible for travel. And though the E&J chair was purportedly designed for travel, the brand was, in Pelka’s words, still intended to serve as “medical equipment” for people who were not expected to need, or want, much access to the public sphere (321). With a hard back and rigid seat, the E&J chair was at best uncomfortable and at worst put its user at risk for developing pressure sores (which can be life-threatening). Because the E&J chair was, on average, heavier than the India-reed chair at sixty pounds, it was still exhausting for a user to propel on her own (Shapiro 212). In fact, these incarnations of

²⁸ Although the circumstances of the E&J chair’s creation are suggestive of a future in which people with disabilities would take control of wheelchair design in ways that would meet the needs of users, Pelka notes that the mass production and institutionalization of E&J chairs were largely in the hands of nondisabled management. From the beginning, these company executives neglected to respond to concerns of wheelchair users regarding the design flaws of the model. The consequences of this business practice eventually led the company to the brink of bankruptcy in 1991, after thirty years of Disability Rights Movement activism and wheelchair innovation on the part of wheelchair users themselves (Pelka 321; Shapiro 219).

²⁹ Rory A. Cooper is the Chair and Distinguished Professor of the Department of Rehabilitation Science and Technology at the University of Pittsburgh. A rehabilitation specialist, bioengineer, and wheelchair user, Cooper’s recent publications include articles on new wheelchair technology, including the pushrim activated power assist wheelchair and the development of a compact chin-operated force sensing joystick in wheelchairs for persons with quadriplegia. Cooper is also a four-time gold-medal winner in the swimming competition of the National Veterans’ Wheelchair Games. Currently, he is conducting a survey among wheelchair users to collect data for an update of the guidelines for the Americans with Disabilities Act.

wheelchairs seem to have been directed more toward meeting the needs of nondisabled family members and attendants of people with mobility problems: the India-reed chair, while easier to push, was not easier for a wheelchair-user to propel; and the E&J model, while it could travel, was still so heavy and bulky that it needed to be folded and stored by a nondisabled person. Cooper critiques the design of the E&J chair when he remarks that Everest, Jennings, and their associates seemed to assume when they designed the chair that all a mobility-impaired person could—or should—reasonably wish for was “some degree of mobility,” when in reality, most wheelchair-users wanted “independence,” “activity,” and “outlets for their energy” (3). In short, neither chair allowed for habitual, autonomous movement in public space for people with mobility impairments.

Although Cooper’s critique comes from a technical manual that details the “engineering fundamentals, biomechanics, and standards” of today’s wheelchairs, I believe that the very nature of his discipline demands that he work directly with the rhetoric of material objects (xii). The fact that the introduction to his book includes a discussion of the Disability Rights Movement, the passage of the Americans with Disabilities Act, and an evaluation of cultural attitudes toward disability shows that Cooper recognizes that wheelchair design is not solely a matter of science and technology but also of cultural construction and ideological frameworks. Joseph Shapiro, in his groundbreaking book on the Disability Rights Movement, cites the fact that E&J wheelchairs were “too wide to get through most doors” as evidence that “wheelchair users were considered useless to society” (214).³⁰ In this sense, both Cooper and Shapiro

³⁰ If I had considered that sufficient evidence, I would not have included such a comprehensive review of the model in this chapter.

attend to the ways in which the wheelchair as a material object is, like the memorials Carole Blair studies, a “constructed site [of rhetoric]” that “do[es] . . . obvious work on the body...[by] direct[ing]—sometimes even control[ling]—the vector, speed, or possibilities of physical movement” (Blair 46). The India-reed chair and the E&J chair of the early and mid-twentieth century were each of a design that made it difficult for people with mobility impairments to move regularly from the private to the public sphere. Thus, the second and third incarnations of the wheelchair acted upon people with mobility impairments by physically enforcing ideologically based constraints on their movements, and it acted upon the nondisabled community by furthering the notion that all people with mobility impairments were a population without the need, desire, or physical capacity for habitual movement in public space.

The Rehabilitation Movement, the Polio Virus, and the Emergence of the Medical Model of Disability

Cooper attributes the development of the India-reed chair to the “legions” of veterans with disabilities returning from World War I, and the increase in mass production of the E&J chair as “standard-issue” in the 1940s as being fueled by the need to provide wheeled mobility to disabled veterans from World War II (2-3). However, I believe that from a rhetorical perspective, it is important to consider the cultural context that gave rise to these new incarnations of the wheelchair more broadly. Cooper does not mention two other important factors that may have influenced wheelchair design and development beginning in 1914 and up through World War II: the Rehabilitation Movement of the late nineteenth and early twentieth century and the recurrence of mass

polio epidemics across the United States, beginning in 1894 in Vermont, then again in 1916 in New York City, and again in Los Angeles in 1934. Polio and Rehabilitation Movement historians consistently emphasize that throughout these years there was a corresponding ascension of what disability studies scholars and disability rights activists today call “the medical model of disability,” a philosophy that isolates disability as solely a medical condition meant to be corrected by medical professionals through treatment or cure (Linton 11). To thoroughly examine the rhetoric of the wheelchair from the turn of the twentieth century through World War II, then, the rise of the medical model must be theorized in terms of how it might have influenced wheelchair design and development.

In his article on Progressive Era hospital schools, historian Brad Byrom describes the Rehabilitation Movement of 1890 to 1930 as a time when social reformers, individual philanthropists, and charitable establishments began creating organizations designed to “improve the lives” of people with mobility impairments, or “cripples,” primarily by institutionalizing practices that “fell in line” with the “emergence of the medical model of disability” (138). Although some reformers focused on the ways in which social prejudice constrained the lives of people with mobility impairments and worked toward eradicating that prejudice, the majority viewed people with mobility impairments as inherently defective, both in body and in character, and directed their efforts toward reforming the character through a “moral education” and repairing the body through medical intervention, specifically orthopedic surgery (138-39). As orthopedic surgeons became increasingly professionalized throughout the 1910s and the 1920s—which Byrom attributes to “the establishment of medical organizations, the creation of medical journals, and the reform of medical schools,” among other factors—hospital-schools

began to “accept only crippled children whom surgery could benefit,” and the institutions dedicated to providing adults with mobility problems access to the “mainstream workforce” became instead “sheltered workshops,” such as the Institute for Crippled and Disabled Men (145, 151). While education and job training were thought important elements in the rehabilitation of cripples, “cure” was often defined as “physical improvement that increased an individual’s chances of getting a job” (135). Physical improvement was gauged based on how close the mobility-impaired person came to approximating “normal” walking. As described in a 1928 publication from the Institute for the Crippled and Disabled, “a limp was less objectionable than a [brace, a brace less objectionable than a] crutch” (135).

Somewhat surprisingly, wheelchairs are not mentioned in Byrom’s study nor in any of the publications he quotes. However, given the quotation above, one can imagine that the body of the wheelchair-user must have represented the most objectionable embodiment of mobility impairment. Polio historians corroborate the existence of such a hierarchy when they describe the objectives of treatment for people with polio throughout the rise of the medical model of disability. Immobilization was the treatment most used from the early 1900s to the late 1920s. People in the febrile stages of the polio virus were wrapped in plaster casts and splints; they remained in that state for weeks or months at a time after the fever broke and the virus passed, in the hopes that if their muscles were fixed into place they would not become paralyzed. Unfortunately, this treatment instead resulted in further paralysis; muscles that may have regained function instead atrophied from disuse (Finger 99). By 1930, once it was finally determined that immobilization was ineffective, people with polio were treated through a combination of heat and stretching

therapy to ease contracted muscles. Although much more logical a method than immobilization, this treatment was often enacted brutally, with boiling hot packs that burned skin and stretching procedures that included being “hung” with canvas straps around the neck and the head so that the feet were “barely touching the ground” or fitted with trunk, hip, and neck braces connected by screws that were adjusted daily until “straightening” was achieved (Wilson 159).

Both these treatments—immobilization and stretching—were designed to maximize the person’s chances of walking again. Once people with polio went through one or the other of these processes, the goal was to move them out of wheelchairs as soon as possible through physical therapy and the use of braces and crutches. Medical professionals judged the person’s “recovery” from polio based upon what Anne Finger³¹ calls the “Law of Orthopedic Appliances;” as long a person could stand, remain upright, and put one foot in front of the other, it did not matter so much if she used a cane, a crutch, or a brace.³² What mattered was that she did not need to use a wheelchair (101). As polio historian Daniel J. Wilson observes, throughout the early to mid-twentieth century, “walking was held up to polio patients as the Holy Grail of recovery,” while use of a wheelchair was considered “an admission of defeat”—both for medical professionals and for the person with polio herself (85, 154).

In this way, the histories of the Rehabilitation Movement and of polio reveal what I argue is a hierarchy of cure that applied specifically to people with mobility

³¹ Anne Finger is president of the Society for Disability Studies, a disability rights activist, and the author of two disability narratives, including *Elegy for Disease: A Personal and Cultural History of Polio* (2006) and *Past Due: A Story of Disability, Pregnancy, and Birth*. She has taught creative writing at Wayne State University in Detroit and at the University of Texas at Austin. In her most recent book she talks about the experience of Post-Polio Syndrome and identifies as using either a crutch or a wheelchair for mobility.

³² Though Finger acknowledges that certainly these, too, were “stigmatized devices” (101).

impairments. Unassisted walking was at the top of the hierarchy; wheelchair use was at the bottom. Thus, the medical model cast those who did not respond to medical intervention, those who did not get up out of their wheelchairs and walk, as failures: they represented both the failure of medicine to do its work and a failure of the individual will in achieving the goals set by medicine. In this way, the impact of the medical model on the design and institutionalization of the wheelchair during the early-to mid-twentieth century cannot be underestimated. If the ability to walk symbolized the achievement of cure, and if the goal of medicine was to achieve cure, then what sense did it make to design a wheelchair that would offer people with mobility impairments opportunities for sustained, independent mobility in public space? To do so would be to admit defeat before the defeat had occurred. The limitations of the India-reed chair and the E&J model make much more sense when put in such a context.

The Rise of the *Rhetoric of Containment*

Whereas in the last section of this chapter I traced the roots of a *rhetoric of invalidity* that dominated nineteenth-century discourse surrounding wheelchair-users, here I pinpoint the rise of what I term a *rhetoric of containment*, including the phrases “confined to a wheelchair,” “wheelchair-ridden,” and “wheelchair-bound.” Determining the origins of these idioms to describe wheelchair-users has proven to be a difficult task. First, the *Cambridge International Dictionary of Idioms* does not recognize these phrases as idioms. Second, the *Oxford English Dictionary* does not isolate this usage as dated or prejudicial in any way; rather, it lists “confined to,” “-ridden,” and “-bound” as status quo modifiers for the word wheelchair. It is suggestive of a dominant ableist ideology at work

that these definitions have not been subject to revision. Yet even in disability studies scholarship, no study as of yet definitively isolates the first known usage of these phrases or even proposes a theory as to why they came into popular use during a particular historical moment.

I utilize the term *rhetoric of containment* to describe these phrases because each phrase casts the material object of the wheelchair as an implement of imprisonment and the body of the wheelchair-user as a prisoner. The phrase “confined to a wheelchair” recreates the wheelchair as a metaphorical prison, while the phrases “wheelchair-bound” and “wheelchair-ridden” suggest a ball and chain. Such metaphors render the body of the wheelchair-user perpetually separate and static, disconnected from others and unable to act, deprived of rights and freedom. Before my own investigation into these phrases, I thought that perhaps the fact that the E&J models were made of tubular steel had triggered associations with a ball and chain or the bars of a prison. However, my research reveals that the *rhetoric of containment* originated over a decade before Everest and Jennings patented their folding steel model. Searches of newspaper archives from 1850 on reveal the first usage of the phrase “confined to a wheelchair” to have occurred in *The New York Times* in 1917, the year the Rehabilitation Movement was at its peak and the year after the 1916 outbreak of polio in New York City, which the Center for Disease Control and Prevention cites today as the most devastating polio epidemic in United States history. Six thousand people died and 27,000 more were paralyzed (www.cdc.gov). The E&J model was not invented until 1932; therefore, the tens of thousands of people who were “confined to wheelchairs” following the 1916 epidemic were pushed by attendants in the India-reed Chair.

Since prisoners are not typically confined to cells of India-reed or weighted down with India-reed implements (the India-reed chair's was appealing precisely because it weighed *less* than the wood and wicker invalid-chair of the nineteenth century), it seems that the *rhetoric of containment* arose not from a concrete material analogy (steel wheelchair, steel prison) but from an ideological one. Throughout the three years preceding the introduction of the India-reed Chair and the emergence of the *rhetoric of containment*, record numbers of people suddenly became disabled through either systematized violence or an identifiable disease; their invalidity could no longer be attributed to random circumstance or inexplicable acts of god. People who had spent their lives "valid" or nondisabled returned from battle or woke from polio-induced fever "invalid." Through the lens of the medical model, people who experienced mobility impairments under these circumstances were granted liminal status as human insofar as they had a condition that could or could not be cured through medical innovation. It seems logical to assume, then, that the wheelchair was designed as a space for a person with a mobility impairment to occupy during—and only during—the "recovery period," while medicine did its work through surgery, stretching, heat therapy, bracing, and whatever other means necessary to restore enough function for the person to walk again. Only when medical innovation failed was the wheelchair thought of—with great reluctance, disappointment, sadness, and even despair—as a permanent option for means of mobility.

In this sense, I argue that at this historical moment the wheelchair came to represent the failure of cure, and that as a result the person who used it could only be conceived of as a sort of "failed human," imprisoned by the inability to be returned to

normalcy.³³ Like the *rhetoric of invalidity* that dominated in the nineteenth century, the *rhetoric of containment* continues to frame wheelchair-users as unfit for the public sphere. Yet it is slightly more progressive than the *rhetoric of invalidity*. In the case of the *rhetoric of containment*, the wheelchair-user is not intrinsically invalid; it is the wheelchair that invalidates him or her. Thus the *rhetoric of containment* suggests that the mobility-impaired person herself might be a viable citizen but for the wheelchair, or the material representation of the failure of cure. If she can free herself from the prison of the wheelchair, she has the opportunity to regain fully human status. In the next section, I will provide a case study of Franklin Delano Roosevelt as a rhetorician who used a wheelchair from 1921 to 1945 in order to illustrate how he was able to respond to the rhetoric of containment in such a way that allowed him not only to enter public space but also to act as a leader of a nation, at a time when wheelchair-users were framed as utterly ineffectual in the civic realm.

Franklin Delano Roosevelt as Rhetorician and “Cured Cripple”: A Case Study

Just as the *rhetoric of containment* was beginning to take hold as the primary means of characterizing wheelchairs and wheelchair-users, Franklin Delano Roosevelt contracted polio and became a wheelchair-user himself. Given that traditional wheelchairs were clearly not meant for use in public spaces, it is not surprising that one of the first people to alter the design of the wheelchair was both a wheelchair-user and a rhetorician. FDR was elected President of the United States by a landslide four times in

³³ In fact, sociologist Erving Goffman, in his influential book *Stigma: Notes on the Management of a Spoiled Identity*, discusses people with disabilities as “failed normals,” stigmatized by the differing configurations of their bodies. While I do not consider Goffman’s theory here, his work is highly influential in disability studies and is evocative for further research into the ways in which assistive devices are stigmatized in culture.

succession, first in 1932, and subsequently in 1936, 1940, and 1944. He was also paralyzed from the waist down as a result of polio, which he contracted in 1921 as his political career was just beginning. Disability historian and Roosevelt biographer Hugh Gregory Gallagher painstakingly chronicles FDR's experience as a person with a disability in arguably the most public of all positions. Frustrated with wheelchairs that were "impractical for work and travel," FDR had his own "built to his specifications and design" (91). According to Gallagher, FDR's chair was lightweight and compact so as to "fit through any width door," to be turned in a "small circumference," and to be stored neatly in "the backseat or the trunk of a car" (92). White House staffers recall him "wheeling past at breakneck speed, a pile of papers on his lap" (91).

Not only did FDR design a wheelchair that allowed him to move easily through public spaces, he also had public spaces altered so as to accommodate his wheelchair. A half a century before the Americans with Disabilities Act was passed, FDR arranged to live in what Gallagher refers to as "quite literally . . . a ramped world" (97). Permanent ramps were constructed for buildings the President frequented, from the Capitol to the War State Navy Building to St. John's Church. Whether FDR was moving about Washington or traveling the country, the Secret Service "went first [to ensure] complete accessibility for the President's wheelchair," building ramps and even at times "raising the entire level of a street to the level of a building entrance by means of temporary but extensive wooden scaffolding" (97). The FDR White House was a paragon of accessibility by any current ADA standards, with an elevator for the President's use, wide corridors and doorways, ramped or leveled entrances, and raised toilets that made effortless what wheelchair-users today call "a transfer" (91). At a time when wheelchairs

were not meant for public spaces and public spaces were not meant for wheelchairs, FDR constructed a world in which each suited the other.

Yet for rhetorical scholars who examine how those with marginalized or othered bodies find opportunities to be rhetoricians, the story of FDR's public career has particular significance. I argue that in a deeply paradoxical, ironic situation, FDR managed to be the first wheelchair-user to be an effective rhetorician and public leader precisely because he was able to hide his wheelchair use. Through a combination of power, privilege, ingenuity, and a devoted circle of family, friends, and political allies, FDR was able to present himself to the public at large as a "cured cripple," one who "overcame" paralysis to walk with only a slight limp and the occasional use of a cane (65). His ramps were said to be a convenience rather than a necessity; the streets raised on his behalf were closed to the public and only re-opened once they were lowered; and, most importantly, and most shockingly, he and his advisors devised ways for him to appear, speak, and participate in public ceremonies as a man who could walk.

FDR was keenly aware that his success as a politician depended on concealing the fact that he was "a cripple" (53). He is quoted as informing his physical therapist that his greatest goal was to learn how to "walk into a room without scaring everyone to death" (63). At a time when people with any visible disability were often prohibited from eating in restaurants, attending theaters, or using public transportation because their appearance might upset the nondisabled, FDR could not hope to "participate in elective politics" unless he could hide his inability to walk (59). Thus, throughout his career as a politician, FDR "perfected" a technique that allowed him to "walk" on paralyzed legs: using leg braces dyed to match his socks, FDR would "grip" the arm of a friend, family member, or

political aide with one hand, “lean on his cane” with the other, and use the “muscles along the side of his trunk” to “hitch one leg forward” while the remainder of his weight rested on the other braced leg (65). Only once he reached a podium (upon which he could balance), a chair (if the function was one in which the nondisabled were seated), or the door of his car (on which he could lean) could the aide let go. Will Durant, a journalist who covered the 1924 Democratic National Convention, at which FDR gave his first public speech after he contracted polio, described him as “a figure tall and proud . . . self-controlled . . . most obviously a gentleman and a scholar” (qtd. in Gallagher 67). Critical here is that Roosevelt was evaluated not on the content of his speech but on his able-bodied appearance as he delivered it. It is widely accepted among Roosevelt historians that his political career could not have been renewed after polio had his participation in the 1924 Democratic National Convention not been successful.

In essence, to achieve and maintain the Presidency, FDR needed to “pass” as nondisabled—and his success in doing so was, in Gallagher’s estimation, nothing short of a “splendid deception” (xiv). No newsreels and only two out of 35,000 still photographs of FDR show him using his wheelchair. Political cartoons of the era depict him as a “man of action—running, jumping, and even fighting in a boxing arena” (94). No articles by journalists throughout his Presidential campaigns or his time in office describe him as physically disabled (94). The only recorded exchange regarding FDR’s disability occurred during his first campaign for President when a (perceptive) reporter asked him

during a press conference if it was true that he was still “wheelchair bound.” FDR is quoted as having replied:

As a matter of fact, I don't use a wheelchair at all except a little kitchen chair on wheels . . . and then only for the purpose of saving time. (92)

In this brief and largely neglected statement, FDR appears to be caught in the act of blatantly contradicting himself; he both admits and denies using a wheelchair, and he seems to try claim able-bodiedness even as his reply begs the question: why would anyone without trouble walking need a kitchen chair on wheels to “save time”? His statement is in danger of being read as hopelessly muddled, but when considered in light the dominant *rhetoric of containment* surrounding wheelchairs and wheelchair-users it in fact shows tremendous rhetorical savvy.

Given the limitations the *rhetoric of containment* imposed upon him as a wheelchair-user, FDR's seemingly dodgy reply is in fact perfectly tailored to address the implications of the reporter's use of the phrase “wheelchair bound.” In his statement, FDR is not “bound” to a wheelchair for two reasons: first, he does not use the traditional wheelchair of the day; and second, the wheelchair he does use he uses *by choice*. And perhaps most significantly, his choice is motivated by the exigencies of an active life, one in which many things need doing, one in which the saving of time, or expediency, is of the utmost importance. Thus, FDR's answer dismantles every stereotype implicit in the *rhetoric of containment*; he is active rather than passive, he is involved rather than disengaged, and he is free to choose rather than forced to comply. By constructing himself in this way, FDR manages to lie without lying, for if he is all these things, then he is also able-bodied—he is the opposite of wheelchair-bound.

In her 2003 public health study of physical, economic, and attitudinal barriers facing persons with mobility impairments, Lisa Iezzoni comments that when FDR chose “silence” as a means to cope publicly with his disability, a “teachable moment was lost” (53). My respect for Iezzoni and her scholarship is immense, but as a rhetorical scholar I am troubled by her declaration. From a rhetorical perspective, FDR was not “silent” on the subject of his mobility impairment by any means. Rather he made a series of material and embodied rhetorical choices specifically tailored to respond to the constraints of a rhetorical situation dominated by a *rhetoric of containment* that denied wheelchair-users access to public space—let alone public voice and the power conferred by public leadership. FDR set aside the material object of the wheelchair during public appearances because he knew it would invalidate his presence in public space even before he had the opportunity to speak. He simulated walking in order to embody the “Holy Grail of recovery” for an audience who expected his body to represent the pinnacle of achievement—upright movement—as dictated by the medical model’s ideology of cure.

I agree with Iezzoni that Roosevelt’s “splendid deception” was certainly part of a “moment”: a sociohistorical moment when war, disease, medicine, and fear configured in such a way that wheelchair-users were recast, through a shift from the *rhetoric of invalidity* to a *rhetoric of containment*, as failed citizens, unsuited for participation in public space because their chairs represented the failure of cure and their bodies were conceived of as prisoners of that failure. In this way, I disagree that the moment was necessarily “teachable” in the sense Iezzoni means. It would be another fifty years—following thirty years of Disability Rights Movement activism and the passage of the Americans with Disabilities Act of 1990—before the extent of FDR’s disability was

revealed to the public, through wheelchair-user Hugh Gregory Gallagher's efforts to recover the history of his presidency from a disability rights and disability studies perspective. For those of us who study the cultural construction of disability in order to challenge ableist assumptions that have written wheelchairs, wheelchair-users, and their participation in public space out of our histories, I believe that it is more accurate to say that the "teachable moment" is now.

Conclusion

In this chapter I have worked to historicize the material object of the wheelchair, the body of the wheelchair-user in public space, and two dominant rhetorics used to characterize the two: the *rhetoric of invalidity* and the *rhetoric of containment*. As the introduction of the representation of the body of the wheelchair-user as an International Symbol of Access in 1969 indicates, over the last fifty years wheelchair-users have gained unprecedented access to public space through efforts to accommodate their alternative means of mobility. Disability Rights activists—many of whom are wheelchair-users—have been at the center of the movement to pass legislation to mandate public accommodations for wheelchair-users and other people with disabilities, including the Architectural Barriers Act of 1968, the Urban Mass Transit Act of 1970, Section 504 of the Rehabilitation Act of 1973 (which was passed by Congress and vetoed by Richard Nixon in 1972), the Voting and Accessibility for the Elderly and Handicapped Act of 1984, and the Americans with Disabilities Act of 1990.

At the same time, Disability Rights Movement activists and wheelchair-users have increasingly taken control of the design, development, and production of the

wheelchair as a material object, most notably in the cases of Ed Roberts, founder of the Independent Living Movement in Berkeley, California, and wheelchair innovator and entrepreneur Marilyn Hamilton. Roberts' own electric wheelchair, complete with an automobile headlight for traveling at night, is now exhibited at the Smithsonian Institute as an historical artifact important to an understanding of the ways the power wheelchair and the power wheelchair mechanics of UC-Berkeley in the 1960s created the first means of independent mobility for quadriplegics (Krizack). Meanwhile, Hamilton's Quickie brand wheelchair, which she designed for herself after she was paralyzed in a 1979 hang-gliding accident, effectively ended the reign of the E&J model when it was introduced to the marketplace by Quickie Designs, Inc. in 1986 (Pelka 321). Made of aluminum tubing, weighing less than twenty pounds, and manufactured in colors that include Traditional Black, Candy Blue, and Razzleberry, Hamilton's Quickie is the most popular brand on the market today as a lightweight and personalized means of independent mobility for wheelchair-users (Shapiro 214; "Quickie Wheelchairs").

Yet despite these efforts to increase access for wheelchair-users in public space and to build wheelchairs designed to meet the needs of users who believe that access is a civil right, the *rhetoric of containment* continues to shadow the material object of the wheelchair and the bodies of wheelchair-users. According to media studies scholar Charles Riley, The Disability Committee of the American Society of Newspaper Editors and the National Center on Disability and Journalism have both publicly censured language use that reflects ableist ideology and released guidelines for avoiding such language, first in 1990 and then again in 2002, when it appeared that the initial release had not resulted in the desired changes (51). The glossary of language to avoid includes

the phrases “confined to a wheelchair” and “wheelchair-bound” (Nelson 213, 216). The entry on wheelchairs explains that these assistive devices “help people with mobility; they do not imprison people” and recommends that people who use wheelchairs be called “wheelchair-users” (216). The guidelines also include a section on interviewing wheelchair-users in ways that are respectful of their humanity and their civil rights; reporters are advised not to “lean on a person’s wheelchair” because “the chair is a part of his or her body space;” to “sit or kneel” so as to “place [themselves] at eye level with the person [they] are interviewing”; and to ascertain that the interview site is fully accessible, with reserved parking, a ramp or step-free entrance, elevators, and accessible restrooms, telephones, and water fountains (Riley 222).

In his 2005 book *Disability and the Media: Prescriptions for Change*, Charles Riley notes that these recommendations have been and continue to be largely ignored by professionals in print, television, cinema and web-based media (4). The *rhetoric of containment* remains pervasive despite continual reminders from the disability rights community that this language is no longer acceptable, as evidenced in studies by John Clogston and Mary Johnson (Clogston 46; Johnson 36). Mary Johnson, editor of the activist disability magazine *The Ragged Edge* (formerly *The Disability Rag and Resource*), remarks that even Disability Rights Movement activists seem unaware of the extent to which ableist terminology such as “confined to a wheelchair” and “wheelchair-bound” disempowers wheelchair-users (38). In her 1994 essay “The Language of Disability” she predicts that these phrases will “continue to plague accounts of disability issues” until people with disabilities themselves begin working together to “protect

against” ableist terminology and “breathe dignity back into” the language used to describe them (38, 42).

Throughout this chapter I have included footnotes to show how many of the scholars who have worked to write wheelchair-users into history are themselves wheelchair-users, and how many of those are both disability rights activists and authors of disability narratives, including FDR historian Hugh Gregory Gallagher, theorist Simi Linton, disability historian Paul Longmore, creative writer and polio historian Anne Finger, and medical professor and public health scholar Lisa Iezzoni. It is my hope that these additions begin to point to the ways in which the recovery of the history and theory of wheelchair-users in public space is an activist gesture oftentimes motivated by personal experience with discriminatory thought or action. As a woman with multiple sclerosis who has in the past year used both a cane and a wheelchair during relapses of my disease, I view my own contribution as both personal and political. A couple of years ago, when a routine blood test revealed that I had developed antibodies to an injectable medication that researchers believe may slow the progression of MS, my neurologist suggested I begin a new treatment regimen, an intravenously administered drug that had caused the death of three in a thousand of its users for reasons as yet not completely understood. “The death side effect,” I joked, “makes me nervous.” He sighed. “You have to remember,” he said, “that statistically you will probably end up in a wheelchair.”

In this exchange I see echoes of the hierarchy of cure and the attendant *rhetoric of containment*, not so much in terms of language my neurologist used—though the word “in” does suggest containment and “end up in” is certainly a passive construction—but in terms of the ideology implicit in his advice: that it may be better to risk death now than to

become a wheelchair-user later. The only way this conclusion could be considered a logical one is if wheelchair use is thought of as a fate worse than death. It is my opinion that the *rhetoric of invalidity* and the *rhetoric of containment* support such logic; if these rhetorics go uncontested, the material object of the wheelchair will, in Iezzoni's words, continue to be culturally constructed as "the quintessential symbol of defeat and despair" and the bodies of wheelchair-users as living representations of "frailty, dependence, and loss" (68, 199).

I hope the preceding chapter reveals that the origins of these rhetorics are more deeply rooted in our culture than we have perhaps imagined, and that their consequences are more far-reaching than we may have wanted to believe. Through theories of material and embodied rhetoric and through a disability studies lens, I have attempted to illustrate that the *rhetoric of invalidity* and the *rhetoric of containment* are not just about the words and phrases that inspired my names for them but about the ways particular bodies become essentialized as inhuman or inferior and the ways our construction of material objects and language reflects the ideologies that marginalize those we conceive of as "Other" as a result of their bodily difference. In the following chapter, I will introduce three disability narratives by wheelchair-users and theorize the ways in which they locate their bodies on a continuum of difference in order to frame their wheelchairs as extensions and reflections of their bodies that confirm—rather than deny—their humanity.

**CHAPTER FIVE: DEFREAKING THE DISABLED BODY: RECLAIMING
SUBJECTIVITY AND RESISTING OTHERNESS IN DISABILITY
NARRATIVES BY HARRIET MCBRYDE JOHNSON, JOHN HOCKENBERRY,
AND DEAN KRAMER**

In chapter four I discussed the nineteenth century in terms of a dominant rhetoric of invalidity that constructed the wheelchair-user as “less than” or “in-” human.

Interestingly, disability studies scholar Lennard Davis also pinpoints the origins of the concept of “the norm” as it applies to bodies as arising in the nineteenth century. Davis observes that the “word ‘normal’ as ‘constituting or conforming to, not deviating or differing from, the common type or standard, regular, usual’ only enter[ed] the English language around 1840”—eight years before the first known usage of the term “invalid-chair” (24). In his influential book, *Enforcing Normalcy: Disability, Deafness, and the Body*, Davis argues that “the disabled body is created by the concept of the normal body” insofar as the existence of the norm necessitates the existence of deviance (30). Davis contends that “‘the normal’ . . . the very term that permeates our contemporary life . . . is a configuration of a particular historical moment” that includes the rise of statistics as a means of “sorting bodies” and the rise of eugenics as a means of “perfecting them” (49). As statisticians began to denote traits that deviated from “the norm,” eugenicists constructed a “ranked order” of physical and mental characteristics, with the “ideal” at the top and “defectives”—including people with disabilities—at the bottom, thus formally systematizing “a dominating, hegemonic version of what the human body should [and should not] be” (30, 33, 35).

Davis argues that today’s conceptualization of “the norm” in relationship to bodies has devolved into a binary construction of the normal body and the disabled body

(4). One of the primary flaws of such a construction, Davis reveals, is that “able-bodied (or temporarily able-bodied) people [are able to] safely wall off the severely disabled so that they cannot be seen as a part of a continuum of physical differences” (7). In his use of the phrase “temporarily able-bodied,” Davis references his argument that many disabilities are “acquired” through disease or accident, and that “most humans, as they age, will find themselves less able to see, hear, walk, or think so well as they did before” (xv). For these reasons, “disability is not a static category but one which expands and contracts to include ‘normal’ people as well” (xv).

I agree with Davis that “one of the tasks for a developing consciousness about disability issues is the attempt . . . to reverse the hegemony of the normal and to institute alternative ways of thinking about the abnormal,” and I admire him for being one of the first people in disability studies scholarship to introduce the ways in which the socially constructed concept of the norm works to socially construct people with disabilities as deviant (and thus, implicitly inferior—and, in the case of the wheelchair-user, invalid) (49). However, I believe his efforts to “challenge the hegemony of the normal” in the passages above fail, almost spectacularly, insofar as he seems to reference a continuum of physical differences that make sense only in terms of implicit norms.

First, Davis seems to believe that he is troubling the concept of normalcy (and the attendant illusion of safety that people who identify as “normal” feel in relationship to people with disabilities) when he presses the point that “disability” is only an accident, injury, disease, or a few decades away. Instead, he inadvertently reifies the notion that “normalcy” is one state and “disability” is another, and that while the “wall” between the two may be thin (may indeed come crashing down more easily than we might previously

have thought if not for his warnings) there are still two states of bodily existence and there is still a wall separating them.

Second, in his use of the term “severely disabled,” he implies that “severely disabled” is a category universally accepted and understood; he seems to assume that he, and everyone reading his chapter, all know and agree upon what makes a person “severely disabled.” I, however, am not so sure. Is he referring to people with visible impairments, such as wheelchair-users or people with prosthetic limbs—rather than those who have limited mobility but use no assistive device? Is he referring to people who are terminally ill, such as those in the advanced stages of AIDS or cancer—rather than those who are HIV positive and in treatment or those whose cancer is being treated and is expected to be cured? Is he referring to people who are blind rather than those who are visually impaired, people who are D/deaf rather than those who are hearing impaired? I could go on and on here, but suffice it to say that I hope my list of possibilities has revealed that Davis’ use of the word “severely” without qualification seems to assume a readership made up of universally “normal” bodies who can all agree what “severe” disability means.

This is not to say that Davis is wrong—that most people who see themselves as normal do *not* agree as to what constitutes severe disability, or that the state of disability and the state of “normalcy” or, better, to my way of thinking, “nondisability,” are *not* two different bodily ways of being. It is to say that, in the spirit of his enterprise, it makes sense to be rigorous in critiquing what he himself calls the “routine assumptions” that underlie such assertions (4). I question Davis’ work so strenuously most of all because, as a scholar and as a person with a disability, I wholly support and believe in his central

argument: that in order to deconstruct the category of disability one must also deconstruct the category of normalcy. However, I believe that this can more effectively be done if one does not locate “normalcy” at one end of the binary and “disability” at the other. To see these two as polarities is to set a body at one end of the binary—the disabled one—and assume everyone will agree as to how it is abnormal, and then to set a concept at the other end of the binary, and assume everyone will agree as to what a normal body is. Instead, in this chapter, I extend Davis’ theory of the binary in terms of a construction that emphasizes that normalcy is equated with a nondisabled body and abnormalcy is equated with a disabled one.

My goal is to reveal how the three disability narratives I analyze in this chapter deconstruct the category of “abnormalcy” in relation to the disabled body and thereby inevitably also deconstruct the category of “normalcy” in relation to the nondisabled body. Therefore, throughout this chapter I will speak of what I call the “normal/nondisabled -abnormal/disabled binary” in order to consistently highlight the constructed nature of the “normal body” in relation to nondisability as much as Davis consistently highlights the constructed nature of the “abnormal body” in relationship to disability. In the following sections, I utilize feminist disability theory—including Rosemarie Garland Thomson’s concept of the freak show and Susan Wendell’s work with the disabled body as “Other”—in order to demonstrate the ways in which disability narrative authors and wheelchair-users Harriet McBryde Johnson, John Hockenberry, and Dean Kramer consistently reverse the mechanisms of the freak show in ways that reclaim their subjectivity, resist the category of “Other,” and thereby explode the normal/nondisabled-abnormal/disabled binary. First, I provide a summary of Thomson’s

theory of the freak show and Wendell's discussion of people with disabilities as cultural "Others." Next, I theorize a process I term "defreaking the disabled body" by showing how Johnson, Hockenberry, and Kramer speak of their physical differences as subjects and define those differences in ways that dislocate the concept of "abnormalcy" from its usual equation with disability on the normal/nondisabled-abnormal/disabled binary. Last, I argue that Johnson, Hockenberry, and Kramer are able to resist cultural constructions of "Otherness" by locating their use of wheelchairs as part and parcel of their humanity as they move through public space as active, meaning-making subjects. In conclusion, I suggest that by defreaking the disabled body and reclaiming it as a site of personhood and agency, Johnson, Hockenberry, and Kramer shift the spectacle of freakdom to the ableist ideology represented by the spectator, whose assumption of a normal body is exposed as a fiction that exists only by virtue of an equally fictive construction of the disabled body as an abnormal "Other."

The Freak as Object or "Other" in Feminist Disability Theory

In order to further theorize the normal/nondisabled-abnormal/disabled binary I enlist the work of literary and disability studies scholar Rosemarie Garland Thomson and feminist philosopher and disability theorist Susan Wendell. In her book *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*, Thomson devotes a chapter to "the cultural work of American freak shows" of the nineteenth and early- to mid- twentieth century. Thomson argues that the freak show exhibited the disabled body as "a text written in boldface to be deciphered according to the needs and desires of the [nondisabled] onlookers" (61). Crucial to this dynamic was the fact that the

freak, or the person with the disability, embodied for her audience abnormalcy while the onlooker, in contrast, felt herself reassured of her relative normalcy. The freak show thus confirmed the normal/nondisabled-abnormal/disabled binary by framing the disabled body as deviant and as “Other.”

In her book *The Rejected Body*, Susan Wendell argues that in contemporary culture and society, it is common for people who identify as nondisabled to consider themselves “the paradigm of humanity” and to see people with disabilities as “Other,” or subhuman. Wendell theorizes the process of “Othering” as follows:

When we make people ‘Other,’ we group them together as the objects of our experience instead of regarding them as subjects of our experience with whom we might identify, and we see them as symbolic of something else—usually, but not always, something we reject and fear and project onto them. (60)

Wendell’s theory of “Othering” as articulated in the passage above is particularly evocative when seen in light of Thomson’s conceptualization of the freak show and Davis’ efforts to decenter concepts of normalcy in relation to people with disabilities. Thomson reveals how people with disabilities as displayed in freak shows were framed as “objects” of nondisabled experience. They did not speak; “showmen” and “pitchmen” spoke for them, representing their bodies in pamphlets, flyers, and speeches in terms that showcased them as “curiosities,” “hybrids,” and “freaks of nature” (57, 60). They were kept at a distance from nondisabled onlookers, set apart on platforms or in pits. Their activities were “choreographed” to “amaze audiences” in a seemingly ceaseless loop of repetitive action, reducing their possibilities for movement and engagement only to those

that showcased their “Otherness”: the microcephalic black man, billed as half-human, half-animal, growled and raged about his pit as befitting an undomesticated creature; the Armless Wonder, dressed in a suit and tie and perched on a stool, silently used his toes to whittle, write, and drink from a teacup—over and over and over again (60). It was crucial that their representation cast them as objects precisely because opportunities to appear, behave, and act as meaning-making subjects would have disrupted the category of the “abnormal” that they were meant to symbolize for a nondisabled/normal audience.

In chapter four of this dissertation, I argued that the exclusion of wheelchair-users as meaning-making subjects from our histories reflects a dominant ableist ideology that at its base sees wheelchair-users as objects. I also theorized two dominant rhetorics—one of *invalidity* and one of *containment*—used to characterize wheelchair-users, each of which, like the concept of the norm and the ritual of the American freak show, originated in the nineteenth and early- to mid- twentieth centuries. The *rhetoric of invalidity*, I argued, constructs wheelchair-users as “invalid” in body and in character, intrinsically incapable of “power, strength, force, efficacy, or cogency.” The *rhetoric of containment*, in contrast, constructs wheelchair-users as “failed humans,” imprisoned by their inability to be “cured” by medicine and restored to “normalcy” through the achievement of upright movement. Both rhetorics frame the wheelchair-user as less than or in-human. In this chapter I focus on the ways in which the construction of the disabled body as “abnormal” or “inhuman” depends upon his or her objectification. The mechanisms of the freak show as described by Thomson—which deprived people with disabilities of voice, meaningful action, and agency—are at work in the rhetorics of invalidity and containment insofar as they serve to create distance between the abnormal/disabled body and

normal/nondisabled body. Framed by the rhetorics of *invalidity* and *containment*, the abnormal/disabled body of the wheelchair-user is object to the normal/nondisabled body's subject. In the next section, I theorize a process I term "defreaking the disabled body" by demonstrating how disability narrative authors and wheelchair-users Harriet McBryde Johnson, John Hockenberry, and Dean Kramer frame their embodied experiences of disability in ways that resist cultural constructions of "freakdom" that objectify their bodies by equating their physical differences with abnormalcy.

Speaking of Physical Difference: The Disabled Body as Subject

In this section I argue that rhetoricians Harriet McBryde Johnson, John Hockenberry, and Dean Kramer each employ the following rhetorical strategies in order to begin the process of "defreaking the disabled body": (1) self-identifying as having a particular medical condition that leads to bodily impairment; (2) speaking as subjects as they name and claim their physical differences; and (3) calling up the figure of an onlooker shocked by their corporeality and troubling the ways that onlooker might view their disabled bodies as living representations of abnormalcy. In their disability narratives, Johnson, Hockenberry, and Kramer each claim specific medical diagnoses that impact their experiences of corporeality: Johnson has a form of congenital muscular dystrophy, Hockenberry has a spinal cord injury as a result of a car accident that occurred when he was nineteen years old; and Kramer has lived with relapsing-remitting multiple sclerosis, a disease I also live with, for twenty-four years (I am three years past diagnosis). Those who subscribe to the social model of disability—which posits disability as solely located in the social oppression of bodies that are culturally constructed as

different—often object to such self-identification on the grounds that to define oneself in terms of one’s medical condition is to reify the notion that disability is pathology, and therefore, as Linton argues, “an individual problem,” a personal deficit and lack (11). Yet recent scholarship critiquing the social model argues that one of its greatest flaws lies in its refusal to acknowledge the ways in which the corporeal experiences of people with disabilities arise out of specific “medical conditions” that do indeed influence bodily form and function, as Tom Shakespeare argues in his essay “The Social Model of Disability” (200).

Perhaps this concept is best understood in terms of feminist theorists Sidonie Smith and Julia Watson’s claim that the body does exist as a “neurochemical system,” that there is a life of the body that takes place on a cellular level—apart from culture (58). Scientists would not be surprised to hear this; social constructionists are usually appalled and outraged, arguing that such a claim is essentialist. Of course, the moment we begin to talk about what happens to the body as neurochemical system we begin to socially construct it, yet I believe it is useful to consider that it is possible for a person with a disability to claim his or her medical diagnosis as a means to begin to explain her experience of impairment and her identification of her body as disabled. The operative word here is “begin.” I argue that in their narratives, McBryde Johnson, Hockenberry, and Kramer each *begin* the process of identifying their bodies as disabled in terms of their medical conditions as a means of locating their bodies as the neurochemical systems Grosz describes, not to essentialize their bodies but to acknowledge what disability studies theorist Tobin Siebers calls the “alive” body, the body as a “biological agent teeming with vital and often chaotic forces.” This “alive” body is “as capable of

influencing and transforming social languages as they are capable of influencing and transforming it” (180). I believe that Johnson, Hockenberry, and Kramer each claim their bodies as “alive” not to uphold notions of disability as pathology, deficit, and lack, but to highlight the corporeality of physical difference while at the same time calling into question the ways physical differences are culturally constructed as “abnormal” and thereby implicitly inferior.

Johnson and the Natural Body

As an initial example I analyze the beginning of Harriet McBryde Johnson’s preface to her 2005 book *Too Late to Die Young: Nearly True Tales from a Life*. She starts with the announcement:

It’s not that I’m ugly. It’s more that people don’t know how to look at me. The power wheelchair is enough to inspire gawking. Much more impressive is the impact on my body of more than four decades of muscle-wasting disease. Now, in my mid-forties, I am Karen Carpenter-thin, flesh mostly vanished, a jumble of bones in a floppy bag of skin . . . [my spine is a] deep twisty S-curve. My right side is two deep canyons. To keep myself upright, I rest my rib cage in my lap, lean forward, plant my elbows on rolled towels beside my knees. Since my backbone found its own natural shape, I’ve been entirely comfortable in my own skin. (1)

In this passage Johnson locates the origins of her physical differences in her medical condition—congenital muscular dystrophy—but the disease itself warrants only a sentence: an acknowledgement that her particular body has been shaped by this particular

biological force. She then moves quickly to a description of her body's particular shape, listing her physical differences relentlessly, in language seemingly as unsentimental as possible. Her diction in fact seems to characterize a body out of order—a “jumble” of bones suggests disarray, a “bag of skin” that is “floppy” implies lack of control, a “twisty” spine and a side made up of “canyons” call up images of vast, uncharted terrain in which a person can become lost.

Johnson's recitation of her physical differences might easily be seen as another example of what Thomson calls the “enfreakment” of the disabled body—“the accumulation and exaggeration of bodily details [that] distinguish the freak from the unmarked and unremarked ordinary body” (59). Johnson can be seen as acting as her own “pitchman”—hyperbolizing her physical difference through language that triggers her audience to associate her disabled body with the idea of chaos and the emotion of fear. Yet I argue that Johnson, in this passage, is in fact engaging in the process of defreaking the disabled body in two important ways: (1) she emphasizes her subjectivity when the enfreakment of the disabled body is contingent upon its objectivity; and (2) she calls up the figure of the shocked spectator and begins a process of rejecting the ways in which that spectator might construct her body as abnormal based on her physical difference.

Johnson's subjectivity is evident first and foremost in her use of the pronouns “I” and “my.” However disorderly her body may seem—may indeed be—it is hers, and it is hers to live in and speak from. The differences she lists are differences that are part and parcel of her bodily way of being: her posture (the way she sits), her movement (through her use of a power wheelchair) and her senses and her sense of self. Her statement that she is “comfortable in [her] own skin” (floppy as it is) can be read both literally and

figuratively. She is “comfortable in her own skin” in the sense that in her particular bodily state, she is relatively free of physical pain, and she is “comfortable in her own skin” in the sense that she is not in any psychic pain over her identity as a person with a disability.

Rather, in Johnson’s narrative psychic discomfort is located in the invisible bodies of the “people who do not know how to look at her.” Johnson does not describe these bodies as nondisabled or disabled, normal or abnormal, indicating that these categories are not important to the discussion. What is important is the relationship between these bodies and her own: the people who do not know how to look at her “gawk,” and Johnson is the object of their “gawking.” Johnson’s rendering of this dynamic recalls Garland Thomson’s description of the freak show’s astonished onlookers, whose “gaze” is drawn [to the freak] “like a magnet” as they “project [onto the freak’s body] cultural characteristics they themselves disavow” (55, 60).

But although Johnson’s onlooker certainly gazes, Johnson herself begins to forestall this onlooker’s implicit attempts to make sense of her body by conceiving of it in terms that link disability and abnormalcy. She takes control of her body’s representation, naming and characterizing its differences, while at the same time refusing the imposition of a normalizing narrative that would cast these differences as lack. When she asserts “it is not that I am ugly,” she argues against the cultural devaluation of physical difference as the embodiment of ugliness. When she claims that her spine has “found its own natural shape,” she resists an attempt on the part of the onlooker to construct from the physical difference of her “twisty, S-curve” spine a body that is unnatural. If the phenomenon of the freak show exists in order to provide the onlooker

with reassurance that she is normal in comparison to the freak, then Johnson's construction of her disabled body as "not ugly" and even "natural" begins to trouble that onlooker's case for Johnson's abnormalcy, even in the face of her obvious physical differences and her medical condition.

Hockenberry and the Unique Body

In his 1996 book *Moving Violations: War Zones, Wheelchairs, and Declarations of Independence*, John Hockenberry similarly calls up the figure of an onlooker trying to make sense of his disabled body when he begins a chapter of his narrative with the statement: "People often ask me what I would prefer to be called. Do they think I have an answer?" (87). Just as Johnson's onlooker does not know how to look at her disabled body, Hockenberry's onlooker does not know what to call his disabled body, and Hockenberry himself claims to be equally confused as to which name might be appropriate. He continues with what appears initially to be a list of possible contenders to characterize his experience of physical disability, asserting: "I'm a cripple for life. I am paralyzed from the waist down. I am a paraplegic. I am a gimp, physically challenged, differently abled" (87). Yet the names he lists are names that have vastly different meanings depending on the context in which they are used, most notably physically challenged, differently abled, cripple, and gimp. "Physically challenged" and "differently abled" have been proposed as "politically correct" alternatives to names that have historically been used to cast mobility impairment as deviance and lack, such as "cripple" and "gimp." Yet many disability rights activists, including Nancy Mairs, Cheryl Marie Wade, and Mary Johnson, have refused these alternatives as inadequate to describe their

experiences of their bodies and have instead focused on recovering the terms “cripple” and “gimp” by infusing them with meaning that locates power and pride in physical difference (Johnson 25, 30, 41; Mairs 9; Wade 412).

Hockenberry, however, does not engage in this debate in his narrative³⁴: a move that I believe goes far in setting up his larger project. Rather than focus on the relative merits and demerits of terms such as “physically challenged” and “cripple,” Hockenberry argues instead that locating his physical difference in a name necessarily depersonalizes his embodied experience. Instead, like Johnson, he begins by characterizing his physical differences in a way that emphasizes his subjectivity. He self-identifies as having “a spinal cord injury” and claims his mobility impairment (“I cannot walk. I use a wheelchair”), but he refuses other labels for his disability by zeroing in on the phrase “paralyzed from the waist down” and deconstructing it as “an arbitrary demarcation” that “describes little of the experience of spinal cord injury” (97). He writes:

In my case I am paralyzed from the nipples down. When people learn of this they are shocked to realize there is no international checkpoint at the waist. In actual fact, relatively few people are paralyzed from the waist down. Everyone has their particular line separating sensation from numbness. Each line of separation is invisible to the eye. In some people, the aspects of temperature pressure and muscle control are separate. Some spinal-cord injured people can feel pressure but not temperature in some parts of their body, and vice versa. There are people with almost total

³⁴ I do not mean to imply here that Hockenberry does not consider the debate important or that he in fact does not elsewhere claim a name for his experience as a person with a disability. In fact, throughout *Moving Violations* he frequently uses the word “crip” to describe himself, suggesting that he follows Mairs’, Wade’s, and Johnson’s line of reasoning.

sensation but no motor control. The trace of each paraplegic and quadriplegic's sensory border zone is as unique as a fingerprint. Each person has a different answer to the question: what does paralysis feel like.

(98)

While Johnson repeatedly uses the pronouns "I" and "my" as she owns her physical differences, Hockenberry moves quickly from his experience of his own body to speak in terms of the broader community of people with spinal cord injury in order to emphasize the sheer number of physical differences (sensory and motor) that fall under the umbrella term. In fact, he argues, the number of particular corporeal experiences of spinal cord injury is as great as the number of people *with* spinal cord injury.

Although Hockenberry does not say it, the implications of his argument are clear: an onlooker who identifies as normal in relation to Hockenberry's body would be hard pressed to prove that any corporeal experience is the same as any other, that all bodies feel and move in the same ways, that each normal/nondisabled person does not have a different answer to the question: "what does *your body* feel like?" In this way, Hockenberry's passage on people with spinal cord injury—himself included—begins the work of defreaking the disabled body. He troubles the normal/nondisabled-abnormal/disabled binary by claiming the physical differences he embodies in terms of the subjective experience of sensation and movement, rather than locating them in terms of cultural constructions of his disability that, in this context, could risk rendering him an object (a physically challenged, differently abled cripple or gimp) to the normal body's subject.

Kramer and the Normal Body

In her 2003 disability narrative *Life on Cripple Creek: Essays on Living with Multiple Sclerosis*, Dean Kramer similarly troubles the normal/nondisabled-abnormal/disabled binary when she explains that multiple sclerosis (MS) is not a “static disease”; although in all cases it is progressive and incurable, it leads to many different kinds of impairment depending on which parts of the brain and spinal cord are affected (52). While Davis insists that the category of disability is not static because ‘normal’ people can become disabled, Kramer insists on the mutability of the category because her particular bodily experience of disability changes from day to day, defying her own—and anyone else’s—efforts to claim what disability is or is not. She claims the physical differences of her multiple sclerosis thusly: “I have times when I can be spastic, limp as a wet noodle with fatigue, dizzy with vertigo trying to walk straight ahead but falling to one side or another, or staggering as if drunk. Sometimes I am all at once” (61). Kramer emphasizes not just the variety of physical impairments she might experience but how they come and go (as her MS relapses and remits), occur all together, occur alone, or occur in different combinations. Kramer calls this “the uncertainty principle” and pokes fun at her own efforts to declare her bodily state or her abilities “fixed” when she says: “whatever [I] decide is true about [my] disease, it’s going to change one way or another, sometimes before the words are out of [my] mouth” (12, 117).

Kramer compares her own frustration at being unable to once and for all locate, name, and fix her bodily state to the confusion others experience when her bodily state confounds their expectations of what disability should be or ought to look like. “People without MS,” she explains, often tell her how “normal” she looks: “[sometimes] with a

tone of reassurance” that leads her to imagine the person is offering consolation, as in: “Don’t worry about your progressive, incurable neurologic disease—you’re still attractive;” and sometimes with “a tone of resentment” that leads her to believe the person is really asking: “What right have you to claim to be disabled when you look so healthy?” (117). Present in Kramer’s description of these encounters is an acknowledgement of a binary construction that associates abnormalcy/disability with an ugly or sickly appearance and normalcy/ability with a visually appealing, healthy one. Whether spoken in reassuring or resentful tones, the comments Kramer hears are efforts on the part of others to reconcile the fact that within this binary construction, Kramer’s body again cannot be “fixed” at either polarity based on how it looks from the outside. In this sense, the “people without MS” Kramer speaks of function in her narrative as representative of the “onlooker” Johnson and Hockenberry describe: the person who does not know how to look at her, who is uncertain as to what she should be called.

In the following anecdote, Kramer does further work with the onlooker by characterizing that onlooker as a “passerby” witnessing her in the midst of a physical undertaking that encapsulates a series of contradictions in relation to the normal/nondisabled-abnormal/disabled binary. Kramer writes:

A passerby sees me out shoveling. “What are you doing?” she asks. “I thought you had MS!” “Well, yes, I do have MS,” I reply. “I’m shoveling the path for my scooter so I won’t have to walk.” [She] look[s] at me as if I’m crazy. But the truth is, I have just enough energy to do this little shoveling, and then I’ll need that scooter to get to and from my neighbor’s

. . . . If I didn't shovel the path, then I wouldn't be able to go there at all.

(97)

In sharing with the reader the onlooker's look of wonder at her explanation, Kramer highlights that within the constraints of the normal/nondisabled-abnormal/disabled binary, it is understandably difficult to comprehend that a person who can move piles of snow with a shovel can at the same time have a mobility impairment or that a chronically ill person would find it less taxing to do such a job than to walk a few blocks. But in Kramer's experience of her body at this moment, it is, as she says, "the truth." By articulating this embodied "truth," Kramer begins the process of defreaking the disabled body by claiming her physical differences as simultaneously normal and abnormal. She is both "normal" enough to appear healthy while shoveling a path for her scooter, and "abnormal" enough to *need* a scooter for which she must shovel a path. In this sense, Kramer's anecdote does not just trouble the normal/nondisabled-abnormal/disabled binary, it explodes it, for the existence of the binary depends upon the perception that a disabled body is entirely abnormal and a nondisabled body is entirely normal. When a disabled body can at the same time and in the same moment appear to function in ways that are culturally constructed as opposites—normal and abnormal—the terms themselves become useless as a means of distinguishing any body from any other body, disabled or not.

Johnson, Hockenberry, Kramer, and the Defreaked Body

Taken together as a whole and viewed through the lens of Thomson's theory of the freak show, the narratives of Johnson, Hockenberry, and Kramer effectively begin the

process of defreaking the disabled body by claiming their subjectivity and characterizing their physical differences in ways that preclude the onlooker's efforts to understand their bodies in relation to cultural constructions of normalcy. Each rhetorician in essence dislocates abnormalcy from its usual position on the binary as the primary means of defining the disabled body, or the body of the freak. In so doing, they also dislocate the concept of normalcy as the primary means of distinguishing the nondisabled onlooker from the freak she observes. The freak, then, is no longer a freak—no longer an object to a subject, no longer a “defective” to a “dominating, hegemonic version of what the body should be,” to recall Davis' history of the rise of the norm. In the next section, I will demonstrate how Johnson, Hockenberry, and Kramer each continue to reverse the mechanisms of the freak show throughout their narratives by shifting their attention to the deconstruction of the normal/nondisabled body and the dominant ableist ideology it represents.

Wheelchair Use and “What-Happens-Next”: Resisting Otherness by Claiming Agency and Enfreaking Ableist Ideology

In Rosemarie Garland Thomson's theory of the freak show, the freak's performance is staged in order to ensure that her physical differences eclipse her humanity. Her movements are constrained by the circumference of the pit or platform; her activities are constrained by the requirement that she follow a choreographed sequence of tricks meant to emphasize her strangeness. The performance of the freak is thus a spectacle wherein her body, presented as perpetually separate and static, “envelops and obliterates her potential humanity” (59). As such, the body of the freak becomes a “mute figure of otherness upon which the spectators can displace anxieties and

uncertainties about their own identities” (61). In this section I will show how Hockenberry, Johnson, and Kramer construct their embodied experiences in public space in ways that invert the traditional freak show performance to a point that “freakery” no longer resides in the spectacle of the disabled body but rather in the ableist ideology that casts them as unsuited for public space. I argue that Hockenberry, Kramer, and Johnson are able to make this shift in two critical ways: (1) they claim their wheelchairs as extensions of their bodies; (2) they resist the category of “Other” by placing themselves squarely in the center of public space as active, meaning-making subjects, thereby declaring the physical difference of wheelchair use to be part and parcel of their humanity.

Whereas the rhetorics of *invalidity* and *containment* frame wheelchair-users as unfit to participate in public space, Hockenberry, Johnson, and Kramer each claim their wheelchairs as extensions and reflections of their bodies and their personhood as they move through public space as full citizens. Hockenberry uses a manual wheelchair with “large bicycle-sized wheels and small diameter hand rims for pushing”: he exults in the “speed [at] which [he] travels,” the “rhythm” of his movements, and the way the act of “rolling” through the cities of New York and Chicago allows him to “glimpse [those cities] in pans and dolly shots, a pedestrian movie with a soundtrack of breathing” (207, 210). In a similar passage, Johnson describes the “great sensual pleasure” of “zooming” by power chair through “the delicious muggy streets” of Charleston, “zip[ping] around the raggedy sidewalks [she] knows so well, loop[ing] around every inconveniently placed garbage can, with maximum speed and also with style and grace” (2, 252). While Hockenberry “rolls,” “pushes,” and “glides” in a manual wheelchair and Johnson

“zooms,” “zips,” and “loops” in a power chair, Kramer “drives” a “motorized scooter made for hunters and fishermen” through the rural Pennsylvania countryside where she runs a farm, “rid[ing] along, the breeze in [her] face, the quiet hum of the electric motor in [her] ears,” her two beloved terriers on the deck for company (146-48).

In theorizing the ways nondisabled people “Other” people with disabilities, Susan Wendell argues that to “Other” another person’s body is “to ignore (at least temporarily) the consciousness that is embodied there and to fail to concern oneself with her/his subjective bodily experience” (86). Rather than make an effort to engage with people with disabilities, to hear how they make meaning of their bodies, Wendell observes that nondisabled people instead tend to project onto the bodies of disabled people a series of bodily characteristics they themselves fear, including a “lack of control,” “vulnerability,” and “weakness, pain, and death” (60). As I argued in chapter four of this dissertation, the *rhetoric of invalidity* cast wheelchair-users as “invalid,” both sickly in body and weak in character, while the *rhetorics of containment* framed wheelchair-users as both literally and figuratively “confined” by their chairs, rendered powerless in body and in spirit. In this sense, wheelchair-users can be seen as enfreaked by such rhetorics. A single physical difference—a mobility impairment that necessitates the use of a wheelchair—comes to “dominate the entire person,” reducing what Rosemarie Garland Thomson would call her “inherent human complexity” to the embodiment of “Otherness” (61). How the wheelchair-user might make meaning of her embodied experience becomes irrelevant.

Thus, I argue that when Hockenberry, Johnson, and Kramer frame their movements in terms that emphasize “freedom,” “beauty,” and “delight,” they resist dominant rhetorics that culturally construct wheelchair use as invalidating or imprisoning

(Kramer 147; Hockenberry 207; Johnson 252). Yet I am aware of Susan Bordo's caution that "attending too vigorously to difference can...construct an 'other' who is an exotic alien, a breed apart" and therefore deprived of the humanity Rosemarie Garland Thomson argues "social structures confer upon more ordinary people" (Bordo 223; Thomson 57). To show Hockenberry, Johnson, and Kramer as solely speaking of themselves in terms of their physical differences—only one of which is the use of the assistive device of the wheelchair—is to risk constructing them as one-dimensional, optimistic "overcomers" of disability who, despite their mobility impairments, take joy in the simple pleasure of moving through space in an alternative way.

In a related argument, Tobin Siebers takes issue with Donna Haraway's discussion of people with disabilities who use prostheses as exemplars of "the cyborg," or the "complex hybridization of machine and organism" (Haraway 149; Siebers 178). Siebers critiques Haraway on the grounds that she is "so preoccupied with power and ability that she forgets what disability is," for the cyborg, as theorized by Haraway, "is always more than human—and never risks to be seen as subhuman" (178). Such a framing of a disabled body does not subscribe to an ableist ideology that conceives of disability as deficit and lack, but—seen in the most sinister light—it risks casting people with disabilities as marvels and wonders that, divorced from other, more humanizing contexts, serve as living representations of power and possibility that exist for the edification of the nondisabled.

For this reason I argue that one of the more important strategies Hockenberry, Kramer, and Johnson employ to resist the category of "Other" is that for the bulk of their narratives their wheelchair use goes largely "unmarked and unremarked," to recall

Thomson's characterization of the "ordinary bod[ies]" the freak show's attendees identify as having. While they continuously use verbs such as "roll," "zip," "zoom," "glide," and at times, "surge," "jiggle," "jostle," and "bounce" to describe how they move, these ways of moving are treated as simply a matter of course. Much more important is what they are doing, where they are going, with whom, and why.

Throughout the course of his narrative, Hockenberry attends college, takes his first job at a reporter at a local radio station, is promoted to on-air correspondent at NPR's headquarters in Chicago, travels to the Middle East to report on the war, gets married, gets divorced, moves to New York City—and in between he gets burglarized, babysits his niece, and trades in his "Ironsides" lift-van for an orange pick-up truck. Harriet McBryde Johnson describes her narrative as "driven by what-happens-next," and what-happens-next is, as in Hockenberry's narrative, made up of the seemingly extraordinary and the seemingly mundane: she protests the Annual Jerry Lewis Muscular Dystrophy Association telethon³⁵, serves as a delegate to the Democratic National Convention, flies to Princeton University to debate Peter Singer on the ethics of genetic testing of fetuses for disabilities, and poses for the cover of *The New York Times Magazine*—and in between she embarks on a new romance, makes new friends, visits old ones, runs her law practice, takes on new cases, and continuously pursues her search for new people to drive her van. Kramer, in her introduction to her narrative, explains that she began writing the essays in part to address the lack of books that described "the

³⁵ Johnson and other disability rights activists that include Laura Hershey and Paul Longmore protest the telethon on the grounds that it frames people who have Muscular Dystrophy as objects to be pitied, thereby shifting attention away from the full lives many people with Muscular Dystrophy live—such as Johnson herself.

ongoing, everyday lives of ordinary people living with [the disease] (2).³⁶ In her collection she takes readers through the four seasons as she runs her farm, searches for—and finds—her life partner, serves as a speaker for the National MS Society, celebrates the holidays with family and friends, attends the crafts shows she loves, and embarks on a quest for the ideal winter coat.

While every one of the experiences I list here is filtered through the lens of disability, and serves as a means for the authors to make meaning of disability as both an embodied experience and a social construction, Hockenberry, Kramer, and Johnson first and foremost claim themselves as active, meaning-making subjects who live full lives personally, professionally, and as members of a variety of communities on local, national, and even global levels. In this sense Hockenberry, Kramer, and Johnson reverse the mechanisms of the freak show by claiming public space as rightfully theirs and defining themselves in terms of their engagement in a full spectrum of activities that confirm their agency and their personhood. In Thomson's theory of the freak show, the freak's "silence, anonymity, and passivity" serves as a testament to the "ideological normalcy of the spectator" (62). In writing their narratives and taking control of their representation, Hockenberry, Kramer, and Johnson replace "silence, anonymity, and passivity" with speaking, naming, and acting, and as such refuse to embody the "Otherness" on which the normal/nondisabled body depends for its existence. The normal/nondisabled body, then, is exposed as an illusion, an ideological construct that can only remain intact if people with disabilities are devalued and marginalized. In refusing such devaluation and marginalization, Hockenberry, Johnson, and Kramer enfreak ableist ideology by exposing

³⁶ Kramer notes Nancy Mairs' work as "one exception" to this rule, and explains that she "took Ms. Mairs as her inspiration" for her work (2).

it for what it is: a failure of cultural imagination to include all embodied possibilities for what it means to be human.

CONCLUSION: IMPLICATIONS FOR FURTHER RESEARCH AND FOR PEDAGOGY

In this dissertation I demonstrate how disability narrative authors Rik Carlson, Dorothy Wall, John Hockenberry, Harriet McBryde Johnson, and Dean Kramer resist dominant discourses of disability that render their bodies invisible or cast them as deviant and thereby inferior. I isolate specific rhetorical strategies they utilize to reframe disability as simultaneously an embodied experience and a social construction, including the use of the metaphor of mystery to make their experiences of disease visible and the reclaiming of subjectivity and agency to cast their physical differences as normalcy. In conclusion I would like to draw attention to the implications of my project for the field of rhetoric and composition in two major areas: (1) the expansion of the rhetorical tradition and (2) disability and the teaching of writing.

In many ways I view my study of disability narratives to be comparable to the recovery work undertaken by feminist rhetorical scholars Karlyn Kohrs Campbell, Shirley Wilson Logan, and Susan Kates. Each of these theorists has worked to write previously neglected speeches and writings into the rhetorical tradition in order to illustrate how rhetoricians who were marginalized due to differing configurations of race, class, and gender managed to speak and write in ways that challenged dominant cultural conceptions of their bodies as unsuited to public space. Campbell anthologizes and analyzes the speeches and writings of early women's rights advocates in her 1990 study *Man Cannot Speak for Her: A Critical Study of Early Feminist Rhetoric*; Logan utilizes neo-Aristotelian rhetorical theory to illuminate the rhetorical strategies of African-American women writers and speakers of the late nineteenth and early twentieth century in her 1999 book *"We Are Coming": The Persuasive Discourse of Nineteenth-Century*

Black Women; and in her 2001 book *Activist Rhetorics and American Higher Education: 1885-1937*, Kates applies contemporary composition theory to the lesson plans and classroom practices of late nineteenth- and early twentieth-century writing teachers in order to demonstrate how their pedagogies were designed to provide previously marginalized student populations access to higher education.

As a particularly evocative example of the similarities between such recovery work and my own project, I draw attention to Campbell's consideration of the rhetoric of early women's rights advocates such as Maria W. Stewart, Elizabeth Cady Stanton, and Susan B. Anthony. Campbell characterizes their speeches and writings as "persuasive masterworks . . . that represent skillful human artistry in the face of nearly insuperable obstacles," most notably the fact that "in nineteenth century America, femininity and rhetoric were seen as mutually exclusive" (9). By placing my chapters analyzing the works of rhetoricians with disabilities in dialogue with chapters on dominant discourses that exclude them from acting as meaning-making subjects in the public sphere, I similarly attempt to demonstrate how throughout history and up to the present day, disability and rhetoric are also cast as "mutually exclusive." Like Campbell, I hope that my project draws attention to the fact that the disability narrative authors I include here create rhetoric under tremendous constraints; at a time when their bodies are still associated with deviance and lack and when dominant discourses deny them full personhood, Carlson, Wall, Hockenberry, Johnson, and Kramer utilize the disability narrative as a means to move their bodies, their voices, and the discourses of disability from the "hospital hallways, physical therapy tables, and remedial classrooms" to which,

as Lennard Davis argues in his introduction to *The Disability Studies Reader*, they are still largely consigned (xv).

For this reason I call for further work by scholars in the field of rhetoric and composition toward the inclusion of the rhetoric of people with disabilities in the rhetorical tradition. In light of rhetorics of the body as a burgeoning area of inquiry, I envision a variety of possibilities for this scholarship, including:

1. Investigating the Rhetorics of the Disability Rights Movement

Scholars might begin this project by examining the speeches and writings of the leaders of the Disability Rights Movement, which began in the 1960s, was modeled after the Civil Rights Movement, and saw the passage of the Americans with Disabilities Act of 1990 as a major victory in that it achieved national recognition for people with disabilities as a minority with a history of discrimination and mandated the provision of access and accommodation for people with disabilities. Such a study might include Ed Roberts, the founder of the Independent Living Movement in Berkeley, California, and Marilyn Hamilton, inventor of the *Quickie* wheelchair—rhetoricians whose speeches and writings I was able to review in preparation for this dissertation but whose work was beyond the scope of this particular project. Scholars involved in recovering this work might attend to the ways in which these activists argued against cultural constructions that cast their bodies as objects to be pitied and reframed their bodies as subjects deserving of rights. Given that today approximately ninety-two percent³⁷ of ADA cases involving employment discrimination are decided in

³⁷ In her introduction to the 2003 collection *Backlash Against the ADA: Reinterpreting Disability Rights*, Linda Hamilton Krieger includes the results of two studies that arrived at this same number: a 1998 study

favor of the defendant, rhetorical scholars could also consider past and current disability rights rhetoric in relationship to recent case law in order to consider how rhetoric by disability rights advocates could be tailored to more thoroughly address judicial misgivings about the ADA as civil rights legislation.

2. Writing Disability Narratives into the Rhetorical Tradition

I call for rhetorical scholars to continue the work of recovering disability narratives as a means of resisting dominant cultural constructions of disability and reassigning meaning to the disabled body. Such scholarship might also consider how other identity categories such as gender, race, and class might intersect with disability and might influence the ways in which authors of disability narratives position themselves as bodies and bodies in culture.³⁸ I regret that my work in this dissertation only considers disability narratives by rhetoricians who identify as white and middle-class, with the exception of Rik Carlson, who considers himself to be working-class. For the future, I envision a collection of essays on the disability narrative that more thoroughly examines the identity categories of race, class, gender, and sexuality as they are framed by disability narrative authors themselves, and that also recognizes the limits of the disability narrative as a genre in relationship to the fact that majority of disability narratives are written by people who identify as white and middle-class.

by the American Bar Association reveals that “plaintiffs [in Title I cases] lost 92% of the time,” while a 2000 study by Ohio State Law Professor Ruth Colker found that “defendants prevailed in 92.7%” of Title I cases (6-7).

³⁸ Thank you to my student Joanna Keyl for drawing the attention of our 2006 honors composition class to the ways in which the identity category of gender seemed to influence Andre Dubus’ and Lucy Grealy’s framing of their disabled bodies as (un)attractive in DuBus’ *Meditations from a Moveable Chair* and Grealy’s *Autobiography of a Face*.

3. Examining the Understudied Area of Disability Rhetorics and Cyberspace

Such a project could investigate sites such as online magazines written and produced by and for people with disabilities, including *New Mobility Magazine* and *The Ragged Edge*, formerly *The Disability Rag and Resource*. Another potential area of study in this vein could involve bloggers with disabilities who write on the subject of their embodied experience of disability and also engage in critiques of cultural representations of disability, such as Simi Linton's Disability Culture Watch³⁹ and the BBC website "Ouch...It's a Disability Thing,"⁴⁰ which includes the anonymous blogger Disability Bitch and entries such as "Smug Cripples" and "Beauty and the Bitch: Parts I, II, and III"⁴¹. The goals of such a project could be to investigate: (a) how people with disabilities represent and advocate for themselves on the Internet; (b) how cyberspace might constrain their discourse; and (c) how online disability communities might—or might not—function as sites of activism.

4. Implications for Disability and the Writing Classroom

While this dissertation does not directly address the subject of disability and rhetoric and composition classroom, I believe that the work herein intersects with the project of "making disability visible" in the writing classroom in three important ways: (a) as a subject position embodied by students and teachers; (b) as a means of creating pedagogies, curricula, and classroom practices that strive to

³⁹ Found at <<http://www.similinton.com/blog/>>. I utilize Linton's theories throughout my dissertation and have found her blog to be an invaluable resource of cultural commentary on disability.

⁴⁰ <<http://www.bbc.co.uk/ouch/>>.

⁴¹ <<http://www.bbc.co.uk/ouch/writers/disabilitybitch/>>. Thank you to my student Micah Traynor for introducing Disability Bitch to our spring 2007 honors composition class with the theme "Disability, Controversy, and Culture."

be inclusive of as many learning styles as possible; and (c) as a concept that provides students with opportunities to examine the politics of representation, issues of access and accommodation, and the ways in which the practices of learning and writing can be construed in terms of “embodied difference” (Brueggemann et al. 368; Brueggemann and Lewieki-Wilson 3).

I believe my scholarship in this dissertation both reflects and responds to Julie Jung’s recent *Rhetoric Review* article that reads Nancy Mairs’ personal narrative of disability against a dominant “coming to terms” model and considers the implications of such a reinterpretation for the college composition classroom (162) as well as Georgina Kleege’s 2005 *PLMA* essay on her experience teaching a course on disability narratives and the ways in which the engagement with the embodied experiences represented in those narratives provided a means for herself and her students to speak openly about issues of access and accommodation in terms of their own embodied experiences of impairment. In positing the narratives I discuss as rhetorical sites that contest dominant cultural readings of disability and revalue the embodied experience of impairment, my study calls for all of us in the field of rhetoric and composition to consider integrating disability narratives into the college writing classroom.

A study such as mine is particularly evocative when viewed in terms of Ann Jurecic’s 2007 *College English* article “Neurodiversity” and the resultant spirited exchange between Jurecic and Jay Dolmage and Cynthia Lewieki-Wilson, published in the January 2008 of *College English*. In “Neurodiversity” Jurecic writes of her own personal experience as a writing teacher working to accommodate a student with Asperger’s Syndrome. She concludes that those of us in the field of rhetoric and

composition must “open ourselves up to learning as much as we can about the neurology of autism...not so that we can exclude, but so we can teach” (439). Dolmage and Lewieki-Wilson, in their “Comment,” critique Jurecic on the grounds that she reads the difference of “autism” from the perspective of the “norm,” situating herself as a hypothetical “compositionist on Mars...blast[ed] off into an alien world” by virtue of engaging with a student with autism spectrum disorder (318). Jurecic, in her “Response,” articulates a central difference between her approach and the approach of Dolmage and Lewieki-Wilson; she maintains that work in the area of “neuroscience” can and should influence our understanding of the embodied experience of impairments of students with Asperger’s Syndrome, not so that we can label these students as deviant and thereby inferior, but so we can use “cognitive analyses of autism” to “inform effective instruction of students who would otherwise struggle to learn in college classrooms” (324).

I must confess I ally myself more strongly with Jurecic’s point of view, perhaps simply because as a person with multiple sclerosis I am particularly aware of the connection between neuroscience and the embodied experience of impairment. However, I believe that most important for pedagogical implications of my dissertation are the productive tensions that the exchange between Jurecic and Dolmage and Lewieki-Wilson reveals. In their discussion Jurecic and Dolmage and Lewieki-Wilson find themselves at what I term in my introduction to this dissertation “the nexus” of disability: the embodied experience of impairment and the social construction of impairment that has served as justification for discrimination based on difference. In order to fully engage with disability into the composition classroom, I call for all of us in rhetoric and composition to locate ourselves within that nexus: as embodied subjects, as teachers, and as writers.

To extend Dolmage's and Lewieki-Wilson's metaphor, once we are there, the planets, Earth, Mars, and all those in between and beyond will become much more visible.

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