The New Disability Studies: Inclusion or Tolerance?

Rosemarie Garland Thomson

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TOLERANCE is an ethical objective most of us would support as a broadly informing principle of literary and language studies. The question of how to achieve tolerance is, of course, more challenging, requiring as it does strategies and approaches that both engage students and produce results. Although the teaching of tolerance often takes place in a classroom setting in interactions among individual teachers and students, broader institutional structures and developments inform what we might imagine as a tolerant academic community. My intent here is to describe the emergence and the content of what I call the new disability studies, an emerging field of critical inquiry in literary and language studies that is contributing to forging a more tolerant academic community. By considering the development and goals of this new field, we can better understand what actually constitutes tolerance and how it might operate in academe.

Tolerance is defined in Webster’s New Riverside University Dictionary as “recognition of and respect for the opinions, practices, or behaviors of others.” This definition implies that tolerating others has three elements: first, that the others are present so that they can be tolerated; second, that those who are becoming tolerant understand “the opinions, practices, or behavior” of those they learn to tolerate; third, that this recognition leads to respect. The essence of tolerance, such a definition suggests, is inclusion. By this I mean including not just the presence but also the perspective of others.

The new disability studies is about inclusion. It aims to introduce into literary and language studies a perspective that will reveal a pervasive presence that has largely been ignored or misrecognized. The new disability studies is attempting to build the scholarly, pedagogical, and institutional structures that will enable us to understand in fresh ways both the fundamental human experience of embodiment and the meanings we have given to bodily variations and changes. This ambitious field aspires ultimately to foster a recognition of and respect for human differences, both in others and in ourselves.

Bestowing the name new disability studies on the collection of scholarship, critical theory, teaching practices, professional activities, and collegial networks that has issued from the humanities on the topic of disability over the last several years is itself a legitimating act—which is precisely my point, of course. Naming marks the fact that this grassroots activity has achieved a certain degree of clarity, momentum, and presence in the academic arena. The title of an article in the 23 January 1998 Chronicle of Higher Education, one of several recent national news items on disability studies, sums up this new area of study accurately and succinctly: “Pioneering Field of Disability Studies Challenges Established Approaches and Attitudes.”

The idea of a new disability studies suggests, of course, that it replaces an older model. The new disability studies, indeed, revises a previous model that views disability as a medical issue to be considered and managed within disciplines such as rehabilitation, special education, psychology, medical anthropology, and other applied professional fields. This approach envisions disability as a physiological problem or a set of unfortunate individual circumstances in need of solutions offered by medical interventions or social work. The new disability studies, in contrast, takes as its model the intellectual transformation of the academy brought about by including race and gender as fundamental structural elements in our systems of knowledge in humanities studies. This new perspective thus uses a social model to study disability, considering it as a culturally constructed minority identity; a political, aesthetic, and ethical concern; a historical system of representation; and a universal human experience. As such, disability becomes a discourse of the body that can be traced, elaborated, and—as we say—interrogated as an appropriate subject of inquiry in language and literary studies and in the humanities in general.

Within the critical framework of language and literary studies, disability becomes a representational system more
than a medical problem, a discursive construction rather than a personal misfortune or a bodily flaw, and a subject appropriate for wide-ranging intellectual inquiry instead of a specialized field within medicine or science. The new disability studies engages the central critical conversations of aesthetics, cultural studies, ethnic studies, feminism, the history of the body, and issues of identity. In this way, then, it approaches disability as a discursive and material cultural artifact, a theoretical issue, and a major register of analysis in our consideration of the cultural construction of the material world. In Claiming Disability: Knowledge and Identity, Simi Linton describes this scholarship and teaching as going “beyond cataloging discrimination and arguing for social change.” Instead, they supply “a prism through which one can gain a broader understanding of society and human experience.” The new disability studies “deepens the understanding of gender and sexuality, individualism and equality, minority group definitions, autonomy, wholeness, independence, dependence, health, physical appearance, aesthetics, the integrity of the body, community, and notions of progress and perfection that pervade every aspect of the civic and pedagogic cultures.” At bottom, this way of studying disability explores “fundamental epistemological issues” that reach into every discipline, into all spheres of intellectual inquiry, and are central to curricula in all fields in the humanities” (117).

The new disability studies emanates from and engages several interrelated developments in critical thought: first, recovering the history of disabled populations is part of the shift in the practice of social history from studying the powerful and the elite to focusing on the perspectives and contributions of the previously marginalized; second, examining figures of disability arises logically from literary theory’s emphasis on discourse analysis, social constructionism, and the politics of representation; third, theorizing disability as an identity category responds to critical theory’s inquiry into the body’s relation to subjectivity, agency, and identity; fourth, framing disability in political terms reflects the post–civil rights impulse toward positive identity politics; fifth, insisting on the integration of disability into the curriculum and disabled people into the classroom corresponds to the humanistic commitment to serving underrepresented populations. By recasting disability from a medical model to a minority model, the new disability studies takes its form from these paradigm shifts as it strives to intertwine the political, the material, and the intellectual realms.

In my view, the fundamental goal of this emerging field is to reimage disability. The most important contribution that a literary and language studies approach brings to the subject of disability is a focus on the issue of representation. I mean here representation in its broadest sense, of course: as the saturating of the material world with meaning. In this sense, disability is a story we tell about bodies. Seeing disability as a representational system engages several premises of current critical theory: that representation structures reality, that the margins constitute the center, that human identity is multiple and unstable, and that all analysis and evaluation has political implications. Disability studies thus uses mainstream critical theory to dismantle the widespread belief that disability is a natural state of bodily inferiority, exposing that assumption as a cultural product fabricated from bodily variation. It is a discourse we can chart over time, an aesthetic motif we can probe, a rhetorical tradition we can contest, and a fiction we can reveal. The important point, of course, is that these narratives shape the material world, inform human relations, and mold our sense of who we are. The cultural work of the new disability studies, then, is to challenge our collective stories about disability: in other words, to renarrate disability, to reimagine it as an integral part of all human experience and history. In this way, we seek to circulate what Eve Sedgwick calls a “universalizing view” of disability that will replace an often persisting “minoritizing view.” Such a view will cast disability as “an issue of continuing, determinative importance in the lives of people across the spectrum” (1). In the words of Michael Bérubé, “the cultural representation of people with disabilities affects us all.”

This reimagining of disability constitutes the new disability studies, appearing in the form of scholarship, teaching, and professional activities. Publishing is burgeoning in both prestigious journals and major university presses. Disability studies appears with increasing frequency on the programs of scholarly conferences and at the meetings of professional humanities associations. New courses are being developed and taught around the country, and disability is being integrated into existing courses. Discussion groups have been formed within many professional organizations, such as the American Studies Association Crossroads Project. The American Studies Association and the Modern Language Association. An electronic discussion list has been mounted through the American Studies Association Crossroads Project. The University of Michigan Press has launched a series entitled Disability and Culture. Some of this new scholarship on disability has won distinguished scholarly prizes. Here are examples of its wide range: the representation of disabled veterans; invalidism in women’s writing; the influence of disabilities on canonical writers such as George Gordon Byron, Alexander Pope, Samuel Johnson, Flannery O’Connor; disability and the ideology of individualism; the concept of normalcy; American Sign Language poetry; disability autobiography; a cultural analysis of telethons; nationalism and disability; the metaphors of deafness; feminist analyses of anorexia; the concept of prosthetics; the politics of appearance; the “crippled” figure in sentimentalism; disability in the religious tradition; freak shows; and an analysis of medical photography of insane people.

Let me offer my own work as an example of the attempt to renarrate disability that I have suggested is central to
this new field. I spent a great deal of time selecting the title, Extraordinary Bodies, for my 1997 book. I wanted to be very precise in identifying the subject of my work, which—simply put—is analyzing the ways that people with disabilities and the idea of disability itself are portrayed in American culture, particularly in literary texts. I use disability and disabled to generally identify my subject because these are the most common terms used now to name the category of persons on which I focus and because this is the language used in the recent Americans with Disabilities Act (ADA). I want disability to invoke notions of civil rights and the legal mandate to integrate a group of previously excluded people. But the literal meaning of disabled—something like “not able”—certainly has its limitations. One thinks, for example, of “disabled vehicles” stranded hopeless on the margins of the interstate, of the mishaps we are warned to avoid as we whiz by them with a sense of smug relief. All terms resonate, of course, bearing long histories and summoning whole discourses. Had I chosen the term crippled instead, I might have evoked sweet-faced poster children, the piles of discarded crutches at Lourdes, and Jerry Lewis’s telethon—in short, an entangled, complex discourse made up of charity, sympathy, rescue, and suffering. Had I chosen such terms as deformed, abnormal, invalid, diseased, or pathological, for instance, I would have conjured the logic of medicine, with its imperative to cure, its reverence for a standard of normalcy, its coercive cultural authority.

Mostly what I wanted to avoid in naming my subject of scholarly inquiry was the almost unavoidable suggestion of lack, inferiority, and personal misfortune suggested by most of the terms we use to name what it was I wanted to investigate. I chose extraordinary bodies to move away from both the concept of “dis” and the idea of “ability,” not to mention all those other terms. I was not pursuing euphemism but rather trying to find a term that might not call up all the negative assumptions about disability. Extraordinary denotes something that is outside the ordinary, neither negative nor positive but simply different from what is expected or usual. Extraordinary, I reasoned, shifts the focus from one’s individual abilities or their supposed lack, to the social system that evaluates and gives meaning to human variation. My work centers on how culture—specifically what we call modernity—creates the ordinary to use as a standard by which all else is measured and valued. Both the stability and coherence of the ordinary, of course, depend on establishing an outlaw category of the extraordinary and policing the boundary between them. And yet, the ordinary/extraordinary dichotomy has a good deal of semantic elasticity compared with the relatively comparable binary set of normal/abnormal, which more clearly connotes opposing poles of value. Extraordinary suggests the remarkable, difference tinged with the distinction of singularity, of the unanticipated. The term extraordinary thus captures the idea of being outside the norm, while at the same time calling the norm itself into question by suggesting its constricted and coercive quality.

Extraordinary, then, gave me a way to reimagine disability, to challenge entrenched assumptions about disability. The informing premise of my work is that cultural narratives—the stories we collectively learn—determine our politics, selves, relations, and world. Because we often imagine disability solely as tragedy, pathos, inadequacy, abnormality, and unattractiveness, our collective stories not only restrict the lives and govern the bodies of people we think of as disabled but limit the imaginations of those who think of themselves as nondisabled. These collective, received, often unexamined assumptions about disability ultimately undergird exclusionary environments, employment discrimination, and social marginalization. Indeed, they warrant the flight from disability so characteristic of our cultural moment. In contrast, extraordinary is a word that allows us to reconceive disability as simply bodily variation rather than lack, excess, or abnormality; to rethink disability as physical transformation rather than catastrophe; to reenvision disability as something we can or will have in common rather than something that is alien to us. Reimagining disability in this way perhaps allows us to become comfortable with the fact of human mutability and to come to terms with our collective attempt to escape from our own bodily vulnerability.

For example, I argue that political and moral agendas of nineteenth-century sentimental narratives, from the abolitionist novel Uncle Tom’s Cabin to the working-class protest “Life in the Iron Mills,” depend on the disabled figure as an image of pathetic suffering. The pathetic sufferer whose body testifies to its own misery was, I suggest, the most effective rhetorical vehicle with which the feminine reform movement could solicit both fine sentiments and a humanitarian impulse, as well as confirm itself as sympathetic. My current project is to tease out what I call the cultural logic of euthanasia used to support the recent surge of physician-assisted suicide. I trace this logic to the American ideology of individualism, the standardization of the body, and the instrumentalism of marketplace ethics, looking at narratives such as Herman Melville’s famous story “Bartleby, the Scrivener” as examinations of the problem of what we think of as disability in the context of modernity.

As well as excavate the narratives that have been used to evade and denigrate such a fundamental human experience as disability, I also work to uncover the resistances to these narratives often found in literary texts as well. For instance, I argue that the disabled women figures that abound in Toni Morrison’s novels reimagine disability as a source of strength and distinction. Figures such as Morrison’s tough, heroic grandmothers—the one-legged Eva Peace in Sula and the disabled Baby Suggs in Beloved—are not diminished by their disabilities but rather empowered by them. The disabilities function in the narratives, I suggest, as the marks of differentiation that are parallel
to blackness and as the bodily manifestations of these women’s collective and individual histories of triumph over oppression. The women do not need to triumph over the disabilities, because the disabilities are enhancements, the distinguishing marks of the women's struggles against racism.

My work is only one instance of a burgeoning of scholarship under the banner of what I'm calling the new disability studies. Lennard Davis, for example, develops the critique of "enforcing normalcy" and suggests that disability studies be reframed as "normalcy studies." David Mitchell and Sharon Snyder delineate an elegant taxonomy of critical approaches to analyzing the representation of disability. Their categories include the negative-images approach, social realism, historicizing disability, disabled authorship, and transgressive disability. The field of literary and language studies, however, needs to do more to recognize and include disability. We can, for example, counter intellectual and curricular ghettoization by including disability as a category of analysis in all our teaching and scholarship. Here are a few examples: We can look at the ways that disability parallels and intersects gender, race, sexuality, ethnicity, and class. The history of the disability rights movement and its legislative victories could be intertwined with the study of the larger civil rights movement. Literary criticism can point to the roles of disabled figures in film, fiction, autobiography, and performance, as it has to those of women and people of color. The disabled figure is an ideological construct that both problematizes American individualism and informs our concept of the subject in a democratic order. Moreover, disability is seminal to women's struggles over oppression. The women do not need to triumph over oppression. The women do not need to triumph over the disabilities, because the disabilities are enhancements, the distinguishing marks of the women's struggles against racism.

Individual scholarship, teaching, and professional activities are not enough to ensure the inclusion of disability studies and the recognition of the disability constituency in language and literary studies. As Michel Foucault has shown, institutional practices rather than individual attitudes are often the most recalcitrant sites of exclusion. For example, in spite of all this scholarly and pedagogical production, disability studies has appeared only one time in a job description in the MLA Job Information List, and disability-centered panels are often rejected at major conferences as being too narrow. Professional organizations, however, have led the way in integrating disability. The Americans with Disabilities Act of 1990 brought disability to the national forefront by defining it as a civil rights issue, mandating the full integration of disabled people, and extending earlier prohibitions against discrimination. It also prompted institutions and professional organizations in the academy to confront the issue of creating access for disabled people into the academy.

The MLA has been a flagship organization in recognizing and including disability. In 1994, the MLA took the initiative by inviting several of us who were working in the area to come to New York to discuss the issue of convention access. This began a process of mutual education in which we informed the MLA about disability issues and the MLA showed us how to use the institutions of our profession to build a field and consolidate a constituency. Since the MLA began addressing disability issues, several other professional organizations have responded to the presence of disability studies and the ADA by forming caucuses or other member subgroups that address integration of disabled members and disability studies. For example, the American Studies Association and the Conference on College Composition and Communication now have disability studies caucuses and are working to increase access. The four-year collaboration with the MLA stands, however, as a model for how to institute a new field. When we began to meet with MLA staff members, we found that their commitment to making the convention accessible was clear. They were responding not only to the legal pressure of the ADA but to a principled position of encouraging diversity in the profession and in the university. They were also responding to the protest resignation of many Gallaudet faculty members over the MLA’s failure to accommodate deaf members. Together with an access consultant, we worked—and are still working—on such tasks as making the request for accommodation procedures for the convention more coherent and efficient, exploring alternative formats for printed materials, and providing sign language interpreters.

What the MLA staff did not initially understand, however, is the complex and subtle ways by which the very structures and practices of both its own organization and the profession as a whole exclude disabled people. To open up the profession and the university, the MLA
needed to remove not only the physical barriers but the countless invisible ones. Like race and gender before it, disability can be neither recognized nor accommodated until the requisite structures and languages are in place. We argued that the study of disability as a system of representation that is integral to human experience and history is essential to creating an accommodating environment. As long as disability as a topic of inquiry and historical subject is invisible, so too will disabled people be. Everywhere we discovered structural resistances to inclusion. For example, the MLA's instructions for interviewing job candidates made no reference to the process of requesting accommodations for disabled candidates; the MLA Bibliography listed American Sign Language as an invented language in the same category as Klingon; graduate studies departments had no procedures for accommodating the differing needs of, say, blind or paralyzed students.

It is important to understand that none of these structural barriers had been erected intentionally; indeed, few of us recognize their presence until we come up against them or they are identified by someone who does. Those of us researching disability in literature, for instance, were frustrated by the lack of bibliographic entries when we knew of much unlisted work. We knew we could not access it, even though we sensed it was there. In a discussion with the MLA's Director of Bibliographic Information Services, Terry Ford, an epiphanic example emerged. He was explaining the problem of cataloging a recent article on what the primary source called “crippled saints” in early modern literature. Because the word crippled was considered derogatory by the MLA's bibliographic system, it was expunged from the system used to categorize entries; thus, the altogether well-intentioned avoidance of a negative term rendered the article only about saints, making the disability content of the article unretrievable to scholars researching disability in literature. The structure of the archive effectively erased disability as a subject of knowledge; the idea of disability as a legitimate subject of study and the recognition of disability as an identity and experience were almost totally absent. Changing the archive and altering the practices make disability and disabled people emerge. What we learned was that institutional structures and practices, not individual acts of intolerance, were largely responsible for the exclusion.

What I am suggesting with this account of the new disability studies is that reimagining disability in this way reveals to students, faculty, administrators, and the larger world that culture saturates the body with meanings that far outstrip their biological bases and that those meanings generate social and political consequences. The bodies that we think of as disabled act as repositories for social anxieties so that difference gets interpreted as deviance. Disability becomes a social relationship in which oppressive attitudes and unaccommodating environments create a situation that puts people with certain kinds of bodies at a disadvantage. Disability, then, can be seen as an exclusionary system—a form of intolerance, if you will, much like race and gender—that produces the disabled as well as the able-bodied through a shifting, interrelated web of linguistic, legal, medical, political, social, economic, and literary structures. These structures hold in place a hierarchy of bodies that values some and denigrates others. Thus, disability is not something to be “tolerated” but rather something to be interrogated in our teaching and scholarship and included in all the institutional structures and practices of literary and language studies.

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**Works Cited**


Disability inclusion involves input from people with disabilities, generally through disability-focused and independent living organizations, in program or structural design, implementation, monitoring, and evaluation.

Three federal laws protect the rights of people with disabilities and ensure their inclusion in many aspects of society: Section 504 of the Rehabilitation Act of 1973. The Americans with Disabilities Act (ADA) of 1990, which was followed by the ADA Amendments Act of 2008 in an attempt to restore the balance between individuals with disabilities and employers.

Describes the emergence and the content of "new disability studies," an emerging field of critical inquiry in literary and language studies. Looks at how it is contributing to a more tolerant academic community. Shows how considering the development and goals of this new field can help improve understanding of what constitutes tolerance and how it might operate in academe. (SR).

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