

Feminist Disability Studies

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Source: *Signs*, Vol. 30, No. 2 (Winter 2005), pp. 1557-1587

Published by: The University of Chicago Press

Stable URL: <https://www.jstor.org/stable/10.1086/423352>

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## Feminist Disability Studies

**Just what is feminist disability studies?** It is more than research and scholarship about women with disabilities, just as feminist scholarship extends beyond women to critically analyze the entire gender system. Like feminist studies itself, feminist disability studies is academic cultural work with a sharp political edge and a vigorous critical punch. Feminist disability studies wants to unsettle tired stereotypes about people with disabilities. It seeks to challenge our dominant assumptions about living with a disability. It situates the disability experience in the context of rights and exclusions. It aspires to retrieve dismissed voices and misrepresented experiences. It helps us understand the intricate relation between bodies and selves. It illuminates the social processes of identity formation. It aims to denaturalize disability. In short, feminist disability studies reimagines disability.

Feminism challenges the belief that femaleness is a natural form of physical and mental deficiency or constitutional unruliness. Feminist disability studies similarly questions our assumptions that disability is a flaw, lack, or excess. To do so, it defines disability broadly from a social rather than a medical perspective. Disability, it argues, is a cultural interpretation of human variation rather than an inherent inferiority, a pathology to cure, or an undesirable trait to eliminate. In other words, it finds disability's significance in interactions between bodies and their social and material environments. By probing the cultural meanings attributed to bodies that societies deem disabled, feminist disability studies does vast critical cultural work. First, it understands disability as a system of exclusions that stigmatizes human differences. Second, it uncovers communities and identities that the bodies we consider disabled have produced. Third, it reveals discriminatory attitudes and practices directed at those bodies. Fourth, it exposes disability as a social category of analysis. Fifth, it frames disability as an effect of power relations. Feminist disability studies shows that disability—similar to race and gender—is a system of representation that

I wish to thank Catherine Kudlick for helpful suggestions.

[*Signs: Journal of Women in Culture and Society* 2005, vol. 30, no. 2]

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marks bodies as subordinate, rather than an essential property of bodies that supposedly have something wrong with them.

Feminist disability studies often uses two critical practices that might seem counterintuitive. First, it tends to avoid impairment-specific or medical diagnostic categories to think about disability. Certainly, feminist disability studies acknowledges communities of people based on shared disability experience, and it recognizes the differences among the wide variety of stigmatized forms of embodiment that constitute disability in its broadest conceptualization—from blindness to intersex to dyslexia, for instance. Nevertheless, it focuses on examining the patterns of meaning attributed to those bodies rather than specific forms, functions, and behaviors. Feminist disability studies scrutinizes how people with a wide range of physical, mental, and emotional differences are collectively imagined as defective and excluded from an equal place in the social order. Social categories parallel to “disabled,” such as “people of color” or “queer,” also embrace a wide range of varying physical characteristics, identities, and subjective experiences, even while they risk flattening significant differences. Such social—rather than biological—labels accurately capture the single, reductive, exclusionary social category that conflates and stigmatizes a range of differences according to a subordinating discourse. Similarly, disability brings together traits that may have little in common in order to create a social class of people designated as defective and politically, economically, and socially discriminated against. Thus, people with chronic or acute illnesses, appearance impairments such as birthmarks or fatness, traumatic injuries, congenital impairments or anomalies, sensory impairments, latent conditions such as HIV or hereditary conditions, learning disabilities, and mental, developmental, or emotional illnesses are grouped together under the medical-scientific rubric of abnormality and its accompanying cultural sentence of inferiority. This process of interpellation and its material consequences are the major critical concerns of feminist disability studies.

Second, feminist disability studies questions our assumptions by using precise language that may seem convoluted when talking about disability. I use phrases such as “the traits we think of as disability,” for example, rather than words like “deformities” or “abnormalities.” We say things like “bodies that violate the normative standards and expectations of bodily form and function” not to obfuscate but rather to clarify by insisting that readers do not fall back on essentialist definitions of disability as inferior embodiment. Sometimes it is important to say “people who identify as disabled” or “people who identify as nondisabled” or even “people who are considered disabled” to make clear the important difference between bodies themselves and the ascribed or achieved identities attached to them

in social relations and cultural representations. This language calls attention to the hidden norm that lurks behind our understandings of disability, one that makes some bodies seem naturally deficient or excessive and others seem superior. In addition, language about “figuring” and “representing” or “narratives” can dislodge the pervasive negative notions we all learn about disability and shake up our assumptions about what constitutes happiness, attractiveness, suffering, dignity, or a livable existence. Feminist disability studies thus reveals both the cultural work and the limits of language.

Disability proves to be an especially useful critical category in three particular concerns of current feminist theory. First is probing identity; second is theorizing intersectionality; third is investigating embodiment. Feminism questioned the coherence, boundaries, and exclusions of the term *woman*—the very category on which it seemed to depend. Consequently, it expanded its lexicon beyond gender differences to include the many inflections of identity that produce multiple subjectivities and subject positions. Our most sophisticated feminist analyses illuminate how gender interlocks with the race, ethnicity, sexuality, and class systems. This focus on how identity operates prompted an interest in the relation between bodies and identity. As a category of analysis, disability provides fresh ways of thinking about the complexity of embodied identity. Feminist disability studies defines disability as a vector of socially constructed identity and a form of embodiment that interacts with both the material and the social environments. Considering disability sheds light on such feminist concerns as the politics of appearance, the ethics of selective abortion and genetic testing, the relation between femininity and embodiment, the commercialization of health and fitness, issues of caretaking and caregiving, the surgical normalization of bodies, the ideology of normalcy, reproductive rights and responsibilities, the stigmatizing of age, and the politics of access and inclusion. Feminist disability studies questions the dominant premises that cast disability as a bodily problem to be addressed by normalization procedures rather than as a socially constructed identity and a representational system similar to gender.

All the works discussed here interrogate the category of disability in ways that parallel feminist challenges to patriarchal assumptions about gender. My aim is to register, sort, and organize this work, reaching back through more or less the last ten years. To varying degrees, each of the citations gathered here unsettles the way our collective consciousness frames disability and being disabled. Rather than attempting a comprehensive review of work on women and disability, I have selected representative books, recent critical articles, and special issues of leading journals

that most trenchantly address feminist disability studies' central critical points. While most of the extensive work on women's health issues criticizes patriarchal structures and social inequality, what I am claiming here as feminist disability studies undertakes a deeper critique that problematizes and politicizes ideological concepts such as health, disease, normalcy, cure, and treatment. I have included only a sample of women's life-writing on illness and impairment, which is an important topic for another review essay. The studies here marshal the critical tools that can reshape teaching, research, and scholarship about gender.

I have organized this selected body of critical and creative work into the broad categories of retrievals, reimaginings, and rethinkings. Within those headings are additional groupings to provide coherence to a large and diverse selection of work. Because I have quite intentionally cast a very broad net here to suggest the diversity of what counts as disability and as feminist, my analysis of each individual work is brief. My aim is to provide readers with a sense of how pervasive a presence disability is in cultural discourse, once one knows how to look for it.

## Retrievals

### ***Narrative retrievals***

Feminist theory's recent concern with multiple identities emphasizes the diversity of women's voices, standpoints, and experiences—including those of women with disabilities. This project of narrative recuperation has yielded several anthologies of writings by women with disabilities that follow the generic conventions of such collections. Although these volumes are not scholarly analyses, they nevertheless offer underrepresented perspectives for women's studies courses. The immediacy of personal narrative conveys disabled women's distinct perspectives on sexuality, reproductive issues, appearance biases, and other shared struggles. *No More Stares*, edited in 1982 by Ann Cupolo Carrillo, Katherine Corbett, and Victoria Lewis—now out of print—is an early and powerful feminist telling of disabled women's stories as a form of self-advocacy, role modeling, and disability pride. The in-your-face politics of *No More Stares* gave way in the mid-1980s and early 1990s to personal testimonies such as *Voices from the Shadows: Women with Disabilities Speak Out* (Matthews 1983), a series of interviews with Canadian disabled women; *Women with Disabilities: Found Voices* (Willmuth and Holcomb 1993), a collection of essays focusing on psychology; and *With the Power of Each Breath: A Disabled Women's Anthology* (Browne, Connors, and Stern 1985), a blend of statistical studies, personal narratives, epistolary essays, interviews, and poetry

on identity, community, anger, parenting, and body acceptance. All these collections are more valuable for the perspectives they convey than their literary merit.

A more belletristic collection is *With Wings: An Anthology of Literature by and about Women with Disabilities*, edited in 1987 by disabled activist Marsha Saxton and by Florence Howe under the imprimatur of Howe's Feminist Press. Composed of poetry and autobiography, this volume both retrieves and recruits. What I call recruitment is the strategy of finding and claiming work that is not explicitly announced as being about disability or that is not authored by women who identify as disabled but that nevertheless captures disability experience. *With Wings*, for example, recruits canonical feminist authors with disabilities, such as Adrienne Rich, Muriel Rukeyser, Alice Walker, and Mary Wilkins Freeman, placing them alongside lesser-known disabled activists, writers, and academics. This gentle outing of disabled writers not only strengthens the canon of feminist disability writing, but it suggests that even though the experience of disability is almost universal, disability identity goes unclaimed by and un-ascribed to accomplished people. Because the identity "disabled" acts as a disqualifier, it is often not associated with success or competence. Thus, claiming authors such as Adrienne Rich as disabled feminist writers becomes a significant political move that anthologies can make.

Several anthologies of disability writing by both men and women can be counted as feminist because they challenge normative perspectives. One is an uneven but pedagogically useful collection with the terrific title *Staring Back: The Disability Experience from the Inside Out*, edited by Kenny Fries in 1997. This volume contributes to disability canon formation by recruiting established authors such as Rich, Marilyn Hacker, Lucy Grealy, Andre Dubus, John Hockenberry, and Ved Mehta—all writers with disabilities. These authors lend authority to lesser known disabled writers such as Anne Finger, Terry Galloway, Victoria Ann Lewis, Nancy Mairs, and Susan Nussbaum.

Two collections of Deaf writing represent the voluminous work by the Deaf community, whose indigenous language is American Sign Language (ASL).<sup>1</sup> Because English is often a foreign or second language to Deaf people, these writers have an adversarial relationship with written English or any spoken language. As linguistic outsiders, whether they use ASL or struggle with speaking, Deaf writers often provide a unique critical per-

<sup>1</sup> Another collection of Deaf writing is Bragg 2001. "Deaf" with a capital "D" indicates a cultural and linguistically distinct identity, whereas "deaf" is a description of physical hearing loss.

spective. The 1992 anthology *No Walls of Stone: An Anthology of Literature by Deaf and Hard of Hearing Writers*, edited by Jill Jepson, collects contemporary poetry and prose by several Deaf women writers. *A Mighty Change: An Anthology of Deaf American Writing, 1816–1864*, edited in 2000 by Deaf studies scholar Christopher Krentz, gathers for the first time Deaf writers from the nineteenth century. One of two women writers included is Adele Jewel, a homeless deaf woman who sold her brief autobiography on the antebellum streets to support herself. Jepson's anthology exemplifies literary retrievals, while Krentz's represents historical recoveries. Both open up an often overlooked world to the dominant hearing culture.

### **Scholarly retrievals**

Historians, literary scholars, and theater critics are recovering unnoticed or lost histories and probing cultural representations of women with disabilities. Much new work, for example, reexamines renowned figures such as Helen Keller from a disability identity perspective, trying to pry loose such icons from the stereotypical scripts that limit how we understand the lives and politics of women with disabilities. For example, in *The Radical Lives of Helen Keller*, historian Kim E. Nielsen (2003) revisits Keller's progressive radical politics. Nielsen argues that Keller's political views were informed by a disability perspective but that this fact was stifled by over-determined sentimental portrayals of Keller as the courageous deaf-blind girl.

Other scholarly studies recover histories of disabled individuals or groups. Two recent books stand out as particularly effective examples. First is *Reflections: The Life and Writings of a Young Blind Woman in Post-revolutionary France*, written by the resourceful and ardent twenty-two-year-old blind novelist Thérèse-Adèle Husson ([1825] 2001). Adroitly researched, presented, and translated by Catherine J. Kudlick and Zina Weygand, this volume is a historical and narrative gem in the tradition of "lost" African-American texts such as Harriet Jacobs's *Incidents in the Life of a Slave Girl* ([1861] 1988). This critical genre demonstrates that the seeming historical silence of women is an effect of sexism. Like Jacobs's emancipation narrative, *Reflections* is a rhetorical feat that witnesses the dignity of a disenfranchised group while simultaneously overturning the dominant order's oppressive views of that group. Addressed to a sighted audience whose resources Husson desperately needs, this commanding manifesto advocates independence and education for blind people. Like Jacobs, Husson eschews the marriage plot, recognizing that what the

multiply disenfranchised need is economic and political inclusion rather than conformity to traditional gender scripts.

A second exemplary historical retrieval is Emily K. Abel's study, *Hearts of Wisdom: American Women Caring for Kin, 1850–1940* (2000). This history of American women's caregiving mounts a disability critique against the ideology of autonomy that casts people with disabilities as helpless foils to the supposedly independent, ruggedly masculine figure that Western individualism vaunts as its ideal. Feminist disability studies enters the controversy about whether feminists should celebrate or be liberated from the ethic of care by accentuating the perspective of the receiver of care and the potential for asymmetry in relationships of caring. Abel frames the history of care as a cultural benefit for women rather than as exploitation. She discusses maternal advocacy for children labeled as mentally defective and for Deaf children, highlighting mothers' resistance to oppressive authorities who would devalue their children. Abel avoids romanticizing caring, recognizing the limits of this maternal support in the face of both internalized and imposed cultural prejudices against disability.

*The New Disability History: American Perspectives*, a collection of essays edited by Paul Longmore and Lauri Umansky (2001b), offers an exceptionally incisive introduction (2001a) that lays out major issues and perspectives in disability history and illuminates the parallels between the development of disability history and U.S. women's history.<sup>2</sup> The volume's leading chapter, "Disability and the Justification of Inequality in American History," by Douglas C. Baynton (2001), exemplifies the feminist method of intersectional analysis. Baynton shows how the concept of disability has repeatedly been used to argue both for and against unequal treatment of women and people of color. This work illustrates the ways in which the categories of disability, gender, and race intertwine and inflect one another in such major U.S. historical discourses as slavery, abolition, immigration, and suffrage.

Whereas historians retrieve voices and figures of disabled women from the past, literary critics examine both familiar and obscure textual representations of women with disabilities. Such investigations extend and deepen earlier images of women. Female biology and feminine ideology have both traditionally been interpreted as forms of disability in Western culture. Aristotle, after all, pronounced women to be "mutilated males"

<sup>2</sup> Other historical studies on disability are Ott, Serlin, and Mihm 2002 and Rose 2003. For a review essay on other disability history books, see Kudlick 2003.



(1944, bk. 2, 175). This gendering of disability—and this disabling of gender—is being scrutinized thoroughly by feminist literary critics. One of the best examples of early feminist disability studies is Diane Price Herndl's *Invalid Women: Figuring Feminine Illness in American Fiction and Culture, 1840–1940*. Appearing in 1993, just at the time when the field of disability studies was gaining recognition in the humanities, Herndl's book does not explicitly announce itself as disability studies. Nevertheless, by retrieving the pervasive figure of the invalid to insist on the connection between the social and textual, it does the critical work of feminist disability studies. Representations of invalid women are not simply metaphors, Herndl confirms; rather, they shape how our culture understands illness, femininity, and normality.

Several studies follow Herndl in using literary critical methods to probe the semiotics of disability and the capacity of representation to construct reality. Although some of this work focuses on the textual construction of specific impairments such as blindness or deafness, disability functions as an explicit identity category and social system in these analyses. Mary Klages's study, *Woeful Afflictions: Disability and Sentimentality in Victorian America* (1999), for example, recognizes the previously unremarked centrality of the disabled figure to sentimental literature, which was perhaps the primary genre of women's writing in the nineteenth century. Klages centers on blindness, not as impairment but as the paradigmatic trope of disability in the nineteenth century, explicating Helen Keller and her predecessor Laura Bridgman as poster children, iconic objects appropriated by the empathetic self that developed during the Enlightenment.

*Fictions of Affliction: Physical Disability in Victorian Culture*, by Martha Stoddard Holmes (2004), also examines the key place of the disabled figure in the culture of sentiment, illuminating the operation of both disability and femininity in Victorian culture and its canonical texts. Holmes shows that sentimental culture instructs readers how to feel about disability. *Fictions of Affliction* is a model study that exemplifies perhaps the most important critical work of disability studies: it always approaches disability as a historical category rather than as a metaphor.<sup>3</sup>

Feminist disability studies politicizes and historicizes textual representations of disability. Indeed, this explicit connection between word and world animates all feminist scholarship. Just as critics have come to recognize that the blackness of an Othello or the madness of an Ophelia,

<sup>3</sup> For my own analysis of disability in sentimental literature, see Thomson 1997, esp. chap. 4, and 1998.

for example, goes beyond metaphor to do the cultural work of racism and sexism, so feminist disability studies understands that textual figures of disability both register and materialize social patterns of bias and exclusion based on ability norms that operate similarly to gender and racial systems. A good deal of feminist theory misses this political potential inherent in a feminist disability studies approach. The prominent interest in hybrid theoretical figures such as cyborgs, monsters, and grotesques—led by Donna Haraway, Rosi Braidotti, Susan Stewart, and Mary Russo—squanders such a critical opportunity by failing to recognize and politicize the relation between these figures and actual women with disabilities. Arrested in the theoretical and metaphorical, these figures for feminist liminality escape confronting the social meanings ascribed to the particularities of embodiment by disregarding the disability system's entanglement with the gender system. One major aim of all of my own work in both literary and feminist studies is to show that the always overdetermined metaphoric uses of disability efface and distort the lived experience of people with disabilities, evacuating the political significances of our lives and mitigating the influence of disability culture.

An exemplary recent collection counters such tendencies to generalize the body that is theorized. *"Defects": Engendering the Modern Body*, edited by Helen Deutsch and Felicity Nussbaum (2000), focuses on the eighteenth century as the historical point at which the modern conception of disability emerges. This volume collectively argues that the cultural meanings of ideological concepts such as "defect," "monstrosity," and "deformity"—all variations of disability and entangled with notions of gender and race—shift as a modern concept of self emerges from early modern and Enlightenment thinking. Rigorous historical accountability, coupled with critical methods such as close readings of literary and cultural texts, yields nuanced analyses of the intersectional alliances among femininity, coloredness, and monstrosity. The volume shows that the monstrous and deformed are antecedents to modern notions of race and are paradigms for understanding sexual and racial differences as well as ugliness and beauty.

Also in the area of literary studies, the Modern Language Association has recently brought out a wide-ranging volume of critical essays called *Disability Studies: Enabling the Humanities* (Snyder, Brueggemann, and Garland-Thomson 2002), which serves as a good introduction to disability studies in a women's studies context. Suitable for graduate and undergraduate teaching in the humanities, this collection includes chapters on topics such as the politics of breast prostheses, disabled fashion models, a spiritual autobiography of a fifteenth-century deaf and disabled Castilian

nun, disabled women's sexuality, the question of so-called physician-assisted suicide, Victorian fiction's use of the twin structure in which one twin is nondisabled and one is disabled, and the radical potential of a queer disability studies.<sup>4</sup> This volume fully integrates feminist disability studies into its contents and critical perspective.

*Disability and Contemporary Performance: Bodies on the Edge*, by Petra Kupperts (2003), offers an excellent introduction to the performance of disability. Kupperts points out that the monstrous and freakish have provided the conventions of disability performance. The book focuses on the place of the disabled body as both spectacle and subject in medical theater, disability dance, trauma theory, and community artwork produced in mental health settings. Firmly linking embodiment and representation, Kupperts addresses the central question in identity studies: that is, how to trouble the identity category "disabled" without evacuating it as a position of communal endeavor and identity politics.

Rachel Adams's study, *Sideshow U.S.A.: Freaks and the American Cultural Imagination* (2001), urges as well an explicit relation between cultural tropes and material conditions. Adams's study recognizes that freak shows are the literal performance of disability as well as part of the labor history of people with disabilities. Adams's book is careful always to denaturalize freaks, insisting on the humanity and materiality of her subjects. Thus she politicizes the social identities of people such as the contemporary bearded lady, Jennifer Miller, as people with disabilities rather than appropriating them as metaphorical figures.<sup>5</sup>

Collectively, these historical and literary retrievals characterize what I take to be the unique strengths of a vibrant feminist disability studies. They theorize identity not as essential but as a product of a complex and intersecting social construction that has profound political implications. At the same time, these retrievals scrupulously address the materiality of bodies firmly embedded in the contexts of their environment and their history. The feminist theoretical concerns of representation, embodiment, identity, and intersectionality are thus elaborated in fresh ways by feminist disability studies.

<sup>4</sup> For a thorough examination of physician-assisted suicide, see Battin, Rhodes, and Silvers 1998.

<sup>5</sup> For more on disability and freak shows, see Thomson 1996, 1997, esp. chap. 10, 1998, 1999.

### Reimaginings

Feminist disability studies not only retrieves overlooked experiences and undertheorized critical perspectives, it strives to rewrite oppressive social scripts. The stories we collectively know shape the material world, inform human relations, and mold our sense of who we are. Because prevailing narratives constrict disability's complexities, they not only restrict the lives and govern the bodies of people we think of as disabled, but they limit the imaginations of those who think of themselves as nondisabled. Stereotypical, often unexamined narratives ultimately undergird exclusionary environments, employment discrimination, and social marginalization.

Women with disabilities, even more intensely than women in general, have been cast in the collective cultural imagination as inferior, lacking, excessive, incapable, unfit, and useless. In contrast to normatively feminine women, women with disabilities are often stereotypically considered undesirable, asexual, and unsuitable as parents. Disability life-writing repeatedly attests that adjusting to an acquired impairment is not as difficult as adjusting to the stigmatization and lowered social status that comes from moving into the community of the disabled. Virulent biases and negative associations discourage one from identifying as disabled. Accomplished women who have physical, mental, or psychological impairments not infrequently flee the category, sometimes proclaiming proudly that they are not "disabled." Nevertheless, a positive identity politics for women with disabilities is nascent, even though not as developed as the early black-is-beautiful racial politics, cultural feminism, or the more recent queer pride movement.

Tearing down such attitudinal barriers is one of feminist disability studies' aims. Consequently, interpreting disability as human variation rather than essential inferiority is one of its most fully developed critical strategies. Reinterpreting disability involves not only working toward ending disability discrimination but also formulating a logic that allows people to claim the identity of disabled without having to conceive of it as a diminishment of the self. To this end, much feminist disability studies centers on revising cultural narratives.

The available, received cultural narratives of disability—similar to those of the gender and race systems—are prejudicial, oppressive, and disempowering. Five narratives of disability dominate our collective understanding of disability. First is the biomedical narrative that casts the variations we think of as impairment as physiological failures or flaws, as medical crises that demand normalization through technology or other allopathic measures. Second is the sentimental narrative that sees people with dis-

abilities as occasions for narcissistic pity or lessons in suffering for those who imagine themselves as nondisabled. Third is the narrative of overcoming that defines disability as a personal defect that must be compensated for rather than as the inevitable transformation of the body that results from encounters with the environment. Fourth is the narrative of catastrophe that presents disability as a dramatic, exceptional extremity that either incites courage or defeats a person. Fifth is the narrative of abjection that identifies disability as that which one can and must avoid at all costs. Seldom do we see disability presented as an integral part of one's embodiment, character, life, and way of relating to the world. Even less often do we see disability presented as part of the spectrum of human variation, the particularization of individual bodies, or the materialization of an individual body's history. Instead we learn to understand disability as something that is wrong with someone, as an exceptional and escapable calamity rather than as what is perhaps the most universal of human experiences. After all, if we live long enough, we will all become disabled. A feminist disability perspective suggests that we are better off learning to accommodate disabilities, appreciate disabled lives, and create a more equitable environment than trying to eliminate disability.

In one of disability studies' germinal critical works, *The Disabled God: Toward a Liberatory Theology of Disability*, theologian and sociologist Nancy L. Eiesland (1994) calls for a reimagining of disability through the powerful cultural tool of religious iconography. Eiesland asserts that the way we imagine disability and disabled people must shift in order for real social justice to occur. In addition to requiring legislative, economic, and social changes, achieving equality for people with disabilities requires what she terms *resymbolization* (98). Pointing to the paradox that Jesus, the central religious figure of Western culture, is portrayed as disabled while actual people with disabilities are often devalued and excluded from Christian communities, Eiesland urges Christian narrative to resymbolize disability through the "liberatory realism" of acknowledging disability as the human condition, embodied in the figure of Christ (103). Eiesland's call draws on feminist thought by interpreting the disabled god as a figure for human interdependence and mutuality of care. Such reimagining can lead to a theology that liberates both disabled and nondisabled people from the estrangement from our bodies that oppressive narratives of disability perpetuate.

### ***Situated theory***

Feminist disability studies often counters our received stories by reimagining disability. The retrievals discussed above challenge oppressive nar-

ratives primarily by exposing them to critical analysis or offering perspectives emerging from disabled experience. Several exemplary works develop what I call situated theory. These are complex, sophisticated explorations of disability issues elaborated not in the genre of the traditional critical study but rather as analyses that are thoroughly situated from the position of the disabled woman subject. Grounding theory in life-writing, these works model feminist standpoint practice at its most effective. Situated theory is not simply disability memoirs or illness narratives, both of which are growing and compelling genres that are beyond the scope of this essay. Rather, situated theory offers a feminist disability epistemology that protests the disability system. Taken together, the books I have singled out here probe most of the central issues of feminist disability studies: appearance, identity, reproduction, sexuality, genetics, passing, access, difference, stigma management, and social interaction.

Perhaps the best known and most often taught of the books I am highlighting is Lucy Grealy's lyrical and wrenching *Autobiography of a Face* (1994), a classic female bildungsroman. Grealy tells her own story of growing into womanhood with significant facial disfigurement resulting from her many surgeries to treat jaw cancer. Following the critical tradition of Audre Lorde's 1980 autobiography, *The Cancer Journals*, Grealy's text goes beyond a powerful illness narrative to become feminist disability studies as it interrogates the gendered politics of appearance and the beauty system. The appallingly painful treatments, the ghastly surgeries, the disrupted life, and the shadow of death are all less oppressive to Grealy than the relegation to "ugly" that comes from a world full of both cruel and clumsy onlookers. Her story makes clear that the limitations impairment imposes are not as disabling as the social prejudices Grealy absorbs so proficiently and naively as she forms her sense of a feminine self according to the mirroring she gets from a society devoted to narrow appearance standards and hostile to human differences. Disability discrimination, not cancer, threatens her life.

Nancy Mairs is a nationally recognized disability author whose work exemplifies situated theory as well. A maestra of the personal essay, she wields the genre with wry wit and passion. "On Being a Cripple," from her collection of essays, *Plaintext* (1986), is probably disability studies' most canonical, if somewhat reductive, meditation on the politics of self-naming. Mairs recuperates "cripple" for its transgressive power, as gay and lesbian activists have reclaimed "queer." "Cripple," Mairs declares, evokes a "wince" from those who imagine themselves as nondisabled. "As a cripple," she avers, "I swagger" (9). Much of Mairs's work enlists a narrative of catastrophe that makes for compelling reading but risks

playing into a kind of disability voyeurism that can be politically counter-productive and reinforce stereotypes of disability as unredeemed suffering.

Mairs's strongest, most overtly political collection of situated theory is *Waist-High in the World: A Life among the Nondisabled* (1996), which she irreverently considered calling "Cock-High in the World." Mairs develops most fully here what I have called a "feminist disability sitpoint theory" by articulating a perspectival account of experiencing the world from a wheelchair.<sup>6</sup> As a perhaps clunky allusion to the well-developed concept of feminist standpoint theory, my use of *sitpoint* particularizes standpoint theory to disabled women by calling attention to the normative assumption that one perceives the world from a standing rather than sitting position. Although the personal narrative that Mairs plies so poignantly is still central, an acknowledgment of group consciousness and wider sociopolitical commitments infuses *Waist-High in the World*. We still learn of the struggles to maintain dignity that disabled—and aging—women face. We see here a deep sexuality that many would deny her. We note her ambivalent relationship with appearance, a kind of sweet vanity that she is at once critical of and nostalgic about. We witness most fully in this book a profound understanding of and moving meditation about embodiment.

Another virtuosa of the personal essay as social critique is Georgina Kleege, whose *Sight Unseen* (1999b) expands on Mairs's implicit project of articulating an epistemology of disability. Ranging from blind figures to film, art, and teaching, each chapter gracefully explicates Kleege's perspective on and experience of blindness and womanhood. Scrupulously eschewing the Helen Keller genre of inspirational overcoming narrative, Kleege moves seamlessly from the personal to the political, revealing how she "became blind," punning smartly on her development of a disability consciousness and claiming of "blind" as an identity category. One of the strongest chapters (Kleege 1999a) is about the stigma-management practice of faking eye contact—which I take to be the disabled equivalent of faking orgasm, the former to feign normative sightedness, the latter to simulate normative feminine heterosexuality.

Whereas Kleege queries blindness, Brenda Jo Brueggemann interrogates deafness in *Lend Me Your Ear: Rhetorical Constructions of Deafness* (1999). Both Kleege and Brueggemann open up a critical gap between identity and biology by exploring the distinctions between the corporeal experience of being legally blind and hard of hearing, respectively, and embracing the politicized identities of Blind and Deaf. Brueggemann is particularly incisive in her elaboration of the politics of passing that those

<sup>6</sup> For an elaboration of my version of feminist disability theory, see Thomson 2002.

in between Deaf and hearing culture must negotiate. In a manner similar to Kleege's sweep of blind figures and tropes, Brueggemann reaches back through classical rhetoric's privileging of "a good man speaking well" (2) as the dominant model of eloquence, from which she ponders the position of a Deaf woman signing and writing within the rhetorical tradition. *Lend Me Your Ear* also surveys Deaf culture, introducing the rich genre of Deaf poetry—or sign poetry—much of which is produced by women. Sign poetry, a literature of presence performed in ASL, is one of the most distinctive and vibrant of the cultural products arising from disability culture.

Eli Clare's brief but eloquent *Exile and Pride: Disability, Queerness, and Liberation* (1999) is more manifesto than memoir. Clare calls on the personal experience of growing up with cerebral palsy as a sexually abused daughter in virulently homophobic rural Oregon to create a vivid portrait of outsidership reminiscent of Gloria Anzaldúa's *Borderlands* (1987). This narrative of coming into political consciousness captures the complexities of intersectional identity and the challenges of repudiating one's origins while accounting for the strengths they provided. This aching but affirmative book is at once a revelation and a sustained critique of such disability stereotypes as the super crip, the disabled figure that assures, soothes, and inspires the nondisabled. *Exile and Pride* explores the politics of naming as well, probing the ambivalent power of terms such as *freak*, *queer*, and *cripple*. What is freshest here is Clare's fusing of queer, disabled, and environmentalist activism in a reworking of ecofeminism that extends disability critique in new directions.

As Clare's impassioned narrative witnesses, one of the most vibrant areas of feminist disability studies is queer disability studies. Two anthologies from disabled lesbians have emerged recently that fall between what I call here retrievals and reimaginings. Each collection is an in-your-face, explicitly political manifesto about a queer disabled perspective. First is a Canadian collection, *Pushing the Limits: Disabled Dykes Produce Culture*, edited by Shelley Tremain (1996). This aptly titled anthology, consisting mostly of poetry, validates the "existence of disabled dykes" by addressing the cultural contradiction that lesbian is a sexual identity while disabled women are considered asexual (15). Second is *Restricted Access: Lesbians on Disability*, edited by Victoria A. Brownworth and Susan Raffo (1999). Complementing the poetry-dominated earlier collection, *Restricted Access* has a less provocative framing that addresses the important questions of what constitutes disability and access. Despite the conventional overview introduction, the prose pieces are radical in content, creating fuller narratives than the poetry makes possible. For



example, fat and disability activist, zine writer, and queer performer Nomy Lamm (1999) gives us “Private Dancer: The Evolution of a Freak,” which she begins by recounting a drag show she performs in which her partner masturbates with Lamm’s prosthetic leg, which she has removed on stage. While most of the essays are tamer, all challenge the assigned abnormality and asexuality against which disabled lesbians must struggle.<sup>7</sup>

Another use of autobiography to articulate a feminist disability perspective is *Past Due: A Story of Disability, Pregnancy, and Birth* by disability activist, feminist, and writer Anne Finger (1990). Reproductive rights take on different valences with regard to disabled women. Whereas nondisabled women must often struggle to escape the mandate of motherhood, disabled women must often battle to claim motherhood. Finger’s straightforward narrative reveals the deeply entrenched prejudice against disabled women as mothers as it probes the complexities of an activist disabled woman’s giving birth to a disabled child. As with many feminist disability memoirs, *Past Due* challenges the medicalization of bodies and birthing, countering that a sociopolitical interpretation of disability is a point of departure for feminist politics.

Alice Wexler’s *Mapping Fate: A Memoir of Family, Risk, and Genetic Research* also explores the medicalization of family relations. Her use of standpoint epistemology transforms medical history into feminist disability theory. Wexler situates this 1995 study in her own story of “the drama of families with Huntington’s disease” to reveal the intricate ethical and interpersonal dilemmas involved in genetic testing for disabling conditions (xi). Wexler critically examines how the “dream of prediction” that geneticists and families adhere to so intransigently translates into the lived experience of embodying risk status for disability (xiii). By probing sisterly entanglements, a daughter’s ambivalent genetic and emotional relation to her ill mother, and the corrosive family scripts of silence and secrecy, *Mapping Fate* narrates how the biomedical personal is political.

The politics of bioethics Wexler elaborates through memoir as medical history is expanded on in several volumes that blend situated theory with academic critical research. *Prenatal Testing and Disability Rights*, edited in 2000 by Erik Parens of the Hastings Center and bioethicist and disability rights activist Adrienne Asch, comprehensively lays out the context and debates on prenatal genetic testing. A feminist disability perspective that extends Finger’s account of motherhood emerges from several pieces

<sup>7</sup> Another informative work on disabled sexuality in general is Shakespeare, Gillespie-Sells, and Davies 1996.

in the collection. Deborah Kent's (2000) meditation on being a blind mother giving birth to a seeing child captures effectively the ambiguities and contradictions disabled mothers face. The volume witnesses most potently the situated knowledge that informs the politics of selective abortion, from Marsha Saxton's (2000) carefully argued position paper on "Why Members of the Disability Community Oppose Prenatal Diagnosis and Selective Abortion," to Adrienne Asch's (2000) "Why I Haven't Changed My Mind about Prenatal Diagnosis," Mary Ann Baily's (2000) "Why I Had Amniocentesis," and Eva Feder Kittay and her son Leo Kittay's (2000) conversation about the effect her significantly disabled daughter has on family life and self.<sup>8</sup>

One of the most provocative examples of situated theory is the recent cover article in the *New York Times Magazine* by disabled civil rights lawyer and activist Harriet McBryde Johnson (2003), whose stunning and dignified portrait on the cover is overlaid with the rhetorical question, "Should I Have Been Killed at Birth? The Case for My Life." In this persuasive piece, Johnson recounts her engagements with the controversial Princeton ethicist Peter Singer, who, intransigently reasoning from pragmatist philosophy, advocates euthanizing disabled newborns. Although Johnson's arguments have been made by such disabled scholars and activists as Asch, Saxton, and the organization Not Dead Yet, her use of personal narrative to wield sitpoint perspective impels the reader to conclude that Singer's chilling logic is indeed a eugenic form of genocide.

### ***Situated scholarship***

Much feminist disability theory takes the form of discipline-specific studies and special issues on disability in professional journals. Whether the authors identify as disabled or nondisabled, they generally situate the critic in relation to the subject of study. This method of locating the perspective from which the analysis emanates serves to humanize disabled subjects and to demetaphorize and depathologize disability.

Feminist anthropologist Rayna Rapp addresses the pressing disability question of selective abortion in her ethnographic study, *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America* (1999). Like Asch and Saxton, Rapp extrapolates the complexities and contradictions between the feminist claim to reproductive freedom and disability rights. Rapp's interviews with women who had prenatal testing and her own situated critical perspective as a woman who aborted a disabled fetus

<sup>8</sup> For more on selective abortion for disability, see Hubbard 1990 and Saxton 1998.

produce a nuanced account of how the discourses, practices, and assumptions of biomedicine shape the choices women make regarding abortion and disability.<sup>9</sup>

As Rapp's study suggests, the academic genre of feminist ethnography can illuminate the lived experience of disability. Geyla Frank's *Venus on Wheels: Two Decades of Dialogue on Disability, Biography, and Being Female* (2000) is a life study of Diane DeVries, a woman with quadruple congenital limb reduction.<sup>10</sup> Frank negotiates the risky terrain of describing DeVries's life and subjectivity as a disabled woman without appropriating her or misrepresenting her experience. Scrupulously unpatronizing, Frank renders DeVries as neither victim, freak, sentimental poster child, nor supercrip; rather, she is sexual, feisty, capable, vulnerable, feminine, often difficult or manipulative, and always dignified.

Several special issues of influential academic journals capture current work in feminist disability scholarship. *Hypatia: A Journal of Feminist Philosophy* published two issues on feminist disability studies under the senior editorship of Eva Feder Kittay, Anita Silvers, and Susan Wendell (2001, 2002), the three leading feminist disability philosophers. In fall 2002, a *National Women's Studies Association Journal* special issue edited by Kim Hall on feminist disability studies appeared; *GLQ: A Journal of Lesbian and Gay Studies*, edited by Robert McRuer and Abby L. Wilkerson (2003), followed with a special issue defining queer disability studies. Packed with interdisciplinary and multidisciplinary essays, these special issues collectively lay out an intricate and fresh matrix of disability theory that will speak to scholars and teachers across feminist disciplines. The *Hypatia* volumes enlist the methods of philosophical inquiry to probe such disability issues as the ethic of care, the healthy/unhealthy dichotomy, trauma, cognitive ableism, developmental disability, genetic counseling, disability in Indian feminism, and disability in public education. The *NWSA Journal* issue gathers interdisciplinary analyses and represents the most explicitly feminist work emerging, ranging from feminist theoretical concerns such as performance, visibility, madness, embodiment, and fatness to sexual agency. The *GLQ* issue critically addresses the intersections of what Carrie Sandahl (2003) calls "queer and crip identities," thus

<sup>9</sup> For other not explicitly feminist examinations of prenatal and genetic testing, see Rothman 1993, 1998.

<sup>10</sup> I have struggled with how to describe DeVries's (and my own) form of embodiment. Medical terms such as *limb deficiency* and *amputation* are normative and suggest a lack that those of us born with unusual bodies do not feel. To be born with an atypical body does not translate into a sense of not being whole.

focusing on issues such as HIV/AIDS, visual culture and the politics of appearance, both crip and queer coming out, and what Robert McRuer has called “compulsory ablebodiedness” (2002, 88).

The collective reimaginings I have highlighted here—whether the genre is life-writing, personal essay, or situated scholarship—not only critically challenge oppression and reductive assumptions about disabled people and their lives but provide us all with new and complex understandings of disability. All of this work refuses the narratives of pathology, sentimentality, catastrophe, overcoming, and abjection that work to circumscribe our lives, limit our imaginations, and crush our spirits. By honoring disability perspectives, such reimagining does feminist cultural work that has potentially wide-ranging consequences in the larger world.

### Rethinkings

#### **Constructivism**

Perhaps the key critical concept used to analyze disability has been social constructivism. The counterintuitive, epiphanic notion that gender is a social construction still holds tremendous power to liberate for newcomers to gender studies, as those of us who teach undergraduates so often witness. Such a concept is even more provocative when applied to disability, which is still generally understood as a natural biological form of inferiority rather than a culturally fabricated, binary, politicized identity category. The feminist disability studies I have discussed so far tacitly views disability as a social construction but draws primary critical force from perspectivism. However, a body of writing—largely from the social sciences, where constructivism is most explicitly articulated—elaborates disability as a social construction, often using gender as a touchstone to mount such an argument. This scholarship collectively focuses on the social context that constructs disabled subjects—in particular, disabled women.

Simi Linton’s *Claiming Disability: Knowledge and Identity* (1998) makes the case for expanding the social science–dominated disability studies into a more capacious cultural critique by developing humanities-based analyses. As the title suggests, *Claiming Disability* persuasively and eloquently argues for a wide-ranging and multidisciplinary disability studies firmly rooted in liberatory identity politics, informed by the consciousness of the disability rights movement, and anchored in the perspectives of disability communities. Linton invites disability studies to construct a cultural narrative that is “an account of a world negotiated from the vantage point of the atypical” (5). Linton’s groundbreaking theoretical treatise

defines a new disability studies and shapes the sociopolitical scholarship and teaching that follow it.

The foundational collection of critical essays that specifically addresses disabled women is *Women with Disabilities: Essays in Psychology, Culture, and Politics* (1988) by Michelle Fine and Adrienne Asch. This volume “discovers” disabled women by contextualizing the facts of their lives within social constructivist theory. Fine’s introduction, “Beyond Pedestals” (1988), remains one of the definitive analyses of how the gender and disability systems converge. The chapters cover multiple disciplinary approaches, including psychology, ethnography, public policy, oral history, and social science, addressing issues such as dependence, subjectivity, medicalization, embodiment, sexuality, and relationships. Every essay uses a constructivist framework and is grounded in a political consciousness about disabled women’s lives.

Almost all of the work that I consider feminist disability studies continues the project that Fine and Asch’s *Women with Disabilities* initiated. The collection *Double Jeopardy: Addressing Gender Equity in Special Education* (2001), edited by Harilyn Rousso and Michael L. Wehmeyer, is a successor to Fine and Asch’s volume. Centering its critique on the politically fraught notion and field of “special” education, *Double Jeopardy* reflects the transformation in feminist theory from women’s studies to gender studies. The essays in this book—especially the five crucial chapters authored or coauthored by Rousso, a national expert on disabled girls—focus on educational equity for disabled women. The volume addresses as well the functioning of the whole gender system, recognizing how gender affects disabled boys and how the race and class systems intersect with gender and disability. Rousso is particularly eloquent on the importance of role modeling and mentoring in her insistent critique of the segregationist assumptions that underpin special education. The logic of the feminist difference/equality debate informs this interrogation of gender equity, posing questions about sexual harassment, gender bias, and restrictive stereotyping.

Several cornerstone monographs authored by disabled women advance a constructivist reading of disability. These recent studies mobilize feminist and critical theory to replace the pervasive medical model of disability with a social model. One is Jenny Morris’s 1991 *Pride against Prejudice: A Personal Politics of Disability*. Always contextualizing her critique through her own experience as a disabled woman, Morris covers much ground: the devaluation of disabled lives, the conflict in feminism between disability and abortion rights, representations of disability, the politics of community and residential care, and the politicization of disability com-

munities. She draws on history to forge a social definition of disability that intertwines the development of feminism and the disability rights movement. Particularly well formulated is her argument—often resisted by skeptics as overstatement—that selective abortion and euthanasia are forms of genocide not unlike the racial hygiene program of the Nazis. Throughout, Morris draws on and challenges feminist theory and politics to consider disabled women in its analyses.

Susan Wendell's 1996 study, *The Rejected Body: Feminist Philosophical Reflections on Disability*, uses the careful reasoning of philosophical discourse to lay out a constructivist logic of disability. She addresses particularly well the definition of disability and the question of who counts as disabled. Feminist theoretical concepts such as standpoint epistemology, difference, othering, caring, body theory, and the politics of language provide Wendell with a set of concepts familiar to feminists, which she productively applies to a disability analysis. *The Rejected Body* targets adeptly the ideological concept of normalcy crucial to the construction of disabled identity.<sup>11</sup> Normal is the category obscured by its own privilege—its normalcy—that casts people with disabilities into pathologized others. Normal grounds the oppressive system of representation that makes cripples and freaks from the raw material of human variation.

Marta Russell's 1998 book, *Beyond Ramps: Disability at the End of the Social Contract*, is a call to activism that presents America's betrayal of disabled people as emblematic of how the politics and policies of late capitalism have ravaged the democratic project. While carefully explicating the particular sociopolitical issues that involve disability, Russell argues persuasively that the failure—indeed the refusal—of our government to honor the American social contract with regard to disabled people indicates the failure of the democratic ideal on which this country was founded. Her economic and political critique of an ethos of economic efficiency used to strip disabled people of access to resources and privilege echoes feminist explications of gender inequities embedded in American liberal ideologies.

The late Mairian Corker's 1998 treatise, *Deaf and Disabled, or Deafness Disabled? Towards a Human Rights Perspective*, wields poststructuralist theory to examine the relation between the Deaf and the disabled communities. She calls for a fuller inclusion of Deaf people in the disability community and of Deafness into disability theory. Her book is self-consciously thick with critical terms such as *essentialism*, *phonocentrism*, *hermeneutics*, *power*, and *liminality*—all of which are clearly defined in the

<sup>11</sup> For critiques of normalcy, see Davis 1995 and Thomson 1997.

text and in a useful glossary. Readers unfamiliar with disability can thus adeptly mobilize critical theory concepts to deconstruct such disability/Deaf issues as the normalization of cochlear implants, the problematics of “helping,” and the relation between individual and communal identity.

Carol Thomas’s 1999 sociological study, *Female Forms: Experiencing and Understanding Disability*, most fully deals with the construction of a gendered disabled subject. Covering similar theoretical terrain and building on the previous work of Morris, Wendell, and the well-developed disability theory of British sociologists, Thomas advances a constructivist critique that centers on disabled women. Not only does she put forward the concept of disability standpoint theory, she practices it by including generously throughout her account the voices of actual disabled women describing their experiences of disability. Thus the women she quotes become not just data or case studies but active theory builders, exactly in the way that feminist standpoint theory suggests.

While these five books traverse similar theoretical territory, each approaches the sociopolitical construction of disability with a distinctive emphasis or from a particular disciplinary perspective, and each can stand alone as a full explanation and critique of the disability system. Each is useful for teaching and provides a complex yet accessible introduction to the often unrecognized notion that disability is an identity category constructed similarly to race and gender.

### ***The politics of care***

An important feminist disability conversation bristles about the dynamics of caregiving and care getting and the power relations between the givers and receivers of care. Two books on the ethic of care emerge from the perspective of the maternal caretakers of daughters with disabilities. First is Barbara Hillyer’s much too capaciously titled 1993 book, *Feminism and Disability*, which is actually a very polemical, personalized account of the relational and institutional dynamics between disabled women and their female—often maternal—caretakers. Hillyer deals with such topics as mother blaming, grief, denial and normalization, caregiving and women, and codependence. Most forcefully, though, she enlarges the notion of the disability community by insisting on the authority of “nondisabled people who nevertheless live with disability” (107). She rejects the positive identity politics that disability rights activists often employ to counter the traditional perception of all disabled people as helpless dependents. She argues that such a rhetoric of enablement harms significantly disabled persons like Hillyer’s daughter by elevating her own and others’ expectations and by minimizing her limitations.

Eva Feder Kittay offers a counternarrative to Hillyer's critical polemic by interrogating the ideology of independence that renders their disabled daughters problematic burdens and devalues their lives. In *Love's Labor: Essays on Women, Equality, and Dependency* (1999), Kittay moves from the personal—her experience of mothering a disabled daughter—to the philosophical and political, framing a persuasive “dependency critique of equality” (4). She asserts that the ideal of equality under liberalism repudiates the fact of human dependency, the need for mutual care, and the asymmetries of care relations. By arguing for care not from an essentialist, cultural feminist perspective but as a critique of liberalism's masculinist excesses, Kittay asserts that disability demands that human interdependence and the universal need for assistance be figured into our dialogues about rights and subjectivity.<sup>12</sup>

The philosopher Anita Silvers offers a sharp and convincing critique of the feminist politics of care from the perspective of the disabled subject. Her germinal 1995 essay, “Reconciling Equality to Difference: Caring (f)or Justice for People with Disabilities,” which appeared in *Hypatia*, argues that being the object of care forestalls the equality that a liberal democracy depends on and undermines the claim to justice as equality that supports the civil rights argument intended to counter discrimination.

### ***The politics of appearance***

The social system of stigmatizing disability goes well beyond those who might be called the classically disabled, such as the blind, deaf, or so-called retarded and crippled people who are the stock figures of literature, art, and religious inspiration. Although variations and limitations in functioning are often the core experience of disability, appearance tends to be the most socially excluding aspect of disability. Bodies whose looks or comportment depart from social expectations—ones categorized as visually abnormal—are targets for profound discrimination. Bodily forms deemed to be ugly, deformed, fat, grotesque, ambiguous, disproportionate, or marked by scarring or so-called birthmarks constitute what can be called appearance impairments that qualify as severe social disabilities. Perhaps the most virulent form of bodily disciplining in the modern world is the surgical normalization of bodies that deviate from configurations dictated by the dominant order. Although this ostensibly corrective surgery often permits otherwise unsustainable lives—as in the case of cleft

<sup>12</sup> For an excellent examination of dependency, see Fineman 1995. Martha Albertson Fineman distinguishes between “derivative dependency” (161–63) and the “inevitable dependency” that every person encounters at some point in a life.



palates or open heart valves—such procedures frequently mutilate in the name of normality. The vast majority of surgical standardizing takes the form of aesthetic procedures such as “Westernizing” Asian eyes, extending the limbs of people with dwarfism, removing so-called blemishes, augmenting breasts, stapling stomachs, and lifting faces. Whether cast as reconstructive or cosmetic, such surgical reshaping of ambiguously or atypically embodied persons is often in fact a sacrifice to modernity’s fierce drive to limit human variation and to its intolerance toward contradictory bodies.<sup>13</sup>

Nowhere is this will to normality more evident than in the medical protocols directed at three regularly occurring, if infrequent, forms of human variation: intersexed newborns, conjoined twins, and people whose bodies are deemed deformed. The ambiguous genitalia of intersexed people disturbs modernity’s conviction that gender is naturally binary. Conjoined twins upset the notion of discreet and autonomous individuals. The supposedly deformed unhinge the belief that the world is predictable and calculable. These embodiments are congenital variations that are disabling not so much in that they present functional limitations—which all embodiment does to one degree or another—but rather in that they are corporeal configurations that violate the dominant culture’s standards.

Of these culturally transgressive, yet biologically natural, embodiments, intersexuality has by far garnered the most study within feminist scholarship, due in part to intersexuality’s contradiction of the gender system. While feminist scholars have taken up intersexuality’s challenge to a naturalized gender division, the self-advocacy movement among intersexed people that challenges the silence and mutilation directed against them is less recognized.<sup>14</sup> The logic of this movement for acceptance, dignity, and humane treatment emerging from the radicalized intersex community informs the scholarship on intersexuality that I am claiming here as a part of feminist disability studies. The activist argument against surgical gender assignment and the history of what might be called the intersex rights movement are most powerfully disclosed in the essay “‘Cultural Practice’ or ‘Reconstructive Surgery’: U.S. Genital Cutting, the Intersex Movement, and Medical Double Standards,” written by Cheryl Chase (2002), an intersexed person and founder of the Intersex Society of North America. Practicing feminist standpoint theory to make her case, Chase reveals

<sup>13</sup> For an incisive analysis of *aesthetic surgery*—the term that encompasses cosmetic and so-called reconstructive surgery—see Gilman 1998, 1999.

<sup>14</sup> For critiques of the normalization of ambiguous genitalia, see Kessler 1990 and Dreger 1998, 1999.

the psychological and physical violence to which intersexuals are subjected and the salvific potential of an activist identity politics movement to transform ideology, practices, and consciousness. The placement of Chase's essay in an anthology titled *Genital Cutting and Transnational Sisterhood: Disputing U.S. Polemics* (James and Robertson 2002) is strategic to her sharp criticism that feminism has protested third-world female genital cutting while ignoring precisely the same kind of mutilation routinely done to intersexed infants by U.S. medicine.

In *Sexing the Body: Gender Politics and the Construction of Sexuality*, biologist Anne Fausto-Sterling (2000) expands her influential early essay on intersexuality, "The Five Sexes: Why Female and Male Are Not Enough" (1993), into a sustained feminist analysis of the ways that the interpretive environment literally shapes the body. While many feminist theorists—notably Judith Butler—have made a strong but often abstract argument for strict constructivism that often neutralizes bodies, Fausto-Sterling addresses how this actually operates on the materiality of living bodies. Intersexuality is the case study she uses to explore the intricate and complex relation between body and world.

In *One of Us: Conjoined Twins and the Future of Normal*, Alice Domurat Dreger (2004) uses the case of conjoined twins to trouble the notion of normal—perhaps the most unchallenged, seemingly commonsensical, foundational idea of Western modernity. She exposes the cultural logic that understands conjoinment as a personal tragedy to be undone by medical intervention at any cost and the view of conjoined people as suffering intensely because they are not singletons. Dreger is exemplary at crafting semantics and syntax that call into question the dominant perspective and accord her subjects dignity and full humanity. In discussing intersexuality, she says that babies "become" boys or girls rather than simply "are" boys or girls (1998). Similarly, she uses terms like *unusual anatomies*, *socially challenging bodies*, and *anatomies that don't fit the social rules* instead of *deformed*, *abnormal*, or *defective* (1998, 1999, 2004). This is not euphemism; rather, it is a rhetorical refusal to participate in the oppressive attitudes and practices that she is challenging. Such linguistic choices work to reframe the dominant understanding of human variation and keep her argument from falling into the typical appeal to a normative "we" who are urged to look with sympathy or disgust on disabled people as unfortunate victims or droll curiosities. Dreger scrupulously avoids inviting "us" to learn from "them." Rather, she challenges the exclusionary boundaries culture sets up around a normative version of "us."

Perhaps the most common bodily form vehemently imagined as failed or incorrect is the fat body. As Susie Orbach famously said, fat is a feminist

issue (1978). But it is also a disability issue. Fat is sometimes a physical impairment, but it is always an appearance impairment. The fat body is disabled because it is discriminated against in two ways: first, fat bodies are subordinated by a built environment that excludes them; second, fat bodies are seen as unfortunate and contemptible.

Fat studies is an emerging field that draws primarily from feminist and disability theory. The abundant scholarship on the slenderness imperative critiques the ways femininity disciplines and pathologizes the female body.<sup>15</sup> The newest scholarship on fatness similarly challenges oppressive body size norms, but it adds a feminist element that slenderness analyses cannot: that is, fat pride as a kind of transgressive positive identity politics.<sup>16</sup> New scholarly work in fat studies uses disability theory to examine the stigmatizing of female fat that replicates the prejudicial dominant view of the conditions we think of as disabilities. For example, Jana Evans Braziel and Kathleen LeBesco's edited collection, *Bodies Out of Bounds: Fatness and Transgression* (2001), captures a feminist disability studies perspective on fatness by infusing fat pride and advocacy into scholarly critiques of body size demands. The volume historicizes modernity's developing prejudice against fat particularly well, even attempting to imagine a culture in which fat is celebrated. LeBesco's book, *Revolting Bodies? The Struggle to Redefine Fat Identity* (2004), redefines fat identities by challenging conventional understandings of nature, health, and beauty, asserting that the bearer of a fat body is marked as a failed citizen. Fat studies frames fatness as a form of disability, not simply as an aesthetic state or a medical condition but as a political issue.

### **From exclusion to inclusion**

Feminism benefits from considering how disability operates as an intersecting vector of identity along with gender, race, sexuality, and class. Feminist disability studies helps us understand in more complex ways that the particularities of human variation are imbued with social meanings and that those meanings comprise narratives that justify discriminatory practices that shape the lives of both disabled and nondisabled women. Most profoundly, feminist disability studies can make us all reimagine more deeply what it means to have a dynamic and distinct body that witnesses its own perpetual interaction with the social and material environment.

<sup>15</sup> The prolific feminist work on anorexia and eating issues, a disability topic treated by so many feminist analyses, is not possible for me to survey here. The most incisive critique of body image and eating issues is Bordo 1993.

<sup>16</sup> On fat pride, see Wann 1998.

A feminist disability studies moves from exclusion to inclusion. It would have us accommodate disabled bodies rather than eliminate them.

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### References

- Abel, Emily K. 2000. *Hearts of Wisdom: American Women Caring for Kin, 1850–1940*. Cambridge, Mass.: Harvard University Press.
- Adams, Rachel. 2001. *Sideshow U.S.A.: Freaks and the American Cultural Imagination*. Chicago: University of Chicago Press.
- Anzaldúa, Gloria. 1987. *Borderlands/La Frontera: The New Mestiza*. San Francisco: Aunt Lute Books.
- Aristotle. 1944. *Generation of Animals*. Trans. A. L. Peck. Cambridge, Mass.: Harvard University Press.
- Asch, Adrienne. 2000. "Why I Haven't Changed My Mind about Prenatal Diagnosis." In Parens and Asch 2000, 234–58.
- Bailey, Mary Ann. 2000. "Why I Had Amniocentesis." In Parens and Asch 2000, 64–71.
- Battin, Margaret P., Rosamond Rhodes, and Anita Silvers, eds. 1998. *Physician Assisted Suicide: Expanding the Debate*. New York: Routledge.
- Baynton, Douglas C. 2001. "Disability and the Justification of Inequality in American History." In Longmore and Umansky 2001b, 33–57.
- Bordo, Susan. 1993. *Unbearable Weight: Feminism, Western Culture, and the Body*. Berkeley: University of California Press.
- Bragg, Lois, ed. 2001. *Deaf World: A Historical Reader and Primary Sourcebook*. New York: New York University Press.
- Brazier, Jana Evans, and Kathleen LeBesco, eds. 2001. *Bodies Out of Bounds: Fatness and Transgression*. Berkeley: University of California Press.
- Browne, Susan E., Debra Connors, and Nancy Stern, eds. 1985. *With the Power of Each Breath: A Disabled Women's Anthology*. Pittsburg: Cleis Press.
- Brownworth, Victoria A., and Susan Raffo, eds. 1999. *Restricted Access: Lesbians on Disability*. Seattle: Seal Press.
- Brueggemann, Brenda Jo. 1999. *Lend Me Your Ear: Rhetorical Constructions of Deafness*. Washington, D.C.: Gallaudet University Press.
- Carrillo, Ann Cupolo, Katherine Corbett, and Victoria Lewis. 1982. *No More Stares*. Berkeley, Calif.: The Disability Rights Education and Defense Fund.
- Chase, Cheryl. 2002. "'Cultural Practice' or 'Reconstructive Surgery': U.S. Genital Cutting, the Intersex Movement, and Medical Double Standards." In James and Robertson 2002, 126–51.
- Clare, Eli. 1999. *Exile and Pride: Disability, Queerness, and Liberation*. Cambridge, Mass.: South End Press.

- Corker, Mairian. 1998. *Deaf and Disabled, or Deafness Disabled? Towards a Human Rights Perspective*. Buckingham: Open University Press.
- Davis, Lennard J. 1995. *Enforcing Normalcy: Disability, Deafness, and the Body*. London: Verso.
- Deutsch, Helen, and Felicity Nussbaum, eds. 2000. *"Defects": Engendering the Modern Body*. Ann Arbor: University of Michigan Press.
- Dreger, Alice Domurat. 1998. *Hermaphrodites and the Medical Invention of Sex*. Cambridge, Mass.: Harvard University Press.
- . ed. 1999. *Intersex in the Age of Ethics*. Hagerstown, Md.: University Publishing Group.
- . 2004. *One of Us: Conjoined Twins and the Future of Normal*. Cambridge, Mass.: Harvard University Press.
- Eiesland, Nancy. 1994. *The Disabled God: Toward a Liberatory Theology of Disability*. Nashville: Abingdon.
- Fausto-Sterling, Anne. 1993. "The Five Sexes: Why Male and Female Are Not Enough." *Sciences* 33(2):20–24.
- . 2000. *Sexing the Body: Gender Politics and the Construction of Sexuality*. New York: Basic.
- Fine, Michelle. 1988. "Introduction: Beyond Pedestals." In Fine and Asch 1988, 1–37.
- Fine, Michelle, and Adrienne Asch, eds. 1988. *Women with Disabilities: Essays in Psychology, Culture, and Politics*. Philadelphia: Temple University Press.
- Fineman, Martha Albertson. 1995. *The Neutered Mother, the Sexual Family, and Other Twentieth-Century Tragedies*. New York: Routledge.
- Finger, Anne. 1990. *Past Due: A Story of Disability, Pregnancy, and Birth*. Seattle: Seal Press.
- Frank, Geyla. 2000. *Venus on Wheels: Two Decades of Dialogue on Disability, Biography, and Being Female in America*. Berkeley: University of California Press.
- Fries, Kenny, ed. 1997. *Staring Back: The Disability Experience from the Inside Out*. New York: Plume.
- Gilman, Sander L. 1998. *Creating Beauty to Cure the Soul: Race and Psychology in the Shaping of Aesthetic Surgery*. Durham, N.C.: Duke University Press.
- . 1999. *Making the Body Beautiful: A Cultural History of Aesthetic Surgery*. Princeton, N.J.: Princeton University Press.
- Grealy, Lucy. 1994. *Autobiography of a Face*. New York: Perennial Press.
- Hall, Kim, ed. 2002. "Feminist Disability Studies," special issue of *NWSA Journal*, vol. 14, no. 3.
- Herndl, Diane Price. 1993. *Invalid Women: Figuring Feminine Illness in American Fiction and Culture, 1840–1940*. Chapel Hill: University of North Carolina Press.
- Hillyer, Barbara. 1993. *Feminism and Disability*. Norman: University of Oklahoma Press.
- Holmes, Martha Stoddard. 2004. *Fictions of Affliction: Physical Disability in Victorian Culture*. Ann Arbor: University of Michigan Press.

- Hubbard, Ruth. 1990. "Who Should and Who Should Not Inhabit the World?" In her *The Politics of Women's Biology*, 179–98. New Brunswick, N.J.: Rutgers University Press.
- Husson, Thérèse-Adèle. (1825) 2001. *Reflections: The Life and Writings of a Young Blind Woman in Post-revolutionary France*. Trans. and with commentary by Catherine J. Kudlick and Zina Weygand. New York: New York University Press.
- Jacobs, Harriet. (1861) 1988. *Incidents in the Life of a Slave Girl*. New York: Oxford University Press.
- James, Stanlie M., and Claire C. Robertson, eds. 2002. *Genital Cutting and Transnational Sisterhood: Disputing U.S. Polemics*. Urbana: University of Illinois Press.
- Jepson, Jill, ed. 1992. *No Walls of Stone: An Anthology of Literature by Deaf and Hard of Hearing Writers*. Washington, D.C.: Gallaudet University Press.
- Johnson, Harriet McBryde. 2003. "Unspeakable Conversations; or, How I Spent One Day as a Token Cripple at Princeton University." *New York Times Sunday Magazine*, February 16, 50–55, 74, 78–79.
- Kent, Deborah. 2000. "Somewhere a Mockingbird." In Parens and Asch 2000, 64–71.
- Kessler, Suzanne J. 1990. *Lessons from the Intersexed*. New Brunswick, N.J.: Rutgers University Press.
- Kittay, Eva Feder. 1999. *Love's Labor: Essays on Women, Equality, and Dependency*. New York: Routledge.
- Kittay, Eva Feder, with Leo Kittay. 2000. "On the Expressivity and Ethics of Selective Abortion for Disability: A Conversation with My Son." In Parens and Asch 2000, 164–95.
- Kittay, Eva Feder, Anita Silvers, and Susan Wendell, eds. 2001. "Feminism and Disability: Part I," special issue of *Hypatia*, vol. 16, no. 4.
- . 2002. "Feminism and Disability: Part II," special issue of *Hypatia*, vol. 17, no. 3.
- Klages, Mary. 1999. *Woeful Afflictions: Disability and Sentimentality in Victorian America*. Philadelphia: University of Pennsylvania Press.
- Kleege, Georgina. 1999a. "Here's Looking at You." In Kleege 1999b, 122–38.
- . 1999b. *Sight Unseen*. New Haven, Conn.: Yale University Press.
- Krentz, Christopher. 2000. *A Mighty Change: An Anthology of Deaf American Writing, 1816–1864*. Washington, D.C.: Gallaudet University Press.
- Kudlick, Catherine. 2003. "Disability History: Why We Need Another Other." *American Historical Review* 108(3):763–93.
- Kuppers, Petra. 2003. *Disability and Contemporary Performance: Bodies on Edge*. New York: Routledge.
- Lamm, Nomy. 1999. "Private Dancer: Evolution of a Freak." In Brownworth and Raffo 1999, 152–61.
- LeBesco, Kathleen. 2004. *Revolting Bodies? The Struggle to Redefine Fat Identity*. Amherst: University of Massachusetts Press.
- Linton, Simi. 1998. *Claiming Disability: Knowledge and Identity*. New York: New York University Press.

- Longmore, Paul K., and Lauri Umansky. 2001a. "Introduction: Disability History from the Margins to the Mainstream." In Longmore and Umansky 2001b, 1–32.
- , eds. 2001b. *The New Disability History: American Perspectives*. New York: New York University Press.
- Lorde, Audre. 1980. *The Cancer Journals*. Argyle, N.Y.: Spinsters Ink.
- Mairs, Nancy. 1986. "On Being a Cripple." In her *Plaintext: Essays by Nancy Mairs*, 9–21. Tucson: University of Arizona Press.
- . 1996. *Waist-High in the World: A Life among the Nondisabled*. Boston: Beacon.
- Matthews, Gwyneth Ferguson. 1983. *Voices from the Shadows: Women with Disabilities Speak Out*. Toronto: Women's Press.
- McRuer, Robert. 2002. "Compulsory Able-Bodiedness and Queer/Disabled Existence." In Snyder, Brueggemann, and Garland-Thomson 2002, 88–99.
- McRuer, Robert, and Abby L. Wilkerson, eds. 2003. "Desiring Disability: Queer Studies Meets Disability Studies," special issue of *GLQ: A Journal of Lesbian and Gay Studies*, vol. 9, nos. 1–2.
- Morris, Jenny. 1991. *Pride against Prejudice: A Personal Politics of Disability*. London: Women's Press.
- Nielsen, Kim E. 2003. *The Radical Lives of Helen Keller*. New York: New York University Press.
- Orbach, Susie. 1978. *Fat Is a Feminist Issue: The Anti-diet Guide to Permanent Weight Loss*. New York: Paddington.
- Ott, Katherine, David Serlin, and Stephen Mihm, eds. 2002. *Artificial Parts: Modern Histories of Prosthetics*. New York: New York University Press.
- Parens, Erik, and Adrienne Asch, eds. 2000. *Prenatal Testing and Disability Rights*. Washington, D.C.: Georgetown University Press.
- Rapp, Rayna. 1999. *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America*. New York: Routledge.
- Rose, Martha L. 2003. *The Staff of Oedipus: Transforming Disability in Ancient Greece*. Ann Arbor: University of Michigan Press.
- Rothman, Barbara Katz. 1993. *The Tentative Pregnancy: How Amniocentesis Changes the Experience of Motherhood*. New York: Norton.
- . 1998. *Genetic Maps and Human Imaginations: The Limits of Science in Understanding Who We Are*. New York: Norton.
- Rouso, Harilyn, and Michael L. Wehmeyer, eds. 2001. *Double Jeopardy: Addressing Gender Equity in Special Education*. Albany: State University of New York Press.
- Russell, Marta. 1998. *Beyond Ramps: Disability at the End of the Social Contract*. Monroe, Maine: Common Courage Press.
- Sandhal, Carrie. 2003. "Queering the Crip or Crippling the Queer? Intersections of Queer and Crip Identities in Solo Autobiographical Performance." *GLQ: A Journal of Lesbian and Gay Studies* 9(1–2):25–51.
- Saxton, Marsha. 1998. "Disability Rights and Selective Abortion." In *Abortion*

- Wars: A Half Century of Struggle, 1950–2000*, ed. Rickie Solinger, 374–93. Berkeley: University of California Press.
- . 2000. “Why Members of the Disability Community Oppose Prenatal Diagnosis and Selective Abortion.” In Parens and Asch 2000, 147–64.
- Saxton, Marsha, and Florence Howe, eds. 1987. *With Wings: An Anthology of Literature by and about Women with Disabilities*. New York: Feminist Press.
- Shakespeare, Tom, Kath Gillespie-Sells, and Dominic Davies, eds. 1996. *The Sexual Politics of Disability: Untold Desires*. New York: Cassell.
- Silvers, Anita. 1995. “Reconciling Equality to Difference: Caring (f)or Justice for People with Disabilities.” *Hypatia* 10(1):30–55.
- Snyder, Sharon, Brenda Brueggemann, and Rosemarie Garland-Thomson, eds. 2002. *Disability Studies: Enabling the Humanities*. New York: Modern Language Association.
- Thomas, Carol. 1999. *Female Forms: Experiencing and Understanding Disability*. Philadelphia: Open University Press.
- Thomson, Rosemarie Garland, ed. 1996. *Freakery: Cultural Spectacles of the Extraordinary Body*. New York: New York University Press.
- . 1997. *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*. New York: Columbia University Press.
- . 1998. “Crippled Girls and Lame Old Women: Sentimental Spectacles of Sympathy in Nineteenth-Century American Women’s Writing.” In *Nineteenth-Century American Women Writers: A Critical Reader*, ed. Karen Kilcup, 128–45. New York: Blackwell.
- . 1999. “Narratives of Deviance and Delight: Staring at Julia Pastrana, the ‘Extraordinary Lady.’” In *Beyond the Binary: Restructuring Cultural Identity in a Multicultural Context*, ed. Timothy Powell, 81–104. New Brunswick, N.J.: Rutgers University Press.
- . 2002. “Integrating Disability, Transforming Feminist Theory.” *NWSA Journal* 14(2):1–32.
- Tremain, Shelley, ed. 1996. *Pushing the Limits: Disabled Dykes Produce Culture*. Toronto: Women’s Press.
- Wann, Marilyn. 1998. *Fat! So? Because You Don’t Have to Apologize for Your Size!* Berkeley, Calif.: Ten Speed Press.
- Wendell, Susan. 1996. *The Rejected Body: Feminist Philosophical Reflections on Disability*. New York: Routledge.
- Wexler, Alice. 1995. *Mapping Fate: A Memoir of Family, Risk, and Genetic Research*. Berkeley: University of California Press.
- Willmuth, Mary, and Lillian Holcomb, eds. 1993. *Women with Disabilities: Found Voices*. New York: Haworth.