

Introduction

Concerto for the Left Hand

Disability Aesthetics

In its short existence as an academic discipline, disability studies has devoted significant attention to the representation of disabled persons in the visual arts, literature, theater, and public life. Disability scholars have studied the ways that cultural forms depend on a putatively normal body to reinforce regimes of national, racial, and sexual normalcy while using the person with a cognitive or physical impairment as a metaphor for the queer, subaltern, or marginal. A common recent criticism among disability scholars is that metaphoric treatments of impairment seldom confront the material conditions of actual disabled persons, permitting dominant social norms to be written on the body of a person who is politely asked to step offstage once the metaphoric exchange is made.¹ Disabled artists and activists have attempted to reverse this pattern, turning their cameo appearances in such theaters back upon the audience, refusing the crippling gaze of an ableist society and reassigning the meanings of disability in their own terms. As Carrie Sandahl says, people with disabilities are “not only staring back, but also talking back, insisting that ‘this body has a mouth’” (“Ahhhh Freak Out!” 13). This book studies the forms in which this body speaks and the constituencies it enlists in the process.

By framing disability in the arts exclusively in terms of social stigma, on the one hand, and advocacy, on the other, we may limit disability aesthetics largely to thematic matters, leaving formal questions untheorized. How might the aesthetic itself be a frame for engaging disability at levels beyond the mimetic? How might the introduction of the disabled body into aesthetic discourse complicate the latter's criteria of disinterestedness and artisanal closure?² Consider Ravel's D major *Concerto for the Left Hand*. Commissioned in 1930 by the pianist Paul Wittgenstein, who lost his right arm during World War I, the Ravel concerto is perhaps the best-known work in a surprisingly large repertoire of works for the left hand. Brahms, Saint-Saëns, Strauss, Janáček, Prokofiev, Scriabin, and Bartók all wrote significant compositions in this vein, often to showcase or strengthen a hand that commonly accompanies more difficult material in the right. It is less often recognized that many of these works were commissioned by pianists who, through repetitive stress disorders, arthritis, or injury, lost the use of one hand. Pianists such as Geza Zichy, Paul Wittgenstein, Leon Fleisher, and Gary Graffman are among the best known of these disabled artists, but most pianists at some point in their career temporarily lose the functioning of one or another hand. In the case of Wittgenstein, at least forty compositions were written at his request, and despite his cool response to the Ravel concerto, it became one of the composer's most popular works.³

The one-hand piano repertoire offers us an interesting site for considering the status of disability in the arts. On one level these compositions might seem to propose a kind of aesthetic prosthesis, akin to that which David Mitchell and Sharon Snyder see operative in narrative works in which the presence of a one-legged Ahab or a hunchbacked Richard III serves as a "crutch" in the representation of normalcy. Adapted to music, this prosthetic interpretation could explain the technical difficulty of one-hand playing as a compensatory response for the missing hand, one that requires the pianist to imitate the full pianistic range, coloration, and dynamics of the nineteenth-century virtuoso style. If we treat Ravel's concerto as an able-bodied response to Wittgenstein's impairment, then the latter's performance becomes a triumph over adversity that has rightly been the subject of much disability studies critique.

We might, on the other hand, read this concerto from a different angle, understanding that by enabling Wittgenstein, Ravel disables Ravel,

imposing formal demands upon composition that he might not have imagined had he not had to think through limits imposed by writing for one hand. Indeed, the *Concerto for the Left Hand* is a considerably leaner, less bombastic work than most of Ravel's orchestral music. In this regard, Ravel's concerto could be linked to the work of artists whose disability, far from limiting possibilities of design or performance, liberates and changes the terms for composition. One thinks of the late works of Goya, Milton, Beethoven, Nerval, Schumann, Monet, de Kooning, Close, and others, composed when the artists were becoming physically or cognitively impaired. I do not mean to substitute for a politically self-conscious disability arts a canon of well-known artists who happened to be disabled, but to broaden the focus of cultural production to include the larger implications of corporeality in the arts.

By bringing such matters to bear on disability I want to foreground the extent to which the aesthetic, from Baumgarten and Kant to recent performance art, is a matter of the body and of epistemological claims created by incorporating its limits into composition.⁴ Terry Eagleton points out that "aesthetics is born as a discourse of the body," an attempt to measure "the whole region of human perception and sensation, in contrast to the more rarefied domain of conceptual thought" (13). Tobin Siebers notes that the term *aesthetics* is based on the Greek word for perception and that "[there] is no perception in the absence of the body" (*Body Aesthetic* 1). In some cases, as in Wincklemann, the physical body becomes the site of human perfection, an ideal that found its dystopic end in National Socialism's vaunting of the ideal Aryan body.⁵ In other cases, as in Kant, the body is most conspicuous by its absence, as though aesthetics formed a *cordon sanitaire* against the encroachments of gross sensation and desire. To some extent Kant's privileging of disinterested observation is the cornerstone for modernist theories of impersonality and objectivism by which the aesthetic provides an alternative to passional states as well as instrumental reason. Yet disinterestedness in Kant can only be validated when it appears to elicit a reciprocal response in others: "A judgment of taste determines its object in respect of our liking . . . but makes a claim to *everyone's* assent, as if it were an objective judgment" (16). Here, the specter of social consensus haunts the aesthetic—as though to say, "My appreciation of that which exceeds my body depends on other bodies for confirmation. The body I escape in my enddistanced apprecia-

tion is reconstituted in my feeling that others must feel the same way.” It is this spectral body of the other that disability brings to the fore, reminding us of the contingent, interdependent nature of bodies and their situated relationship to physical ideals. Disability aesthetics foregrounds the extent to which the body becomes thinkable when its totality can no longer be taken for granted, when the social meanings attached to sensory and cognitive values cannot be assumed.

In chapters that follow I trace some of the implications of this claim by looking at a variety of cultural arenas—poetics, narrative, film and film theory, performance, and photography—through a disability optic. In this introduction I want to focus on three interrelated issues that govern my concerns in this book: thinking through the body (embodied knowledge), performing visibility (ocularcentrism and disability), siting disability (the spaces of disability). My attempt in each case is to show how the phenomenological world invoked by these forms depends less on the objects represented than on the knowledge that such phenomena produce and verify. As such, considerations of disability deconstruct or “crip” discourses of compulsory able-bodiedness that underwrite epistemological claims. Crip theory, like queer theory, promises an oppositional critique of bodily normalcy by working within the very terms of opprobrium and stigma to which disabled persons and queers have been subject (see McRuer, *Crip Theory*). What would it mean for the humanities to think through the body and reimagine curricula not around the “history of ideas” but through an armless Venus de Milo, a crippled Oedipus, or a madwoman in the attic? The field of poetics is dominated by tropes of the ear and page—voice, orality, meter, line, consonance—that are complicated in the case of deaf poets whose manual signing challenges the presumed link between text and voice. The same could be said of much modernist art whose ocularcentrism is made problematic by blind photographers such as John Dugdale, Alice Wingwall, or Evgen Bavcar, who create images as much inspired by sound and memory as by visual objects. As I say in chapter 2, disability also complicates feminist film theory’s treatment of filmic gaze predicated on an able-bodied male viewer whose castration anxiety is finessed by the director’s specular control over the female protagonist. Laura Mulvey’s influential essay avoids the alliance between the objectified woman and a disabled male, the latter of whose loss of limb or eyesight is a necessary adjunct to masculine specular plea-

sure. In each case, aesthetic discourse is underwritten by bodies whose imperfections become the limping meters, fatal flaws, castration complexes, and nervous disorders by which literature is known. The images that often epitomize bodily perfection and that adorn brochures for humanities programs and colloquia often feature Leonardo's Vitruvian Man, who has, after all, four arms and four legs.

The estrangement posed by disability is a corporeal and sensory version of modernist *ostrenenie*, which the Russian formalists and futurists saw as art's primary function. In their various formulations, "laying bare the device" exposes the routinized, conventional (today we might say "constructed") character of daily existence. Victor Shklovsky notes that habitual acts such as holding a pen or speaking in a foreign language become automatic, devouring individual objects and turning signification into an algebraic function. Art exists to "recover the sensation of life; it exists to make one feel things, to make the stone *stony*" (12). The technique of art "is to make objects 'unfamiliar,' to make forms difficult, to increase the difficulty and length of perception" (12). The formalists designate defamiliarization as the ethos of the aesthetic, a "making strange" that recuperates a world too familiar to notice. Adapting this view to our concerns with embodiment, we might say that disability becomes the ethos of the social insofar as it exposes cultural assumptions about the corporeality of the social body.

A good example of such defamiliarization can be seen in a recent French ad for Electricité de France (EDF) that shows a series of able-bodied persons negotiating an urban landscape designed entirely for persons in wheelchairs or who are deaf and blind. A woman is jostled on a sidewalk by persons speeding by in wheelchairs; a man stoops in the rain while attempting to use a payphone at wheelchair height; a woman asks directions from an attendant who only speaks sign language; a sighted man becomes frustrated by attempting to read library books entirely written in Braille. The concluding epigraph, *Le monde est plus dur quand il n'est pas conçu pour vous* (the world is harder when it is not conceived for you) offers a nice variation on commercials promising greater access and accommodation by making the able-bodied consumer the minority figure. EDF's claim, *Désormais, le monde les espaces EDF sont accessible à tous. Quand votre monde s'éclaire* (From now on, the spaces of EDF are accessible to all. When your world lights up: EDF), resonates powerfully for dis-

abled persons who have benefited from new electronic technologies such as Internet, TDY telephones, and voice-recognition software. Unlike ads that signal inclusiveness by adding a person in a wheelchair to a crowd of able-bodied models, EDF's ad imagines a world where change is not supplemental but structural.

Essays in this book define various ways in which disabled bodies, far from occupying roles at the margins of aesthetic discourse, are constitutive of cultural productions in general. In this respect, I am following a common thread within disability studies that understands disability not as a medical condition or bodily infirmity but as a set of social and cultural barriers to full participation in social life.⁶ If disability is treated strictly as a medical matter, confined to specific regimes of therapy, rehabilitation, and social services, then the disabled subject is reduced to his or her impairment, not unlike the ways that racialist discourse reifies individuals around phenotype and pigmentation. Viewed through a social model, disability becomes a marker of social attitudes about bodies and cognitive ability in general, located not in the body but in society itself. As Rosemarie Garland Thomson says, disability is "not so much a property of bodies as a product of cultural rules about what bodies should be or do" (*Extraordinary Bodies* 6). The work of disabled and Deaf artists such as Terry Galloway, Peter Cook, Aaron Williamson, Homer Avila, Lynn Manning, Larry Eigner, Carrie Sandahl, Derek Jarman, Evgen Bavcar, and Clayton Valli suggests that what it means to be disabled or deaf may depend less on the impairment than on adjustments made to social rhetorics and formal genres in which disability is framed.

Despite the recognition of disability as embedded in social attitudes, reception of disability in the arts has never been easy, despite the presence of blind, deaf, or disabled figures (Homer, Milton, Beethoven, Kahlo) as signifiers for artistic genius. Even when a critic approaches a disabled artist with sympathy, there is often the anxiety that such art must, at some level, be a form of advocacy rather than a productive element of innovation. In a review of a dance performance by Homer Avila at the Merce Cunningham Studio in February 2002, dance critic Jennifer Dunning acknowledges her "considerable trepidation" at seeing Avila's performance in his inaugural program following the loss of a leg and part of a hip to cancer. Her review is devoted not to what Avila *does* in the program but to

her “trepidation” at seeing a one-legged dancer. She imagines that the experience will be “rough going for anyone who, like me, feels faint at the sight of a paper cut,” but she is reassured that the “solo did not attempt to make up for the absence of Mr. Avila’s leg” and that he displayed “few of the expected, dreaded hops” (8). Dunning does worry that his movements “veered close to the kind of tricks beloved of ballet pyrotechnicians,” but on the whole she feels that such movements “have a rightful place in his vocabulary.” Dunning concludes with a caveat: “Understandably but regrettably, Mr. Avila seems intent on doubling as a spokesman for the disabled. His use of a hearing-impaired composer for ‘Not/Without Words’ suggested that he means to make a point, as he did with his charming insistence on lifting the dancer who had just lifted him in the improvisational audience participation piece that ended the evening.” Such qualified rhetoric (“charming insistence”) and faint praise is reminiscent of Arlene Croce’s similar judgment of Bill T. Jones’s *Still/Here*, a performance that deals with chronic illness. Croce, who did not see Jones’s performance, nevertheless felt obliged to complain, “I can live with the flabby, the feeble, the scoliotic. But with the righteous I cannot function at all” (qtd. in Dunning 8). Dunning agrees: “I’m with her there.” Such attitudes remind me of intellectuals of the 1940s and 1950s who acknowledged the technical skills of Richard Wright or Gwendolyn Brooks only to qualify their praise with the caution that by writing about black experience they would remain merely “Negro artists.”⁷ Dunning and Croce ask for a disinterested dance, one curiously divested of bodies. They criticize “righteousness” in dance, but exhibit a righteousness of their own by assuming that the disabled body must not speak of (or by means of) its condition.

My emphasis on the aesthetic in this book is not to create a safe haven for disabled artists but to counter the prevalent view in cultural theory that views matters of form, design, and structure as inherently ahistorical and apolitical. As I will point out, matters of aesthetics are deeply implicated in social attitudes toward disabled persons. As Martin Pernick shows in *The Black Stork*, it was precisely the use of aesthetic values that drove early proponents of eugenics and racial science to argue for sterilization of mentally retarded children, and to establish “ugly laws” to protect society from unsightly physical specimens (22–24). In this sense, the aesthetic was used to validate and reinforce the so-called objective science of heredity by

declaring what should or could be seen in public.⁸ Artists, fully cognizant of how those values apply to them, have taken the aesthetic not as a means of transcending the body but as a means of thinking through it.

Thinking through the Body

Thinking through the body has been an important component of cultural studies, from Michel Foucault's theories of bio-power to Judith Butler's theories of performativity, Donna Haraway's formulation of cyborg identities, Michael Omi's and Howard Winant's ideas about racialized bodies and eugenics, and Eric Lott's, Gayle Wald's, and Michael Rogin's work on racial cross-dressing. In such cases, female, queer, and racialized bodies challenge categories of normalcy and expose the degree to which bodies are constructed within narratives about deviance, abjection, and difference. Given the importance of nontraditional bodies and sensoriums in cultural theory, it is surprising that disability is seldom mentioned within such venues. The reasons for this absence may be related to the importance of certain identity categories (race, class, gender, sexuality, and nationhood) that have been the centerpieces of social movements and that dominate cultural studies and minority discourse. Although as disability theorists have pointed out, such categories are deeply imbricated in ideas of physical and cognitive impairment, the idea of expanding identity categories to include disability may threaten an already embattled territory. Critics on the left fear a dilution of hard-won political positions and civil rights legislation by expanding the category of oppressed persons too broadly. Critics on the right fear the economic impact of expanding the class of potential plaintiffs in legal cases filed under the Americans with Disabilities Act (ADA) and worry about alliances with more militant political movements. The fact that disabled persons have historically been identified with the institutional and carceral systems that have defined racial and sexual otherness makes alliances between disability and minority populations problematic.

Another significant reason why disability has been left out of cultural and social theory is the problem of definition. It is difficult to forge a social movement around such a wide spectrum of impairments and conditions. The World Health Organization defines disability as "[any] restric-

tion or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being” (Barnes and Mercer 13). Under this definition, does a person with an invisible impairment or chronic disease qualify? What about persons whose disabilities are controlled by medication, dialysis, or pacemakers? Do persons who are HIV-positive fall into the same category as other blood-borne diseases such as hemophilia or other autoimmune disorders such as kidney disease? What about mental illness? Are persons with Down syndrome or bipolar disorders disabled in the same way that a quadriplegic or person with cerebral palsy is? Early activists often accompanied political protests that led to the passage of the ADA with the chant “We’re not sick,” thus alienating persons with chronic diseases or mental illness. Deaf persons often repudiate the disability label, preferring to think of themselves as a linguistic minority, but even here, the definition is complex. A hearing child of deaf adults (CODA) may be considered culturally Deaf through his or her fluency in ASL, whereas a person who becomes profoundly deaf late in life, however fluent in ASL, will never be considered a member of Deaf culture. Such differences exemplify the problem of trying to define a unified “disability community” held together by common social goals and shared beliefs.

To some extent the very diversity and pervasiveness of disability argues for its centrality as an identity position that destabilizes identity categories altogether. In Lennard Davis’s terms, disability “dismodernizes” modern narratives of genetic improvement and social normalization that were formed in the nineteenth century. If postmodernism dissolves the grand narratives of modernity and its humanist core through an emphasis on social construction and performance, it may, in Davis’s view, leave nothing upon which to build a social movement. Dismodernism deconstructs modernist narratives based on the body and negotiates the wandering rocks of essentialism and social constructionism by calling attention to the “differences” we share:

What dismodernism signals is a new kind of universalism and cosmopolitanism that is reacting to the localization of identity. It reflects a global view of the world. To accomplish a dismodernist view of the body we need to consider a new ethics of the body. (*Bending* 27)

I flesh out some of the implications of Davis's thesis in the chapters that follow, but I would observe here that what Stuart Hall sees as a need for "conjunctural knowledge"—situated, historically specific understandings of phenomena—in cultural studies complicates a dismodernist view that might collapse identities into some global category.⁹

It would be relatively easy to point out that each of the identity categories I have mentioned as central to cultural studies has a specific coefficient in some aspect of disability discourse and that the historical emergence of class, race, gender, sexuality, or nationality coincides with taxonomic and scientific attempts to contain and control certain subjects during modernization. A class analysis of disability discourse, for example, would observe that the great majority of disabled persons in the world are poor (it is estimated that worldwide, two-thirds of the disabled live below the poverty line), are often diseducated, and can be found at the lowest levels of the workforce. The labor movement in the United States is written around struggles for a workplace that provides adequate disability insurance, accessible workstations, medical care, and protection from workplace accidents. Feminist disability scholarship has pointed out the degree to which gender has been defined through various nervous disorders and psychological categories (neurasthenia, castration anxiety, hysteria) that are the product of a male medical and psychoanalytic establishment. Similarly, one could point to the historical linkage of homosexuality and mental illness, a proximity that has led to various forms of incarceration, sterilization, and, in times of ethnic cleansing, genocide. The same could be said for late-nineteenth-century constructions of race through eugenics and comparative anatomy in which minority populations and immigrants were often linked to persons with cognitive impairments. The condition now known as Down syndrome was originally called "mongolism" in order to equate persons with mental illness with the weakening of the Aryan gene pool by immigrations coming from East Asia. As I point out in chapter 3, Deaf persons often find themselves in a colonial relationship to hearing culture that repudiates manual sign language in favor of oralist education. Oral pedagogies in the postbellum period were often motivated by attempts to naturalize deaf individuals into U.S. citizenship by making any gestures of separatism—such as the use of ASL—a threat to national cohesion. What such connections suggest is not a universal category of dis-

ability so much as a spectrum of discrete convergences of hegemonic social attitudes and discrepant psychological and somatic conditions.

Some sense of the imbricated relationship between cultural production and disability can be seen in recent controversies over assisted suicide. The case of Theresa Schiavo, a young Florida woman, who suffered severe neurological damage in 1990 and who remained in a coma for fifteen years, became the site of a culture war between civil libertarians, on the one hand, and an unlikely coalition of religious conservatives and disability rights advocates on the other. Similarly, critical response to films such as Clint Eastwood's *Million Dollar Baby* and Alejandro Amenabar's *The Sea Inside* has brought issues surrounding euthanasia and medical ethics into conflict with disability activists. In each case, basic questions about the "quality of life" and the "right to die" have been debated through representations of a disabled body and its ability to respond to social agendas formed around it.¹⁰

The case of Theresa Schiavo may not appear to have anything to do with aesthetics or cultural production, until one realizes that much of the controversy surrounding her concerned the question of images and the ability of others to interpret them. Critics and pundits on the left and right have understood that the meaning of Schiavo's condition was a synecdoche for tensions in the culture over the question of "quality of life." Feminist legal scholar Patricia J. Williams noted that Schiavo's "in-scrutable silence has become a canvas for projected social anxieties" (1). Katha Pollitt described the "Terri Schiavo freak show [as] deeply crazy, so unhinged, such a brew of religiosity and hypocrisy and tabloid sensationalism" (1). And Tom DeLay, speaking at the Family Research Council in Washington, saw a redemptive message in the Schiavo case; the "one thing that God has brought to us is Terri Schiavo, to help elevate the visibility of what is going on in America." Prior to her cardiac arrest in February 1990, Schiavo had not indicated what special procedures should be implemented in the case of extreme trauma. As a result, interpretation of her wishes was left to her husband, who claimed she would have rejected any extreme measures and who therefore wanted her feeding tube removed, and to her fundamentalist Catholic parents, Robert and Mary Schindler, who fought to maintain life supports. Television images showed Schiavo interacting with her parents and doctors, and these pictures were sub-

jected to minute scrutiny to verify if, as her parents claimed, she was responding to stimuli or whether her eye movements and facial expressions were simply reflexes. The fact that she maintained normal sleep-waking cycles, breathed on her own, and occasionally smiled and blinked her eyes made it seem as though she was responding to her parents' presence. Furthermore, there was the matter of terminology. Doctors and Florida circuit judge George Greer (the primary judge in her case), for the most part, described her as "brain dead," living in a "persistent vegetative state," and recommended the removal of life-prolonging feeding tubes. Michael Schiavo, on the other hand, sought to end her "suffering with dignity."

In order to assign blame for the 1990 incident that caused Schiavo's cardiac arrest, critics began to look at her early life as well as at her husband's actions in the intervening years. Right-to-life advocates accused Michael Schiavo of wanting to cash in on her illness, citing an earlier medical negligence suit for \$1.1 million that he received in 1992. The fact that he had taken up with another woman with whom he had fathered two children was adduced as evidence of his weak moral character. On the other side, critics of the Florida Department of Children and Families that sought to gain custody of Schiavo claimed that the neurologist from the Mayo Clinic hired to evaluate her condition was a conservative Christian and therefore could not deliver a disinterested opinion. As Joan Didion points out, in the absence of a clear diagnosis of Schiavo's physical condition, public opinion tended to search for clues in Schiavo's "bad habits." She quotes Patricia Williams, who, in *The Nation* noted that Schiavo's "bulimic aversion to food was extreme enough to induce a massive systemic crisis that left her in what doctors describe as a 'persistent vegetative' state" (61). Didion concludes that "in this construct [Schiavo] had for whatever reason played a role in her own demise, meaning that what happened to her need not happen to us" (61). Commentators defined the political importance of the case as a "right-to-die" issue, or, more subtly, a "personal choice" matter," yet in the absence of legal documents by Terri Schiavo claiming those rights, the case became one in which the disabled body was interpreted by others.

This latter issue is important for disability studies insofar as, once again, the body of a disabled woman was deemed a "life not worth living" and therefore disposable. Not Dead Yet, the activist group that opposes euthanasia and assisted suicide, protested alongside fundamentalist Christians at Schiavo's home, yet their rather different reasons for supporting

Schiavo's parents were often left out of the discussion.¹¹ Katha Pollitt ignores disability implications in her *Nation* article, seeing the Schiavo case as an example of a slippery slope leading to the reversal of *Roe v. Wade* and the elimination of all civil rights. Pollitt segues quickly from Schiavo and euthanasia to abortion and to stigma leveled against "bad girls" who get pregnant. Theresa Schiavo becomes merely a point of departure. Even a balanced report such as that of Joan Didion mentions Not Dead Yet's protest only in passing, thus avoiding the implications of the case for disability rights advocates. As persons who have been historically vulnerable to medical interventions, a large majority of persons in the disability community knew very well what commentators meant by Schiavo's life being one "not worth living": one not like theirs. That life became the site for a national debate about medical ethics, abortion, stem-cell research, "activist judges," Supreme Court nominees, and the future of the filibuster. The U.S. House of Representatives and Senate's attempts to block the removal of the feeding tube—ordered by Judge Greer—and their subsequent attempt to create a law pertaining only to Theresa Schiavo (with George W. Bush's support) brought chills to many Democrats and members of the Left who saw such actions as the beginning of a conservative Armageddon. Whatever Schiavo may or may not have wanted for her mortal remains became obscured by secondary and tertiary narratives about the future of civil liberties, *Roe v. Wade*, and the Supreme Court.

My second example, Clint Eastwood's film *Million Dollar Baby*, offers a more obvious object for cultural analysis, having been the site of extensive media debate over its representation of euthanasia. It joins a rather large number of disability-themed movies made in recent years, including *Elephant Man*, *A Beautiful Mind*, *Ray*, *The Sea Inside*, *The Station Agent*, and the documentary *Murderball*, that have raised the presence of disability issues in the public arena. The almost unanimous positive critical acclaim (and financial success) that the film received when it was first released was countered by the almost unanimous complaint from the disability community over the film's seeming advocacy of euthanasia for persons with spinal cord injuries. The complaint was less concerned with the dramatic and cinematographic qualities of the movie than with the way it made assisted suicide seem the logical result of those qualities.¹² As in the Schiavo case, the question of a nondisabled person's ability to speak for a disabled person generated a public debate far beyond the movie.

The film concerns a spunky, working-class woman, Maggie (Hillary Swank), who enlists an aging boxing trainer, Frankie (Clint Eastwood), to coach her so that she can win a title match. Frankie's taciturn character and lined face bespeak a checkered past whose ghosts he attempts to assuage by vigorous pursuit of his Catholic faith. He is reluctant to train a "girl" boxer, having lost his own daughter to some unexplained parental error, but when his top fighter leaves him for a more lucrative shot at a title, Frankie gives in and takes Maggie on as his charge. He is encouraged in this act by his gym manager, Eddie (Morgan Freeman), a former boxing champ who lost his eye in an early fight for which Frankie feels responsible. Eddie is the movie's Sybil, offering sage opinions on boxing and life that resonate with Maggie's dream. Eddie muses,

If there's magic in boxing, it's the magic of fighting battles beyond endurance, beyond cracked ribs, ruptured kidneys, and detached retinas. It's the magic of risking everything for a dream that nobody sees but you.

This dream of self-fulfillment, despite the odds, has implications for Eddie as a disabled African American that rhyme with Maggie's own "disability" as a poor woman from the rural South.

The first two-thirds of the movie constitute a straightforward boxing movie, tightly acted and brilliantly shot in dusty gyms and smoky boxing rings. Maggie's boxing improves under Frankie's careful, if cranky, tutelage. She becomes a formidable athlete, winning fight after fight by knocking out her opponents in the first round. The final third of the film switches direction dramatically when, in the women's welterweight championship match, Maggie sustains a serious head injury and becomes paralyzed from the neck down. Now the "true" drama of *Million Dollar Baby* begins; what had been a story of triumph over class and gender limits becomes a triumphalist parable about disability. After being immobile for a time, relying on a ventilator to breathe, and sustaining bedsores that require a limb to be amputated, Maggie decides that she wants to terminate her life.¹³ Inexplicably, she does not ask her doctors to remove life supports but wants Frankie to do the job. He wavers for some time, consulting with his Catholic priest, who urges him not to accede to Maggie's wishes, but in the end decides to euthanize her by injecting her with a fa-

tal dose of adrenaline and then disconnecting her ventilator. Maggie dies quickly, and Frankie leaves town, never to return. In the film's last scene, we see a grainy shot of a lonely rural cafe—one that Frankie in an earlier scene hinted he might buy one day—with Morgan Freeman's voice-over reciting what appears to be a letter to Frankie's absent daughter. At this moment we realize that Eddie's voice-over has been an extended epistle to the estranged daughter, trying to explain to her "what kind of man your father was." Eddie's monologue reinforces the fact that although Maggie is essential to the film's pathos, the real drama is about Frankie. In Mitchell and Snyder's terms, she serves as a prosthesis for a narrative about Frankie's tragic fate, his Lear-like burden of familial, religious, and ethical burdens.¹⁴

Like many disability-themed movies, the disabled figure is terminated in the end in what John Hockenberry calls a "crip ex machina," providing the able-bodied viewer a measure of compassion for the victim while permitting an identification with the able-bodied hero who survives. As members of Not Dead Yet and the National Spinal Cord Injury Association pointed out, the ending avoids the legal fact that in the United States, Maggie could have requested the removal of life-sustaining treatment and did not need Frankie's assistance (see Weiss, "Boxing Flick"). Critics also point out that as the film's director, Eastwood, does not provide alternatives to assisted suicide that might have modified Maggie's ultimate decision. Frankie does offer to buy her an electric wheelchair and enroll her in college, but Maggie refuses any amelioration. As doctors reported of Schiavo's condition, Maggie's life is deemed "not worth living" and therefore disposable. Film critics and commentators dismissed the disability complaint, saying, as Maureen Dowd did in the *New York Times*, the "purpose of art is not always to send messages. More often, it's just to tell a story, move people and provoke ideas. Eastwood's critics don't even understand what art is" (Davis, "Why Disability Studies Matters" 3). But one might turn Dowd's remarks around and say that although Eastwood may know about boxing and male angst, he doesn't know much about disability, and what he does know is influenced by his own personal legal difficulties through a suit filed by one of his employees under the ADA.¹⁵ As in cases we have already encountered, an appeal to a disinterested "art" trumps content that calls the terms of interestedness into question.

As Lennard Davis points out, had *Million Dollar Baby* been a film that

denigrates gays or women, the progressive community would speak out against “films, novels, plays or any artwork that demeaned people of color, gay people, or any oppressed group” (“Why Disability Studies Matters”). But because the film was viewed as a compassionate look at “personal choice,” it was read as a civil rights document, in this case an appeal to an artist’s right to make a movie as he sees fit and a woman’s right to commit suicide. For people with disabilities, the message was viewed not as a matter of choice but one of untenable ethical alternatives. They saw that given the chance, society, reinforced by films like *Million Dollar Baby*, would terminate their lives as well. The fact that the film was also criticized by Christian conservatives on moral grounds helped create an alliance that blurred the differing reasons for the film’s detractors.

To return to my initial concern with what it means for cultural studies to think through the body, we could see the debate that surrounds Theresa Schiavo and *Million Dollar Baby* as a limit case for the binary opposition that organizes disability studies. A too strict reliance on impairment as biological rejects the social meanings that Schiavo’s or Maggie’s conditions produce and consigns their bodies—as the popular press seems to have done—to regimes of rehabilitation and medical treatment, on the one hand, or euthanasia on the other. By denying them agency and treating their bodies as inert, neutral elements, medical science may then impose agency on them from without. At the same time, strict reliance on a *social* model of disability may jettison the physical impairment altogether and focus on social and material obstacles. As Tom Shakespeare says, “The social model so strongly disowns individual and medical approaches, that it risks implying that impairment is not a problem” (200). What is missing, as Sharon Snyder and David Mitchell have pointed out, is a *cultural* approach to disability that would take into account the experiences and meanings that disabled people have constructed about their bodies. The divide between medical and social models needs to be retheorized as an “interactional space between embodiment and social ideology,” and in the process needs to take into account the social meanings that bodily differences assume by disabled individuals (7). To anticipate the subject of my next section, disability studies needs to bring into alignment what the world sees as the disabled subject and the world through which the disabled subject sees.

Performing Visibility

If everyone in the world were blind, perhaps touching would be called seeing.

—JOSEPH GRIGELY

A picture held us captive. The convergence of ethics and disability that I have been discussing depends on an image, the picture of a disabled person that, to continue my use of Wittgenstein, “lay in our language, and language seemed to repeat it to us inexorably” (48e). Theresa Schiavo’s or Maggie’s bodies become disabled in discourses that swirl around their public presentation and reception. Their physical bodies are forgotten in the attempt to recuperate them as metonyms for what “we” don’t have or don’t wish to have. Visibility, as Lennard Davis points out, is the modality within which disability is constructed: “The person with disabilities is visualized, brought into a field of vision,” and as such monitors (or polices) the field of embodiment for the “normal” viewer (*Enforcing Normalcy* 12). Because the gaze is so powerful in constructing claims of truth and reason, it is often the hardest condition to “see,” provoking Joseph Grigely in his “Postcards to Sophie Calle” to wonder what would happen if everyone were blind. In that case, would “touching be called seeing”?¹⁶

Such a condition is elaborately developed in José Saramago’s *Blindness*, a novel in which the entire population of a city—and eventually a nation—becomes blind. Saramago may have been creating an allegory about Fascism during the Salazar regime in Portugal—the blind leading the blind, perhaps—but in the process he imagines a world no longer dependent on sight, one in which “touching becomes seeing.” Characters in the novel (who have no names) begin to rely on other senses for communication, location, locomotion, and survival. Early on, the government tries to contain this contagion by incarcerating the blind in an asylum, but soon their guards also become blind and the prisoners escape, rendering the need for prisons and asylums moot. Only one character retains her sight, the wife of a doctor, and she functions as a guide and helper for the blind, although there is the possibility that she could in time become a leader (or a despot) because of her sensory advantage. At the end, people gradually regain their sight, and one character seems to speak for the author: “I

don't think we did go blind, I think we are blind, Blind but seeing, Blind people who can see, but do not see" (292). The idea that we are all prisoners in Plato's Cave, seeing only shadows, suggests how powerful the connection between sight and knowledge has been from the outset. It also reminds us how convenient blindness has been as a metaphor for personal misfortune and social disorder.

We could see Saramago's novel as offering yet another example of aesthetic prosthesis in which disability serves a master narrative of normalcy and wholeness. It also reminds us of the importance of scopic regimes as agents of personal and national identity. The medical gaze, as Michel Foucault defines it, is a technology of power that naturalizes bodies through consensus and agreement, whether the gaze is directed at a movie screen or at a sonogram monitor.¹⁷ Erving Goffman observes that the term *stigma* referred originally to bodily signs that "expose something unusual and bad about the moral status of the signifier" (1). That association of visible marks, cut or burned into the body, continues in categorizations of bodies that are "disfigured" or "deformed" or "freakish." But the stigmatization of certain bodies through visible signs belies the extent to which the idea of a "normal" body is naturalized around those signs. In Robert McRuer's terms, a disability analysis reveals "compulsory able-bodiedness" as the condition for visibility, as that which must be asserted and affirmed. Of course, my use of the binary opposition *visibility/invisibility* reveals an ableist agenda of its own that becomes problematic when the subject is blind. The very fact that knowledge is represented through ocular metaphors ("I see what you mean"; "he was blind to the facts") testifies to the difficulty of stepping outside of disability in order to gain a critical perspective on it.

Viewed through a Foucauldian frame, disability becomes visible historically through various medical and scientific discourses emerging in the late eighteenth century, in which power relations of the dominant are inscribed on a body rendered "docile" so that it may assist productive apparatus of capitalism. From nineteenth-century freak shows and carnival acts, through the photographic displays of eugenics textbooks to Jerry Lewis telethons, disability has been synonymous with the theatrical display of "different" bodies. At the most immediate level, disability is constructed through complex rituals of staring and avoidance that occur when people confront a person with an empty sleeve, a prosthetic limb, a

scarred face, a stutter. These social pragmatics are double-edged: the able-bodied viewer averts the gaze or looks clandestinely, the disabled subject “performs” invisibility—acts as though invisible or else compensates in some way to make the viewer feel comfortable. Disability memoirs are filled with descriptions of what we might call a crip double consciousness in which the individual in a wheelchair must simultaneously “act normal” while negotiating an inaccessible and sometimes hostile environment. The late actor and playwright John Belluso, who used a wheelchair, describes the theatricalization of disability as a continuous public performance: “When I get on a bus, all the heads turn and look, and for that moment, it’s like I’m on a stage. Disabled people understand the world in a different way. You understand what it’s like to be stared at, to be looked at, and in a sense you’re always performing your disability” (Breslauer 4).¹⁸

Performance artist Mary Duffy, who is armless, makes this performative aspect of disability the site of many of her works. She merges the act of staring with the act of aesthetic appreciation by posing nude in the posture of classical sculptures. Appearing as what Rosemarie Garland Thomson calls “the Tableau Vivant Venus” (“Dares” 36), Duffy’s monologues expose the gendered character of staring, making herself into an object of scopical interest (a nude, armless woman) and then addressing—even hectoring—an art establishment that wants to keep its distance. By this act, Duffy deconstructs a pictorialist aesthetics based on the Horatian formula *ut pictura poesis*, by making sculpture speak. She also deconstructs ideals of feminine beauty by exposing her own armless body as the object of the gaze through which beauty is framed.

Thomson has taken the transgressive act of staring as a key issue in her recent work. She describes the ways that social relations are created out of acts of staring, looking, and gazing that offer, to the able-bodied viewer, a form of guilty pleasure. Unlike glancing, scanning, or glimpsing, staring at a disabled person “registers the perception of strangeness and endows it with meaning” (“Dares” 30). Staring is a “potent social choreography that marks bodies by enacting a dynamic visual exchange between a spectator and a spectacle. Staring, then, enacts a drama about the people involved” (31). Although modern philosophers like Sartre and Levinas have formulated intersubjectivity around a constituting look, they do not address the politics of embodiment articulated through that look.¹⁹ For Sartre, the constituting “look” (*le regard*) engages two presumably neutral

subjectivities on either side of a keyhole; for Levinas, the “face” of the other exposes the contingency and vulnerability of the one looking.²⁰ Neither philosopher imagines that the encountered other is blind. As Thomson points out, cultural theory has diagnosed the social implications of such staring through scopic regimes that include feminist gaze theory, which studies the formation of the patriarchal gaze, materialist critiques of consumerism and control, and ethnographic treatments of the colonizing gaze. All three of these regimes reinforce staring as a visual practice “that materializes the disabled in social relations” (“Dares” 32).

As Thomson and others have shown, disability performance like that of Mary Duffy has made the multiple levels of staring into a primary issue, turning the disabling gaze back on the audience and forcing its members to confront their own discomfort at the sight of the disabled body. She cites the work of Cheryl Marie Wade, for example, who foregrounds her “claw hands” in the video documentary *Vital Signs*:

Mine are the hands of your bad dreams.
Booga booga from behind the black curtain.
Claw hands.
The ivory girl’s hands after a decade of roughing it.
Crinkled, puckered, sweaty, scarred,
a young woman’s dwarf knobby hands
that ache for moonlight—that tremble, that struggle
Hands that make your eyes tear.
My hands. My hands. My hands
that could grace your brow, your thigh
My hands! Yeah!

(Qtd. in Thomson, “Dares” 35)

Wade stares back, acknowledging the social anxiety that her hands evoke, while reclaiming them for acts of tenderness and intimacy. Rather than perform invisibility by hiding her hands, Wade brings them forward, both physically on stage and verbally in her performative rhetoric. We are refused the passive gaze that maintains the observer’s authority and forced, instead, to violate that childhood adage, “It’s not polite to stare.”

A further complication of the disability/visibility rhyme can be seen in Terry Galloway’s performances, which often merge discourses of deaf-

ness, queerness, disability, and gender through references to popular media and film. As a performer she wonders

how to have a voice in theatre. How to be heard. How to be a poor, queered, deaf, unbeautiful girl and still make a claim on that empty space. Everything I do is autobiographical, but I'm trying to code it differently. ("Making a Claim" 51)

Deaf since a young age, Galloway creates memorable, often hysterically funny, performances that interrogate a wide range of cultural signage—from noir radio dramas and movie melodramas to celebrity telethons. As the preceding quotation implies, Galloway seeks a "voice" in a theater that has little room for deaf actors, but she also seeks a form of autobiography that uses the "empty space" of an inaccessible theater for a "queered, deaf, unbeautiful girl." She wants to "code it differently," by acknowledging limit as a constitutive force:

What if your whole performance is predicated on the fact that you are not: not the usual performer, not the usual beauty, not what is usually seen. And that you are deliberately not saying the same old things about art and life that are usually said. ("Making a Claim" 51)

One might add to this list of negatives the fact that Galloway does not present herself as a member of Deaf culture with a basis in ASL, having been mainstreamed as a child in public schools. Although her oral basis removes her from more traditional venues of Deaf culture, it permits her access to a wide range of acoustic environments, including film, radio, verbal monologue, and standup poetry, on which she draws with caustic wit and broad satire.

In her video performance *Annie Dearest*, Galloway takes on a sacred text of disability literature, Helen Keller's autobiography and its representation in the 1962 film *The Miracle Worker*. The first part of the performance features a black-and-white reenactment of the moment in the film when Keller (Patty Duke) makes the verbal connection between the word "water" and the water being pumped out of a well by Annie Sullivan (Ann Bancroft). Galloway parodies the sentimental framing of this moment—

the swelling music and epiphanic discovery by Keller of language—by linking Sullivan, Keller’s patient teacher, to Joan Crawford as the abusive mother represented in her daughter’s memoir, *Mommie Dearest*. In Galloway’s version, Annie Sullivan, the patient, heroic, hearing teacher, is transformed into a demonic oralist instructor who forces Helen to endure various forms of water torture until she pronounces the acceptable phonemes: “wa . . . wa . . . wa . . . water!” *Annie Dearest* is a parody not only of sentimental portrayals of disabled persons but an exploration of sensationalist human interest stories (of which Crawford’s memoir is an example) through which disability is represented.

In an afterword to the film, Galloway appears—now in full color—as the cocreator of *Annie Dearest* and, most importantly, as an “authentically deaf person.” She explains that despite her hearing aids and deaf accent (lateral lisp), she is technically not supposed to be in a film about deafness since she does not use ASL in her performances. In her faux documentary voice, she avers that if she were an “authentically deaf person” she would sign her remarks, but fortunately she has a stand-in—or “hand in”—in the form of her interpreter Stevie, who stands behind her and signs across her chest. This irreverent coda has, at its heart, a serious subtext: the claim for an authentic Deaf identity marked by exclusive use of manual signing. Galloway’s controversial critique of official Deaf culture focuses on the exclusions of cultural nationalism by acknowledging her awkward relation to both hearing and deaf worlds. Her coda is also about the fragile trust between the deaf individual and the oral world that interprets experience for her. The more Galloway claims to be authentically deaf, the more unstable becomes the claim. She “performs authenticity” while acknowledging her marginal status among deaf persons. But while she is critical of the official hierarchies of Deaf culture, capital D, she is also aware of the insidious role that audism plays in performance itself—through the use of various forms of visual translation (voice-over, closed-captioning, and hearing ASL signer) that she deploys in *Annie Dearest*. At the end she asks Stevie if she (Stevie) has been “talking behind my back,” and Stevie nods her head affirmatively. “I was afraid of that,” Galloway concludes. Here, she foregrounds the complex and multifaceted implications of depending on others who may literally and figuratively wrest power from deaf persons by “talking behind our backs.”

My second example of language mediated by sight is taken from the

work of deaf artist and philosopher Joseph Grigely. As I point out later in this book, Grigely creates installations in which the walls are plastered with small slips of paper that he collects from his “conversations with the hearing,” as he calls one of his installations. These ephemeral texts are the written half of dialogues that the artist has had with hearing interlocutors, the other half of these conversations completed by Grigely’s voice or by gestures. What we see in the gallery or museum space is a rough patchwork of tiny texts, ephemeral post-its and bar napkins that become—quite literally—a wall of words. Affixed to the walls are brief descriptions of the circumstances of each conversation that become, in themselves, metaconversations with the viewer. Grigely wants to turn the docent commentary on the artist’s work into the work itself, while debunking the “authoritative” art commentary on the work’s origins.

Grigely’s interest in the interface between the visible and the textual can be seen in his “Postcards to Sophie Calle,” a series of responses to the French photographer from 1991. Calle’s exhibition *Les Aveugles* was featured at the Luhring Augustine Gallery in New York and involved photographs of blind people who had been asked to respond to the question of “what their image of beauty was” (31). In addition to printed responses to this question, the exhibition featured photographs of the blind respondents and the “beautiful” objects to which they refer. Grigely’s postcards are an extended meditation on the sighted viewer’s gaze at the blind face and on the sighted artist’s ability to render the blind experience. Grigely admits to being “taken in” by the written responses as they describe touching bodies and sculpture, but his pleasure is “mitigated by something troubling” about them:

They [the blind subjects] do not apologize for the fact that it is the body, the engendered body particularly, that must be touched to be seen. This is the tactile gaze of the blind. It is a gaze unconditioned by whatever feminism and sexual politics have taught us about touching. The terms and conditions by which this tactile gaze exists thus cannot be judged by our own standard, where the actions of the blind become rendered . . . into *our* vocabulary of tactile violence. This touching is not about feeling, not about touching even, but about seeing. Touching itself is elided; it is a semantic projection of our own physiology, not that of the blind. If everyone in the world were blind, perhaps touching would be called seeing. (33)

I will return to the idea of tactile seeing in chapter 6, but here I would observe that Grigely questions the presumed erotics of tactility—and the sexual politics that limits its meaning. He compares the blind person's touching of sculpture in the museum to the deaf person's use of sign language, the latter of which is not a "pretty way of communicating—it's language, language pure and simple" (33). Of course language is never "pure and simple," as his epistolary pretense makes clear, but he wants to differentiate a romantic view of the blind—as simple, naive, sensual—from an ontological view—as subjects for whom touch is a form of communication. Our inability to imagine alternate configurations of sensation stems from ingrained attitudes about what constitutes perception, the "inevitable effect of an imposed transmodality: it reconfigures our physiological conventions and the language with which we describe those conventions" (33).

This "transmodality"—what I have been calling defamiliarization or what Terry Galloway calls "coding it differently"—lies at the heart of a critical disability aesthetics in which practice—performance, textuality, visuality—redirects epistemological questions onto the body. If classical aesthetics has been based on a theory of disinterested contemplation, what does this disinterest mean for those who do not see and who become the objects of another's contemplation? Grigely admits to feeling profoundly disturbed by such questions because Calle has permitted no reciprocity to the gaze. The blind are asked to respond to beauty as subjects, but their faces become the objects of the sighted gaze:

I am arrested by the fact that these images do not, because of their visual modality, return themselves to the blind. *Since your face is not available to me, why should my face be available to you?* (34)

Sophie Calle's camera captures the face of the blind but leaves her own face out. The panoptical gaze of the camera keeps everyone in sight, yet protects the seer from view. As a deaf viewer, Grigely understands what it means to be looked at strangely and provides his own disability perspective on the act of looking: "I am able to gaze, look, stare into the faces, into the eyes, of faces . . . I feel I am in the presence of a social experiment. I feel I am being watched, feel as if I am a part of this experiment. Alone and not alone, I am uncomfortable" (34).

Although Grigely's postcards are critical of Calle's project, they nevertheless recognize the compelling nature of her attempt to give a place to blindness visitors to the museum, her interest as "social archaeologist" in the ordinary details of blind response.²¹ The problem, however, is that it is not an exhibit for the *blind* but for the *seeing viewer*, a form of colonization similar to ethnographic scrutiny of primitive peoples or the modernist's fascination with non-Western art ("What difference is there between gazing at the eyes of the blind or the labia of the Hottentot Venus?" 36). He notes that progressive critics often use negative stereotypes of disability to refer to those who are "blind" or "deaf" to cultural diversity, even though these same critics are acutely sensitive to the ways that sexism or racism are encoded in language. Such obtuseness to the material reality of blindness is reinforced by an image that Grigely finds most arresting in the exhibit, a photograph of a Braille text by Claude Jaunière. It is the ultimate oxymoron of display—a text meant to be touched that has been flattened into a photograph, encased in plexiglass. As Grigely looks more closely at the image, he realizes that the text has been printed upside down, the epitome of disregard in an exhibit designed to represent blindness. Grigely's "monospondence" (as he calls it) with Sophie Calle engages the artist in a dialogue about the aesthetic use of disability. By writing his response to *Les Aveugles* in the form of postcards, Grigely signifies on Calle's own vernacular, exploratory form. Since she does not include her face in the exhibit, Grigely does not represent himself, but in his final postcard, he offers a solution: "Perhaps, Sophie, you might some day return what you have taken, might some day undress your psyche in a room frequented by the blind, and let them run their fingers over your body as you have run your eyes over theirs" (58).

Siting Disability

As the work of Terry Galloway and Joseph Grigely indicates, disability may be a theater or a museum, a place where something is seen. If disability is a matter of sight, it is no less one of site, a series of locations and spaces where political economy, bioregional differences, cultural representations, and medical bureaucracies converge. I am not speaking metaphorically here. Anyone who has gone to a hospital for even a minor procedure

knows what it means to enter the labyrinth of waiting rooms, doctors offices, pre-op wards, and operating theaters while wearing a hospital gown that ties badly in the back. And there are other kinds of spaces—the chilly warren of insurance documents, liability waivers, and postoperation directives that map the body's passage through the new HMO-driven medical bureaucracy. The site itself—doctors in green scrubs, clots of medical residents appearing at any hour of the day, strange noises in the hallway, and lights turned on in the middle of the night—creates a phantasmagoria that is unnerving for an adult patient and terrifying to a child. Whatever physical ailment brings one to the hospital is quickly displaced onto regimes of diagnosis, cure, and analysis. These are the sites through which the body becomes medicalized, the subject becomes object.

Medical anthropologists have begun to study the etiology of disability in such phantasmagoric spaces, observing that when disability is located in society, rather than individual pathology, the diagnosis of a condition is always driven by factors beyond the information contained in an MRI scan or platelet count. In terms that Homi Bhabha uses to describe the hybridic nature of global culture, we might ask, what is the “location of disability,” and how does consideration of space alter the meaning of impairment? Does HIV exist in the individual's cell structure or in the compromised immune system or in the social attitudes toward persons deemed at risk in a given cultural frame? Is HIV-positive the same for a white male in the United States as it is for an African woman in Botswana? Is menopause a natural hormonal change in middle-aged women or a disease, invented by pharmaceutical companies to promote hormone replacement therapy?²² Do diseases such as silicosis, carpal tunnel syndrome, or “Gulf War syndrome” exist in patients or in the workplace environments where these conditions have historically emerged? Feminist scholars have noted that S. Weir Mitchell's famous “rest cure” for women who in the late nineteenth century suffered from nervous disorders was as much an attempt to impose a spatial constraint on the sexually and economically emancipated “new woman” as it was to solve her nervous disorder.²³ As Charlotte Perkins Gilman's short story about the ill effects of Mitchell's cure on one woman demonstrates, the space of what used to be called “hysteria” may be the prisonlike nursery in which the female narrator of “The Yellow Wall Paper” is incarcerated.

In one of his talk performances, David Antin describes the patient's interaction with a doctor as a kind potlatch:

... a patient comes to a doctor with a complaint not with a disease and what the doctor offers him is a disease a disease is the doctors prospective gift to the patient which is then followed by other gifts since one gift leads to another a course of therapy drugs surgery who knows (281)

The idea that a patient is "given" a disease and that such a "gift" leads to further exchanges reinforces medicine's anthropological associations with myth and ritual. This counternarrative complicates the usual model of disease as something that one "has" and resites it onto something that others interpret. This hermeneutic activity, as I point out in chapter 1, has been especially important to hematological diseases because of the symbolism that attends blood within national narratives of patriotism and sacrifice. In his study of the blood distribution industry, Richard Titmuss notes that in the early days of transfusions, blood donations were thought to be a "gift relationship" since they were given without thought of payment. When blood could be sold for profit, the "gift" of blood was no longer an appropriate model and was replaced by a commodity relationship between seller and client. The ill effects of the commodity model were evident in the infection of thousands of individuals with HIV/AIDS in the early 1980s through transfusions from pooled blood products.

In a similar vein, Keith Wailoo has pointed out that the diagnosis of certain diseases such as sickle-cell disease or Tay-Sachs, by their identification with African American and Jewish populations, become visible less by the particular biological features of the disease and more by questions of race and heritage. He notes that such racialized diseases "are not so much new inventions of the science of genetics; they are rather, reinterpretations that draw on particular notions of group history, identity, and memory" ("Inventing the Heterozygote" 236). Wailoo points out that early studies of sickle-cell disease emphasized the recessive traits inherited from the parents. The heterozygote or carrier of the recessive gene became as important as the one afflicted; the focus of medical research was redirected from curing the afflicted patient to containing of the spread of

disease and contamination of others. The importance of the carrier “highlights how new technologies gave rise to new forms of identity, and to widespread anxieties about social interaction and new methods of surveillance” (237). The biological definition of the heterozygote and the carrier’s identification with the diseased population became a social issue that often attends the arrival of new migrant populations. In such examples, the siting of blood extends to the economic and spatial forces of modernity in which racial identity was often measured by the “one-drop rule.”

If we think of disability only in terms of an unitary physiological or sensory limit, we will fail to understand the complex matrix of sites that are brought into play, making it impossible to say where a disability ends and the social order begins. As I say in my final chapter, if we imagine that disability is something pertaining only to bodies, then we restrict the term to a medical frame, but if we imagine that disability is defined within pharmaceutical exchange, blood donation centers, labor migration, ethnic displacement, epidemiology, genomic research, and trade wars, then the question of the location of disability must be asked differently. Does disability exist within a cell structure, a caregiver, a trade agreement, an insurance claim, a special education program, or, as the recent devastation caused by hurricane Katrina exemplifies, a disaster preparedness plan?

If we consider disability as a series of sites, then we would have to include those places in which awareness of disability emerges, in which the “handicapped” population becomes empowered as a political entity. The independent-living movement often charts its origins to the ward at the Cowell Hospital on the University of California, Berkeley, campus where Ed Roberts and other disabled students lived and pursued an education previously deemed inaccessible.²⁴ Their relationship to the campus’s then-active antiwar and free speech protests was instrumental in gaining a site for their assisted living and ultimately in launching a social movement that shifted the rehabilitation model of impairment to one based on communal, self-sufficient living. The same might be said for the history of Deaf culture, which is written around residential schools, clubs, and camps where deaf families have historically placed their children and around which thriving Deaf communities have emerged. The importance of such educational venues for Deaf people is reflected in two ASL signs that could be translated, “Where do you live?” One version means, “Where are you currently living?” (WHERE-LIVE-YOU?) and another means,

“What residential school did you attend?” (WHERE-FROM-YOU?) (see Padden and Humphries, *Learning 7*). In this sense, Deaf identity is linked as intimately to the sites of instruction as the site of local habitation.

Michael Bérubé has provided a case study of how disability exfoliates within multiple locations and discourses. *Life as We Know It* is a memoir of his son Jamie, who was born with Down syndrome, a chromosomal imbalance in the fetus that leads to delayed mental and physical growth. Bérubé surveys the ethical and philosophical challenges raised by forgoing amniocentesis and chancing the birth of a child with what are usually described as “birth defects.” The primary question he asks is “defects” for whom and by what definition? Answering this question turns out to engage major bioethical problems of the current period. When they became pregnant, Bérubé and his wife, Janet, decided against prenatal screening, believing that it is an “invasive procedure that would only ‘catch’ things we didn’t think we wanted caught, and that might induce a miscarriage to boot” (46). Jamie’s birth and early life were admittedly difficult, but, as the book chronicles, he gradually emerges into a curious, funny, and engaging four-year-old child. His parents’ obvious pleasure in Jamie and their acceptance of his idiosyncrasies challenge easy ethical choices around “pro-choice” and “pro-life” positions, although the passage between these Manichaeian poles is fraught.

The memoir is also a bioethical study of social attitudes about persons variously labeled “mongoloid idiots” or “retards” as well as the more benign “special needs” or “differently abled” children. Such labeling becomes as much a part of Down syndrome as the undivided twenty-first chromosome that is its genetic cause since it marks in advance what procedures will be considered inevitable for parents. As Bérubé observes, “[After] Jamie had been in the ICU for two weeks or so, he started becoming a narrative” (40). He is referring to the daily reports on Jamie’s development that he delivers to friends and relatives, but he is also referring to his child’s status as a medicalized entity, subject to stories around which parental choices and public policy are made. Bérubé recounts how difficult it would have been if, upon receiving the results of amniocentesis, he and his wife had been told that their baby would “never be able to live a ‘normal’ life” or that he would never be a “conscious being, never learn to talk, read or recognize his parents,” the sorts of things that parents have historically been told about Down’s children (47). Such attitudes from

medical professionals often leave parents with few alternatives to abortion. The fact that Bérubé is writing his memoir some years after Jamie has been born at a moment when the (now) four-year-old boy does talk, does read, and does recognize his parents makes this book a cautionary tale about the wonders of genetic engineering.

Among the narratives that Berube wants to redirect is the American individualist version that says that having a “defective” child is a form of narcissism, that bringing a “less than normal child” into the world is a social burden. He worries about a functionalist society that bases childbearing decisions on eugenicist ideas about nontraditional fetuses combined with cost-accounting criteria. But he is no less critical of pro-life constituencies who lump all matters of childbirth into a single, all-purpose definition of “life” without making distinctions around who best to define that life. Social libertarians and conservatives who oppose special programs, parental leave laws, and school lunch programs may be willing to defend the rights of the unborn, but they pay little heed to life beyond the womb. Bérubé feels that his decision not to have prenatal testing in no way contradicts his and his wife’s pro-choice beliefs but is, in fact, an extension of them insofar as both are based on a woman’s right to control what happens to her body (46).

As Bérubé makes clear, issues like abortion or neonatal testing are a matter of framing. If the case is defined in terms of the state’s ability to override a woman’s right to choose, then the issue is about the right to privacy protected by legal precedent. This means something very different than if the case is framed in terms of whether a woman has a right to kill an unborn child. As the Genome Project nears its goal of mapping the DNA of every individual, the question of framing becomes all the more significant as we debate the pros of biological engineering against the cons of biological determinism and neo Eugenics.

A similar debate is already occurring within the Deaf community over the use of cochlear implants. These electronic devices are surgically implanted in the brain where they stimulate the cochlear nerve to receive certain sounds that have been sent by a transmitter located in the ear. While they do not restore full hearing, cochlear implants do permit a spectrum of sounds to be recognizable, permitting persons who become deaf later in life to retain a degree of connection to hearing friends and family. Persons with hereditary deafness, however, do not fare as well. They have fewer

nerve cells in the cochlea and thus receive fewer auditory signals, thereby limiting the effectiveness of the implant.²⁵ Harlan Lane describes a series of tests performed on deaf children before and after implantation showing that ability to recognize words improved only slightly and that deaf children wearing hearing aids fared better than those wearing the cochlear implant (220). In order to channel novel sounds into recognizable words, an extensive regime of speech therapy and training must follow surgery, posing, as Carol Padden and Tom Humphreys have observed, an ominous return to the days of oralist education if such therapies are predicated on prohibitions against signing (*Inside Deaf Culture* 168).²⁶

The documentary film *Sound and Fury* attempts to provide a balanced overview of both sides in the debate and illustrates the importance of considering the role of space in disability. It explores the fears expressed by many Deaf people that the implant poses a kind of technological genocide designed to eliminate Deaf culture altogether. *Sound and Fury* shows the lives of two Long Island families in which genetic deafness extends across several generations. When the hearing son, Chris Artinian, decides to have cochlear surgery for his deaf son, his deaf brother, Peter, is profoundly upset at what he interprets as his sibling's rejection of Deaf culture and family. For the hearing brother and his wife, the decision to have surgery for their child is self-evident; why wouldn't they want their son to hear? Why would anyone, given the opportunity, choose to remain deaf? Their strident arguments in favor of surgery are accompanied by a more troubling condescension toward their deaf parents and toward deaf people in general.

Despite his anger over his brother's unqualified endorsement of the hearing world, Peter and his wife, Mari, contemplate a cochlear implant for their deaf daughter, Heather, when she tells them that she wants one in order to participate with other hearing children. Peter and Mari consult a number of families with children who have had the surgery, but they see how antipathetic the hearing world is to deaf children and how qualified the results of the device are. They also worry that their daughter will live in a cochlear implant limbo, neither a full member of Deaf world, nor of the hearing world either. They also visit an oralist school in which neither Deaf culture nor ASL are mentioned as a component of deaf experience. As a result of these forays into a hearing world, they decide against implantation and move to another city where there is a larger deaf commu-

nity and a more extensive network of deaf schools and social services. Although the two brothers deal with their deaf children in opposite ways, the rift that the film exposes between the two families goes beyond deafness to issues of family and community.

In terms of my concern with the location of disability, *Sound and Fury* suggests that cultural deafness is very much a matter of class, generation, and education. The deaf parents of the sons are fiercely protective of their Deaf heritage and cannot understand why anyone would want to perform an operation that is both physically invasive and culturally destructive; they experience the operation as a personal rejection of them and the extensive network of deaf families that we meet in the course of the film. They are clearly less affluent and less educated than either of their sons, relying on cultural traditions and heritage as hedges against what they see as cultural suicide. Their more affluent, hearing son and wife see their parents' culturalist definitions as outmoded and think of the cochlear implant as a sign of forward-looking progress, an opportunity to utilize technology to integrate their daughter into the hearing world. What is most interesting, however, is that their deaf son has moved firmly into the middle class and has a managerial job, permitting him a degree of movement between hearing worlds (his colleagues are hearing) and deaf culture. The two sons must negotiate a complex set of responsibilities to their children, their class affiliations, and their parents.

These two examples suggest that the local conditions that produce Down syndrome or deafness are profoundly linked to social attitudes that are reinforced and naturalized by medical science, genetic engineering, and media. For disability studies to study disability adequately, it must situate a physical or cognitive impairment in a landscape larger than either the individual or the impairment. The ADA defines a disability as something that "limits one or more major life activities," which, of course, means defining in what environment such activity occurs. Recent challenges to the ADA have been fought precisely over whether a person with a correctable disability can claim redress under the law—whether a pilot who wears glasses can sue for being denied an opportunity to fly or whether a person with repetitive stress injury who can do some household chores is therefore ineligible for damages because she cannot work on a factory assembly line. Such examples suggest that defining disability will always include the place where disability becomes visible.

Living in the Hurricane

What we might conclude from the preceding discussion of sight, site, and space is the idea that disability is a matter of barriers, both physical and attitudinal, that prevent an individual with an impairment from participating in all forms of social life. But as my example of Ravel's Concerto in D suggests, those barriers may be as culturally productive as they are socially limiting. Political movements and aesthetic innovation that emerge in response to sexual or racial difference may be motivated all the more for what they *fail* to recuperate, for what they *refuse* to resolve. When the deaf performance artist Aaron Williamson was asked by a student, "When did you lose your hearing," he responded: "I choose not to say when I *lost* my hearing but rather when I *gained* my deafness; everything I do as a performer begins with that."²⁷ A disability politics needs to respect such choices and remain cautious about substituting for the impaired or deaf body a hypostatized healthy or hearing body that, were it not for social barriers, could serve as the horizon of identity.²⁸ The concerto that Ravel created for Paul Wittgenstein is significantly different from *Bolero* (some might say, for the better), just as Beethoven's late quartets, written while the composer was becoming deaf, pushed harmonies and rhythms into levels unimaginable in the age of Mozart and Haydn. One might say that Beethoven "triumphed" over adversity, but a disability perspective might add that adversity made the Grosse Fugue possible.

While I have described the defamiliarizing effects of disability on cultural objects and genres, I realize that such a formulation presumes that there is a "familiar" body that must be validated, a "young, married, white, urban, northern, heterosexual, Protestant father of college education, fully employed, of good complexion, weight and height, and a recent record in sports," as Erving Goffman famously described him (128). Such a figure is a necessary fiction in the enforcement of normalcy. Hence, one of the key tasks of disability studies is to take the ordinary out of ordinary language, the familiar out of defamiliarization, the ability out of disability in order to understand the essentialist and ableist core to our definitions of difference. Instead of insisting on a common humanity and a healthy body as a default to difference, what about making *alterity* a position from which to develop an imagined community?

The familiar was not long ago dominated by sights of devastation

caused by Hurricane Katrina, the floods, fires, social displacement, and death that lay in its wake, the city of New Orleans transformed into a wasteland of abandoned, flooded houses and stranded refrigerators at the curb's edge. The media rightly focused attention on the fact that the population most affected in New Orleans and surrounding areas was, by and large, poor and black. Images of angry African Americans yelling at FEMA representatives, children and women looting stores, bloated bodies floating in flooded streets, black families hauling belongings in shopping carts—such graphic images are being compared to those in a third-world country. And indeed, the comparison reminds us of what social critics have been saying for a long time about the decline of social programs in favor of market-driven alternatives to everything from education to health care to infrastructure repair, to the ongoing war in the Middle East. If Katrina was a natural disaster “waiting to happen,” as the experts say, the anticipated destruction of social levees like Social Security and Medicare are political disasters awaiting the aging baby boom generation.

Often unmentioned among the images coming from New Orleans are those of white *and* black people in wheelchairs, lying unattended on gurneys in hospitals, breathing through ventilators pumped by hand, dying from lack of pure water for dialysis, resting on crutches in food lines. Persons with disabilities who were trapped in the World Trade Center on 9/11 or those who drowned in their houses in New Orleans's Ninth Ward are protected by the most comprehensive disability law in the world, but the access guaranteed by the ADA is hardly adequate to the human and natural disasters of recent history. If our imagined national community is made strange by the eruption of an American third world into the public consciousness, it is no less defamiliarized by the sight of bodies left vulnerable to rising water and slow-moving relief efforts. Perhaps this new narrative of the United States as a third-world nation will spark a new debate about disability on a global scale, not merely as a matter of health care but as a matter of political economy and redistribution. At such a point, disability studies will no longer need to plead its case from a marginal position within cultural studies and civil rights legislation but will join the broad quilt of social movements in pursuit of truly equal access.