

# Prelude

## *The Pool*

What a curse, mobility!

—WINNIE IN SAMUEL BECKETT'S *Happy Days*

At the community pool where I swim every day you can see Disability Nation in broad relief. Today, lanes 1 and 2 are given over to the special ed kids from the nearby middle school. They include at least one child with cerebral palsy, another who is probably autistic, others developmentally and neurologically impaired. In lane 3 Helen, who walks with braces and double canes, shares the lane with Denise, who is doing aqua exercise and whose floppy hat indicates that she is back on her chemotherapy regime. I'm sharing lane 4 with a young man I've never seen before, but when he gets out I notice that he walks with a cane, limping noticeably. The two triathletes doing sprints in lane 5 have bodies that are nontraditional by any standard. One of them, Bev, a national masters freestyle record holder, is deaf and is a fabulous lip-reader. George and his wife Faye are in lane 6, although Faye has just had hip surgery and is taking it easy. Prostheses litter the pool deck. Fins, goggles, and floats are piled at the ends of the lanes. Helen's two canes and braces are at the pool's edge; glasses cases are on the table along with George's hearing aid. I'm wearing a brightly colored earplug in my one "good" ear to protect what little hearing I have left. We're all working out, floating, diving, doing laps in our lumpy, bony, bald, flabby, hard of hearing, sight-impaired, gimpy bodies. No one is disabled. Everyone is disabled.

A swimming pool is a good place to begin thinking about the complex nature of disability—and perhaps, as Samuel Beckett’s Winnie, buried up to her waist in sand, exclaims, the “curse” of compulsory mobility. For one thing, it’s a place where bodies are on display, for better or worse. And swimming is easy on joints and cartilage, ideal exercise for persons recovering from injuries or who want to regain muscle tone after an operation. Most of the persons mentioned above probably do not think of themselves as Disabled, capital *D*, yet their wheelchair-adapted school buses, medications, handicap parking stickers, walkers, canes, and glasses are components of a vast medical-industrial complex that often defines the meaning of bodies and the limits of care. If they do not identify with the disability rights movement, they nevertheless are consumers of disability-related products and services. And because many of them qualify for support under the provisions of the Americans with Disabilities Act, they—we—live in its shade. One might say, then, that although each swimmer enjoys a degree of independence and agency at the public pool, each is dependent on material products, social agencies, and public policies that mediate between bodies and meanings that bodies assume. Hence one of the conundrums of disability studies is that it concerns an identity category often unrecognized as such by those who fall under its terms, thereby allowing others to define the category for them. The international disability rights movement, under the banner “Nothing about us without us,” has worked to reclaim and define disability as a social category that applies to everyone in the public pool.

The pool offers a Whitmanian metaphor for social inclusion and independent living, yet when that metaphor is subjected to the lived experiences and attitudes of individual swimmers, it begins to dissolve as a term for inclusion. Each of my examples poses a unique variation not only on the theme of disability but on the liberal ideal of social equality and access. The question remains, can this ideal stand the test of differently abled bodies? Can a model of independent living coincide with what Alasdair MacIntyre calls the “virtues of acknowledged dependence” that implicate everyone? (133). When the poet of *Leaves of Grass* invokes his desire for twenty-eight male bathers in section 11 of “Song of Myself,” he does so by imagining himself as a wealthy woman, peering at the young men through a curtain of her large house. Adapting this metaphoric vantage to disability, we might say that to “come out” as disabled may involve recognizing

forms of dependency and contingency that challenge our ingrained dependence on independence. We become the twenty-ninth bather by becoming someone else.

This mediated relationship to the social contract through disability has been the subject of discussion recently by philosophers and cultural critics who have redefined ethics for a wider, more diverse constituency. Alasdair MacIntyre, Martha Nussbaum, Michael Berubé, Eva Kittay, Anita Silver, and others have pointed out that ideas of justice based on a social contract seldom take disability into account. We may assent to Locke's belief in the "free, equal, and independent" individual who benefits from social intercourse, but we do so by avoiding the contingent nature of social relations. As Nussbaum points out, liberal theories of justice from Rousseau and Hume to Rawls imagine individuals departing the state of nature to contract with each other for mutual advantage. Such contractarian thinking presumes an equal status of all members and does not take into account asymmetrical, unequal levels of access posed, for example, by poverty or mental illness, or, indeed, by our connections to an animal nature. Where Rawls does acknowledge such disproportionate access, his account "must handle severe mental impairments and related disabilities as an afterthought, after the basic institutions of society are already designed" (Nussbaum 98). By imagining a two-stage approach to social justice, the first, foundational stage created by those with adequate means, and the second, created to aid those less free and independent, the idea of a universal theory of justice begins to fray. Although persons with impairments may benefit from the institutions a rational society designs, they "are not among those for whom and in reciprocity with whom society's basic institutions are structured" (98). This disjunctive relationships between a social ideal of inclusion and the absence of disabled persons in the framing of that ideal limits Rawls's Kantian model of justice.<sup>1</sup>

Although *Concerto for the Left Hand* is largely about cultural forms and disability, it begins and ends with issues of social justice to emphasize what is ultimately at stake in the enjoyment of those forms. Whether we are discussing the meaning of Tiny Tim's limp or Ahab's missing leg, or the works of disabled artists, the question of what bodies mean for a social covenant is paramount. Noting how much Rawls's definition of justice relies on ideas of social normalcy, Nussbaum poses what she calls, following Amartya Sen, a "capabilities approach" that recognizes the inherent rights

of all persons, regardless of income or property. These capabilities or “core social entitlements” include access to health, bodily integrity, ability to use one’s senses and emotions, practical reason, affiliation, play, and control over one’s environment, among others (76–78). Although this open-ended catalog of capabilities may not resemble rights as conventionally understood (it would be hard to imagine Hegel or Kant including “play” or “health” as an inalienable right), its stress on a political conception of the individual as dependent and vulnerable challenges a liberal model of social justice. For Nussbaum a rational society, based on shared rights, must imagine forms of mutuality that take into consideration impairment and disability, unequal economic status, or species membership—human relationships to animals. Nussbaum’s emphasis on cognitive and physical disabilities is important because it recognizes that although severely disabled individuals are citizens, they require “atypical social arrangements, including varieties of care, if they are to live fully integrated and productive lives” (99). As my chapter 7 suggests, universal design is an admirable goal in architecture and city planning, but it cannot easily translate to underdeveloped nations that cannot afford repairs to existing infrastructure. If Rawls hopes to create a universal theory of justice, he must account for unequal distribution of property, goods, and services.

How might a disability aesthetics intervene in such unequal distribution—not only of goods and services but of ideas and images—to imagine alternative access to the public pool? Or to invoke my title, how might a consideration of works written for a one-armed pianist resituate both music and disabled performer? Unfortunately, the most convenient terms for such consideration stress the *modification* of a norm, *adapted* to special needs, affording *compensation* for a *handicap*. What those modifications and adaptations do to the structure and, indeed, the meaning of art is seldom confronted. Throughout this book I adapt the Russian formalist idea that works of art defamiliarize routinized patterns of thought and usage to speak of the ways that disability challenges ingrained attitudes about embodiment. Rosemarie Garland Thomson notes that identity categories like “able-bodied” and “disabled” are “produced by way of legal, medical, political, cultural, and literary narratives that comprise an exclusionary discourse” (*Extraordinary Bodies* 6). As she says, the task of a critical disability studies is to problematize such categories and in the process expose the cultural logic of their production. But a critical dis-

ability perspective also attends to the impact of disability on the life course itself, the ways that physical or cognitive impairment affects everyday life practices. The presumably healthy individual who becomes paralyzed from a spinal cord injury or who undergoes chemotherapy understands how unstable terms like *healthy* and *normal* are (and how inert the body becomes within medical care). Such life-changing experiences demand a narrative that does not reduce the entire life course to the disability, one that provides a redemptive meaning for those who have *not* undergone such trauma and by the grace of some higher power (or better insurance policy) have been spared distress. A good deal of self-help literature has been written to explain how to “endure” or “triumph over” such adversity, and figures who do—Helen Keller, Christopher Reeve, Steven Hawking—are celebrated as exemplars. This ideology of ableism works in part to shore up a fragile sense of embodiment, on the one hand, and to erase the work of those who have lived with a disability all their lives or who have struggled for changes in public policy and social attitudes. Ableism also helps to reinforce a Manichaean binary that divides the world into lives worth living and those that are not, a division that has provoked an extremely shrill debate recently over physician-assisted suicide. A critical disability aesthetics defamiliarizes such entrenched binaries to offer not simply a more humanized perspective on suffering but a way of translating the materiality of the artwork, both as form and practice, into the materiality of the different body.

Lennard Davis points out that ideas of physical and cognitive normalcy are a relatively recent invention, coinciding with the rise in statistics, comparative anatomy, and racial science (see *Enforcing Normalcy* 23–49). I would add that these technologies parallel the emergence of modernist art, which, at the moment the body was being regularized and quantified, shattered ideas of sculptural integrity, single-point perspective, narrative coherence, and tonal harmony. The aesthetic values of modernism that art historians and literary scholars use to explain these changes are seen differently through a disability optic. The ocularcentrism of modernist painting is “seen” differently if we imagine it through an artist who is sight-impaired, such as the late Monet. The values of orality, rhythm, and voice in poetry “sound” differently when viewed through the works of deaf poets who use sign language. The rigorous formal athleticism of modern dance receives new meaning when accomplished through

the body of a dancer with one leg such as Homer Avila. Feminists have long argued that considerations of gender and power lie behind genre and canonicity, an observation that applies as well to works whose apprehension demands precisely what Kant said acts of aesthetic appreciation do: imagine that others are similarly moved. If we imagine that those “others” (whom Kant never specified) are moved through identification with a disabled body, then the apprehension of beauty in works of art means something rather different from disinterested appreciation. Returning the body to the aesthetic, then, becomes one of this book’s primary concerns. Returning the aesthetic to issues of bodily impairment becomes its second priority.

In *Concerto for the Left Hand I* present various frames through which disability and cultural production exchange terms, methods, and interpretations. In my introduction I define some of the key issues raised within disability studies as it moves into its second (or even third) stage of development. Among the most salient of these is the question of visibility and the various ways that disability is performed, both on the social stage of everyday life but also in artworks that utilize performance as a venue for bringing disability to the foreground. The problem of sight is also one of *site*, the spaces in which disability is defined and the multiple locations in which it occurs—from the interior of the body exposed through neonatal screening to the clinic and asylum where the medicalized body is diagnosed and rehabilitated to the art venues in which disability is displayed. By emphasizing disability as a series of locations rather than a condition or medical diagnosis, I hope to complicate its presumed location in the body and, at the same time, question social constructionist views of disability as discursively produced.

As a test case for studying the intersection of disability and cultural studies, I look in chapter 1 at the case of hemophilia during the AIDS pandemic of the 1980s. This was a time when a blood-borne disease was spread as much by discourses about sexuality and deviance as by a virus. I study two homosocial communities, gay men and hemophilic males, who became infected with HIV through pooled blood products in the early 1980s. I am interested in the ways that a chronic disease, carried in the blood, becomes a syndrome carried by homophobia and racial anxiety, a “disease of signification,” as Paula Treichler calls it. In order to understand the discursive meaning of the disease, I survey the long cultural history of the

bleeder and the threat that such figures present to U.S. national narratives from the early days of the Republic. My example of a modern text that brings these various strands together is William Faulkner's *Absalom, Absalom!*, a novel that frames blood culture through the triangulated relations between sex, race and the Caribbean as they overlap in the rural South following Reconstruction. By studying narratives about fears of racial amalgamation, I notice the degree to which national identity is linked to fears of shared blood and bodily fluids.

The relationship between disabled and queer bodies forms the basis of chapter 2, which looks at representations of disability in film noir of the late 1940s and 1950s. In films such as *Double Indemnity* or *The Lady from Shanghai* or *Walk on the Wild Side*, a figure with a disability often displaces the representation of homosexual or lesbian relationships that must be contained or monitored. My concern here is not only to understand disability as a prosthesis for the film's narrative of sexual normalcy but to show the historical specificity of this prosthetic function in relation to cold war anxieties about bodies in general. At the same time, I want to survey the limits of feminist film theory's psychoanalytic treatment of film noir through its study of the male gaze. I see the emphasis on psychoanalytic models of castration anxiety among male viewers as drawing on disability as "lack" or "absence" that links woman as object with impairment as bodily limit.

In chapters 3 and 4, I focus on deaf poets and the challenge that American Sign Language (ASL) poses for traditional theories of poetics. In the first of these chapters, I diagnose the "scandal of speech" when it appears in the work of poets for whom the use of vocalization or English translation is often considered a violation of culturally Deaf positions. The tendency among many ASL poets to repudiate English translation as a residual sign of hegemonic oralism is modified in the work of Peter Cook and Kenny Lerner (the Flying Words Project), the British performance artist Aaron Williamson, and Joseph Grigely, an artist and critical theorist. In their work, the eruption of speech into works that deal critically with the position of the Deaf person in hearing society appears not as a concession to that culture but as a critique of its assumption about the authority of orality.

In chapter 4 I continue this investigation of signed poetry, this time by looking at the ways it resites the ocular character of much modernist liter-

ature. As in chapter 3, I am interested in the ways that ASL poetry utilizes its site-specific character and visual features to “signify” (in the sense used by Henry Louis Gates) *on* sight but also upon the spaces and places in which deaf persons have formed communities. In the Flying Words Project’s whimsical variations on Ezra Pound’s use of Ernest Fenollosa’s essay on the Chinese written character I see a paradigm for ways that deaf poets intervene into ocularcentric features of modernist poetry. Then through readings of poems by Clayton Valli and Patrick Graybill, I look at the ways that ASL poets use manual signing to represent and “contain” voice and, at the same time, foreground the bicultural nature of many deaf families.

My focus on poetry and poetics continues in chapter 5 with a study of Larry Eigner, a poet who contracted cerebral palsy at birth and who lived with severe mobility impairment throughout a long and productive literary life. My title, “Missing Larry,” refers to Eigner’s absence from critical accounts of the New American Poetry, despite his importance for the generation that includes Allen Ginsberg, Robert Duncan, and Robert Creeley. The title also refers to the avoidance of cerebral palsy in treatments of his work, thus replicating a new critical tendency to read his work as if his precise observations of his surroundings are not connected to his physical condition. Because Eigner himself seldom mentioned his disability during his lifetime, he poses a test case for thinking about impairment when it is not represented. At the end the chapter, I focus on an unpublished sequence of poems dealing with the Nazi Holocaust that integrate Eigner’s position as disabled with his cultural identity as a Jew.

In chapter 6 I continue my exploration of ocularcentrism, this time to investigate the work of blind photographers such as Alice Wingwall, Evgen Bavcar, and Derek Jarman. Their work asks us to question our assumptions about the function of museums and other sites of display when we place the work of sight-impaired artists in them. This question has been the focus of a number of recent exhibitions and symposia dealing with the implications of accommodating blind viewers in museums, but it is a topic that immediately is raised when we consider artists who work in that most visual of media. In the work of Slovenian photographer Evgen Bavcar, oneiric, brightly lit images engage philosophical issues around sightedness and memory, ocular distance and personal signature. In Derek Jarman’s last film, *Blue*, the artist creates a work that consists entirely of a blue screen with a voice-over, a gesture that places the viewer in the direc-

tor's position as someone who lost his sight due to complications of AIDS. By refusing to provide images of AIDS but rather the blank space that AIDS creates, Jarman implicitly criticizes attempts during the 1980s by photographers and journalists to represent the pandemic via images of emaciated, wasting gay bodies. By *not* providing an image, curiously, he imagines alternative—even restorative—lessons to be learned by non-sightedness.

Chapter 7 studies, as its subtitle suggests, the work of disability in a global context. Disability studies has largely been developed in first world countries and academic venues, while the preponderance of disabled persons live in the underdeveloped “majority world” and where access to adequate health care, clean water, and medicine is inadequate or nonexistent. Economic globalization has proposed numerous solutions to this problem, but many of them are founded on restrictive, neoliberal policies for development. Structural adjustment and debt relief proposed by the World Bank or the International Monetary Fund often curtail public sector aid, education, and medical assistance that such relief was designed to address. One function of this chapter is to ask what a disability studies perspective might bring to the debates about global economics. Another issue the chapter raises is what happens to disability studies if we look at the subject globally. To what extent are methods and issues surrounding disability raised in developed countries applicable to cultures with different attitudes toward medicine, religion, health, and the body? To deal with some of these questions, I look at the films of Senegalese film director Diop Mambety and theater for development “edutainment” projects in Africa concerning AIDS education—to show the ways that the invisible form of globalization is being represented in specific sites and spaces.

My final chapter extends this concern with transnational disability by looking at one of the chief narrative tropes through which globalization is being seen: the international trade in body parts. In a number of recent films and novels, the specter of the body as a commodity sold on the black market by unscrupulous dealers and doctors has become the cultural dominant of a globalized economy. Stephen Frears's film *Dirty Pretty Things*, Manjula Padmanabhan's play *Harvest*, and the novels *Never Let Me Go*, by Kazuo Ishiguro, and *Almanac of the Dead*, by Leslie Marmon Silko, are among numerous recent works in which the illegal trade in organs is a primary issue. Although this narrative has not been seen as in-

volving disability, it joins with a larger medical ethical debate about bodily integrity and vulnerability in the long shadows cast by in vitro fertilization, physician-assisted suicide, and genetic engineering. So dominant has the organ sale narrative become in recent fiction that it often serves as a cultural sign of globalization itself, much as hysteria, neurasthenia, or tuberculosis served to mark the effects of industrialized society in the nineteenth century. Moreover, the organ sale narrative links disability with sexuality insofar as it revises a nineteenth-century focus, exemplified in Baudelaire and Marx, on the prostitute as the epitome of the body as commodity form. In these twentieth- and twenty-first-century narratives, the commodity is less the prostitute's body than the body as a series of replaceable parts whose commercialization epitomizes unequal economic relations between donor (seller) and recipient (purchaser).

One theme that knits many of these chapters together is embodied in the brief quote from Samuel Beckett's *Happy Days* that serves as my epigraph. The main character of the play, Winnie, is buried up to her waist in sand, and she spends her day sorting through objects in her purse, hoping—sometimes desperately—that someone is watching her. At one point she turns to watch her husband, Willie, attempt to crawl backward into his cave. Seeing his difficulty, Winnie tries to help: “The hands and knees, love, try the hands and knees. (*Pause.*) The knees! The knees! (*Pause.*) What a curse, mobility!” For the able-bodied world, mobility is the default, the position from which agency proceeds. By looking at the world from her disabled perspective, however, Winnie denaturalizes the Darwinian evolutionary imperative and substitutes interdependence as liberatory possibility. However insufficient, Winnie's “strange feeling that someone is looking at me” allows her to see beyond a condition of limited mobility. Winnie is one of many characters in Beckett's novels and plays who are, in some way, disabled. All of the characters in *Endgame* are disabled—Hamm is blind and lacks the use of his legs; Clov is crippled; Nagg and Nell have lost their limbs in an accident. They join dozens of others—Molloy, Malone, Vladimir, Estragon, and Lucky in *Waiting for Godot*, A & B in *Rough for Theater*—who are variously blind, deaf, crippled, bedridden, and while it would be easy to see their impairments as metaphors for alienation and solitude in the modern world—Heidegger's being-toward-death—we might see their codependence as a means of survival, the social contract reduced to its most naked form: two persons who sustain life by

telling stories to each other. In a world where dependence implies a hated subservience, in Beckett's work it resembles the human condition itself stripped of its humanist trappings. That Beckett chose to represent his human comedy by disabled figures who stay alive by telling stories offers a parable about the work—the practice—of disability in making normal life strange.