Chapter 15
Writing, Identity, and the Other: Dare We Do Disability Studies?

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15.1 Introduction

Although inclusive education is often characterized as a special education initiative, both general and special educators must assume responsibility for all children's learning as mandated by 1997 amendments to the Individuals With Disabilities Education Act. The practice and implementation of inclusion policy in both K-12 public education and teacher education necessitates close examination of many issues that extend beyond compliance concerns. This article problematizes two related aspects of inclusion reform and its implementation in practice: persistence of unexamined assumptions about disability and uninspired curriculum. The author begins with an overview of humanities-based disability studies, an emerging field of scholarship that holds great promise for reimagining disability. Then the author describes a partnership between a secondary language arts teacher and herself wherein they created and cotaught Writing, Identity, and the Other, a curriculum unit informed by humanities-based disability studies. This example provides insight to the question, Dare we do disability studies?

15.2 Building a Cultural Critique

> I can’t ignore my disability, why would you?
> —Karen, high school student, *Writing, Identity and the Other*

> The messages we receive are very strong and clear and we have little access to different values, which may place a more positive value on our bodies, our lives and ourselves. Our self-image is thus dominated by the non-disabled world's reaction to us. Jenny Morris (1991)

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Cultural perceptions of disability do not emerge in a vacuum; they accrue slowly and over time, informed by normalizing discourses in medicine and psychology, and reinforced by institutions and unchallenged beliefs of deficiency and need. Historically, disability has been the exclusive domain of the biological, social and cognitive sciences that shape practice in education, rehabilitative medicine, and social work. As a consequence of this limited understanding, disabled people are generally stereotyped as weak, pitiful, dependent, passive, tragic and many times, deserving of their predicament (Gilman 1985). With the medical lens fixed on the individual and their disability, the larger political, economic and material forces at play in an abelist society fall somewhere outside the frame. Despite claims to the contrary, public education, higher education, and teacher education are likewise guilty of ignoring the complexity of disability in our society. Tensions remain when attempting to consider disability as a concept or a constituency in educational settings. In higher education when disability moves beyond the diversity category to include pedagogical issues, status as an emerging field of study, and a civil rights mandate, "teachers, administrators, and students recognize the pedagogical, scholarly, and practical implications of integrating disability fully into all aspects of academe" (Longmore and Garland-Thomson 1999, p. 2). Thus, when the context responds to disability as more than a diversity category, concept and constituency merge to create important opportunities for learning. In K-12 settings *disability* has typically been defined as constituency—special education students who receive educational services in separate settings. As a consequence of the Individuals with Disabilities Act (Individuals with Disabilities Act 1997) the inclusion of students with disabilities into general education classrooms now challenges both the constituency and concept of disability. However, there remains much to learn about understanding disability as part of the larger human experience. At large, policies and practices that have a direct impact on the material reality of living with disability are rarely examined by society, as many believe that disabled people already won their rights. In much the same way that racism is believed to have been resolved by civil rights legislation, similar unexamined beliefs hold that the Americans with Disabilities Act (1990) ended injustice for the disabled. However, disabled people and those who research the lived experience of disability know that "the fundamental issue is not one of an individual's inabilities or limitations, but rather, a hostile and unadaptive society" (Barton 1999, p. xi).

15.2.1 Media Influences: In Brief

How is it that society can still be cast as "hostile and unadaptive" despite three decades of important social policy reform for people with disabilities?[1] There are several ways to respond to this question. From a historical perspective disability has

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[1] The reforms include, principally, the Americans with Disabilities Act, (ADA, 1990), the Individuals with Disabilities Education Act (IDEA, 1990) and the reauthorization of the Individuals with Disabilities Education Act (1997).

been a specialized field limited to analysis within medicine, rehabilitation, special education, and social work. From a sociological perspective, others suggest that because many of the legal battles for disability access were won in the courts, with little involvement of non-disabled people, the assumption follows that people with disabilities have long since won their rights (Peters and Chimedza 2000). The media have played a critical role in perpetuating hostility to disability in numerous ways, including the negative portrayals of disability in television and films (Longmore 1987; Longmore and Umanksy 2001; Norden 1994; Shakespeare 1999) and in broadcast media depictions that reify unexamined assumptions about disability culture. Consider for example, the recent newspaper accounts to mark the 10-year anniversary of the Americans with Disabilities Act (ADA) of (1990). Of the many nation-wide variations on the triumph-over-disability theme of America's overcoming narrative (e.g., "Just Keep Moving" in *The Atlanta Constitution*, "Keep the 'able' in disabled," *The Kansas City Star*; "Improved Access for All, thanks to the ADA," Minneapolis *Star Tribune*), few made mention of the *Alabama v. Garrett* case recently before the Supreme Court. *Garrett* was the latest in a series of cases in which states challenged congressional power to enact legislation regulating state conduct—in this example, its authority specific to Title II of the ADA. Despite its obvious threat to dismantle the ADA, the *Garrett* case was cast as a "states rights" issue rather than a "disability rights" issue in both the courts and the media. Although this is not intended to suggest a media conspiracy, one has to wonder how naivete plays into complicity with societal hostility when the public relies on an ill-informed media.

15.2.2 Humanities and Education Influences: In Brief

Scholars in the field of humanities-based disability studies begin with the view of disability as a cultural signifier to problematize a range of unexamined attitudes, beliefs, and assumptions (Davis 1995, 1998; Garland-Thomson 1997; Linton 1998; Longmore and Umanksy 2001; Mitchell and Snyder 1997). Finally, education is just coming to name the inherent hostility to disability in education policy and practice as an evolution of its ongoing internal critique of special education (Brantlilnger 1997; Gabel 2019b; Erevelles 2000; Gallagher 1998; Heshusius 1989, 1995; Skrtic 1991, 1995; Ware 2000b, f). Critical special education theorists interrogate teacher preparation, special education, educational administration, and educational and social policy. Among the questions raised are those that implicate the organizational pathology of schools; for example Skrtic (1991) asks, if special education a rational system. Gallagher (1998) challenges the scientific knowledge base of special education by asking if weknow what we think we know. And, borrowing from Foucault (cited in Philip 1985), my research asks, "What have we done to ourselves by doing these things to them?' (Ware 2000b). This question interrogates teacher practice that ignores its own complicity in perpetuating exclusion as well as the administrative practice of "meaning-management" (Anderson 1990) which casts disability as a non-issue in general education in both secondary and post-secondary settings.

Critical special education now in it's "fourth wave" according to Heshusius (2000), provides an increasingly sophisticated range of issues beyond behaviorism. Included here are considerations of postmodern and postsructuralist reimaginings of disability (Erevelles 2000; Gabel 1998, 2001; Peters 1996, 2000; Smith 1999a, b, 2000; Ware 1999, 2000a) reinvigorated calls for open inquiry motivated by concerns for equity and recovery of the original moral grounding of special education's roots (Brantlilnger 1997; Danforth and Gabel 2000; Heshusius 2000; Kleiwer 2000; Ware 2000b), and research in comparative contexts that makes linkages to international critical special education theory (Gabel 2019a, b; Peters 1995, 1996, 2000; Ware 1995, 1998, 1999, 2000b).

Regardless of the origin of the critique when unexamined attitudes, beliefs, and assumptions about disability are challenged, multiple perspectives prove more useful than any one field's perspective. This is particularly important for teacher educators who seek to interrupt the contradictory subtexts in pedagogy and practice when special education's core concerns of cure, care, and remediation are contrasted with the reflection, transgression, and emancipation that lie at the center of liberatory praxis.

In the first part of this article, I consider two important critiques that have emerged to challenge status quo assumptions about disability. The first is the Disability Rights Movement (DRM), and the second is the emerging field of humanities-based disability studies. Each of these critiques is useful alone, but when taken together they provide a strong argument for educators to consider disability through a cultural lens, one that interrogates the medicalized view that has powerfully shaped both general and special education, and more important, public perceptions of disability.

15.3 The DRM

> Historically, the only choice people with disabilities had in their personal struggle to survive was to individually resist isolation, even death, by relying on others. This meant, practically speaking, begging and becoming dependents of family or charities. That has begun to change. Now there is a movement of empowered people that seeks control of these necessities for themselves and their community. (Charlton 1998, p. 165)

> There are 43 million of us in this country. But we're as invisible as Casper the Ghost. (Billy Golfus, cited in Golfus and Simpson 1994)

According to Longmore and Umanksy (2001), disability has been "present in penumbra if not in print, on virtually every page of American history" (p. 2), yet, history has failed to include disability other than in medical case histories. In an effort to fill in the "historical gaps" of disability in American history, Longmore and Umansky have edited a collection of essays that capture the social, cultural, and political history of disability and disability rights activism. For example, during the Great Depression, the League of the Physically Handicapped staged actions in protest of job discrimination resulting from the medical model of disability that had begun to shape policy, professional practices and social arrangements of the early twentieth century (Longmore and Goldberger 2000). Most Americans, including historians will be surprised to read the rich documentation supporting the essays in this collection, given the commonly held belief that only a "small fraction of the population appears to be disabled" (Davis 1995, p. 6).

The origin of the DRM is typically associated with the late twentieth century, from the 1960s through the present. Activism erupted in simultaneous waves in Berkley, Boston, and Houston giving rise to the DRM and paving the way for important legislation and social policy for disabled Americans. During this time, civil rights protests for accessible housing, transportation, employment, and education invited new conversations about self-determination and the real meaning of access. Through well-planned actions, disability advocates challenged public perceptions and raised consciousness about social justice and living conditions for the millions of Americans who live with disabilities (e.g., Block 1997; Brock 1998; Charlton 1998; Golfus and Simpson 1994; Shapiro 1993). A recent show at the Smithsonian National Museum of American History, titled, *The Disability Rights Movement* (June, 2000–01), captures much of the history of this era with original protest placards, footage of activism, and reform legislation documents cast among the objects on display. According to the curator, Katherine Ott (2000), the social progress of this era is most evident when contrasted to an earlier show, *Triumph Over Disability* (Davis 1973) which displayed various medical instruments, devices, and aids that signaled the rise and development of physical and rehabilitation medicine in the United States. Consistent with the new disability history outlined by Longmore and Umanksy (2001), the Smithsonian exhibit departs from the medical model of disability to instead relocate the disability experience in social rather than biological constructs.

The DRM characterizes a rich history of liberation by individuals claiming rights and staging actions that should have earned a more central place in the history of American life. Because DRM history has been elided from common understanding, its reintroduction into the collective consciousness will prove timely as it informs humanities-based disability studies and liberatory praxis in teacher education.

15.4 Humanities-Based Disability Studies

> Humanities-based disability studies is grounded in the desire to challenge our collective stories about disability, to renarrate disability, [and] to reimagine it as an integral part of all human experience and history (Longmore and Garland-Thomson 1999, p. 2).

Recent efforts to problematize disability through a cultural analysis are found in the emerging multidisciplinary scholarship and research in humanities-based disability studies.[2] History, literature, philosophy, anthropology, religion, medical history, and rhetoric rooted in the humanities rather than in the social sciences and rehabilitative medicine inform this scholarship. With an emphasis on understanding disability as discursively and materially created, the medical model is problematized such that questions of civil rights and social justice are privileged over those cast as personal problems. Among the critical issues in humanities-based disability studies are those related to: identity, education, representation, sexuality, personal meanings of disability, access, employment, religion and spirituality, and strategies for empowerment and activism. Representing an unprecedented shift from the modernist project of biological determinism and the medicalization of disability, the new disability studies defines *disability* as a way of thinking about bodies rather than as something that is wrong with bodies (Longmore and Garland-Thomson 1999; Mitchell and Snyder 1997).

In sum, disability studies "takes as its domain the intricate interaction among cultural values, social arrangements, public policy, and professional practice regarding disability" (Longmore and Umanksy 2001, pp. 15–16). This interpretation of human differences draws from postmodernist and post-structuralist analyses in which the person with disabilities becomes the "ultimate example, the universal image, the modality through whose knowing the postmodern subject can theorize and act" (Davis 1997, p. 5). Although this scholarship is infinitely broad in topic and scope, and beyond an adequate presentation in this article,[3] a key strand that cuts across this burgeoning literature is the problematizing of the ability/disability binary. That is, when disability is considered through a cultural lens, ability is interrogated in much the same way as feminist studies scholars interrogate gender, and ethnic studies scholars interrogate whiteness. The instance of the normal/abnormal binary is central to the problematization of disability, particularly as it has morphed to the ability-disability binary central to the invention of categorical systems institutionalized by society (e.g., education, medicine, law, and social policy). Given that many cultures (primarily Western) maintain disability as alterity through the ideology of assigning value to the normal, able body and its functioning parts, stigmata is often equated with impairment and the disabled body. How we "other" the disabled body, according to L. J. Davis (1995), is determined by society.

> We tend to group impairments into the categories of either 'disabling' (bad) or just 'limiting' (good) …. Wearing a hearing aid is seen as much more disabling than wearing glasses, although both serve to amplify a deficient sense …. Loss of hearing is associated with aging in a way that nearsightedness is not" (p. 130).

The subtle, yet pervasive practice of assigning value to the body is most evident in cultural representations of disability, where, according to Garland-Thomson

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[2] See Longmore and Umanksy (2001) for a more thorough discussion of this history in the United States, Campbell and Oliver (1996) for a discussion in the context of the United Kingdom. In academia, Berube (1997) and Cassuto (1999) provide abbreviated accounts of humanities-based disability studies.

[3] Overviews can be found in Corker and French (1999), Davis (1995), Linton (1998), Longmore & Umansky (2001), Mitchell and Snyder (1997), Shapiro (1993), and Wendell, (1996.)

(1997) disability exists in opposition to the *normate*[4]. This neologism characterizes the socially constructed identity of those who by way of the "bodily configurations and [the] cultural capital they assume, can step into a position of authority and wield the power it grants them" (Thomson 1997, p. 8). In her analysis of the cultural representation of disability, Thomson reveals how disability operates in texts, to expose the tensions between people who assume the normate position and those "assigned" the disabled position. Incomplete, prototypical disabled characters are more common than are dynamic and complex individuals and for the most part, representations rely on cultural assumptions to fill in the missing details of personhood (e.g., agency, subjectivity, desire, sexuality, etc.).

With respect to cognitive disabilities, moral philosophers have begun to reimagine reason as the center of what makes us human. The moral philosopher, Eva Feder Kittay (1999a, b) draws from her experience parenting her adult daughter with significant disabilities to pose provocative questions about independence, dependence, and interdependence in pursuit of developing a radical theory of equality that extends to both political and social life. Similarily, MacIntyre (1999) in his discussion of who contributes to the common good, suggests that many children in schools experience "too constrained and impoverished [a] view of future possibilities" (p. 75), bound as educators often are, by systems that extinguish imagination. Finally, Carlson (1997, 1998) contends that given the ambiguities and intricacies of classification systems of cognitive impairment, to more fully consider the social nature of disability, questions about cognitive ability must move "beyond the boundaries of bioethics" (1997, p. 283). She urges that when feminists theorizing physical disability, many "connections can and *should* be applied to persons with cognitive disabilities" (1997, p. 280).

Intersecting issues for educators. The cultural analyses emerging from disability studies scholarship offer challenging theoretical insights for educators to examine both societal attitudes, beliefs and assumptions, and more fundamentally, the lived-experience of disability. In example, McRuer (2001) analyzes a fundamental ideological cultural demand he terms, *compulsory able-bodiedness* borrowing from Adrienne Rich, Judith Butler, and a memior by Berube (1996), who writes about life with his son Jamie, who has Down Syndrome. According to McRuer (2001):

> Berube writes of how he 'sometimes feel[s] cornered by talking about Jamie's intelligence, as if the burden of proof is on me, official spokesman on his behalf' (p. 180). The subtext of these encounters always seems to be the same: *"In the end, aren't you disappointed to have a retarded child? … Do we really have to give this person our full attention?"* (p. 180).

In his analysis, McRuer (2001) suggests two related questions drawn from Berube's experience, and bound by the same common ground of "able-bodied consciousness" to tease out important subtext at play in interactions between able-bodied and disabled people. These often-unarticulated questions are juxtaposed to make a critical point. In the end, wouldn't you rather be hearing? In the end, wouldn't you rather not be HIV positive? Although two seemingly different ques-

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[4] The term *normate* was originally coined by Daryl Evans (see Thomson 1997).

tions, the former typifies the subtext of the "thinly veiled desire for Deafness not to exist … and the latter, "more obviously genocidal" (p. 8). By his analysis, these questions are more alike than they are different and more reflective of the able-bodied culture posing the question than about the "bodies being interrogated" (p. 8). The dialectic is one in which abelist culture uncritically assumes an "affirmative answer to the unspoken question, *yes, but in the end, wouldn't you rather be more like me?* (p. 8). The significance of these questions is that of the "compulsory able-bodied" desire for neither people who are deaf, nor those with AIDS to exist.

Although educational researchers have just begun to challenge these unarticulated questions and their relationship to the hostility and unadaptive structures in society previously cited by Barton (1999), they parallel the issues of critical race theorists and feminists who seek to move beyond the essences and the unvoiced in policies and practices. However, these conversations are not easily had in schools or in teacher development. In my own research with pre-service and practicing teachers there is sometimes a general sense of relief as we begin to unpack abel-ist assumptions in education and society, or just the opposite occurs resulting in defensiveness and denial. Initially, teachers cite the lack of resources, training, parental support, and administrative vision that reinforces the hegemony of abelist assumptions, as if to say, "That's just the way it is." Others, upon reflection, acknowledge that they have ignored disability issues, confident that systems and specialists were better able to address these issues. And a few recount personal experiences with disability which serves as the catalyst for moving beyond the normalizing discourse of disability. Regardless of the response, each is marked by emotions similar to those outlined by Tatum (1992) in her efforts to teach race and racism in college classrooms. The parallels are more obvious when considered against the larger meaning of social inclusion and the value of creating a shared responsibility for teaching all children. In the section that follows I suggest that analyses offered by humanities-based disability studies can inform educators about educational and social inclusion.

15.5 Disability Studies in Education

> At stake here is the necessity for progressive educators' studies to provide some common ground in which traditional binarisms of margin/center, unity/difference, local/national, public/private can be reconstituted through more complex representations of identification, belonging, and community. (Giroux 1996, p. 53)

Critical educational discourse informed by critical theory and critical pedagogy has, for more than two decades, inspired many activist educators to form alliances in pursuit of educational and social justice. With social transformation at the center of mutual reform efforts, this legacy of morally driven activism has its roots in Freirean efforts to promote justice, equality, democracy, and freedom through liberatory praxis--*conscientization* (Freire 1970). However in a recent special issue of *Educational Theory* (1998), the success of this reform project was challenged. Given its failure to disrupt the inequities in society related to race, class, gender, and ethnicity, critical pedagogy was problematized from several perspectives. The discussion included concerns, criticism, and solutions as in the example of Peter McLaren's (1998) 10 step manifesto for critical pedagogy in the age of globalization--a revivalist revolutionary project—"performed in the streets … [and] public spaces of potential political, cultural, and economic transformation" (pp. 452–453). In this same issue, Patti Lather (1998, cited in in Ellsworth 1997, pp. xi, 9) voiced concerns that the "big tent" of critical educational discourse had come up against a "stuck place"—thus her calls for praxis informed by Derrida's question, "What must now be thought and thought otherwise?" (p. 495).

In response to this challenge, I would answer that disability must now be thought and thought otherwise. By that I mean disability is a long overdue conversation among critical theorists, pedagogues, and educationalists, who fail to recognize disability as a cultural signifier, nor do they include disability as a meaningful category of oppression (Erevelles 2000; Gabel 2001; Ware 2000f). This silence on disability issues suggests the typical societal absorption of cultural stereotypes related to disability. Of equal significance is the unexamined assumption about the taken-for-granted category of disability in educational discourse—one shaped by ideologies, history, medicine, and social and political assumptions whose central binary is ability/disability. In an argument informed by the previously cited disability studies literature, I suggest that this binary is the root of all binarisms that inform social formations such as race, class, gender, ethnicity, sexuality, and disability.

15.6 Finding Alliances

Although critical theory might seem useful in this analysis, there exists a substantial body of critical special education literature that is readily positioned to merge with humanities-based disability studies. For more than three decades, critical special education literature has challenged the traditional normative paradigm of special education. This literature is doused with references to critical theorists and pedagogues in an effort to integrate the big tent discourse into critical special education scholarship. However, critical special education research has yet to be acknowledged by critical educationalists. In practice, critical special education literature has earned little more than sideshow status in education even though this work represents an exhaustive list of interdisciplinary and international theorists and researchers. With the exception of a handful of teacher preparation programs in the United States, alternative special education theory remains on the margins in both special and general teacher education, and it is off the page among critical theorists.

In fact, it is often the case that among general education audiences, critical issues in special education from an alternative paradigm of analysis must be "contextualized" to insure general educators' understanding. In her discussion of inclusion in a mainstream education research journal, Brantlilnger (1997) felt it necessary to provide a "brief background of the trends and issues in special education in order to place the debate about inclusion in context" (p. 427). Although the boundaries between general and special education evolved as an unintended consequence of

IDEA (Giroux 1996), why is it that these exclusionary structures remain? Given the legacy of critical theory in education and contemporary practice with multicultural issues at the forefront, the preservation of a dual and separate system of teacher training with categorical divisions and a clinical orientation to disability can no longer remain unchallenged. However, critical theorists avert their gaze from both the disabled subject and the dual system of education, as if to suggest that liberatory praxis would naturally exclude the disabled. Exclusionary practices such as these suggest clear complicity when teachers and teacher educators unwittingly preserve and prop up "cycles of oppression that operate in our courses, our universities, our schools, and our society" (Lawrence and Tatum cited in Cochran-Smith 2000). In sum, general ignorance on issues of disability as a category of educational and social oppression evidenced by its absence from professional meetings, scholarly journals, and texts devoted to critical pedagogy, prompts this author to ask, "Why does the academic nod to diversity morph to cringe at disability?" (Ware 2000e).

In the absence of purposeful alliances among critical theorists and critical special education theorists, I suggest a new avenue for solidarity through humanities-based disability studies in education and the involvement of colleagues in humanities[5]. That is, if as Giroux (1996) suggests, cultural studies promises "new spaces for collaborative work" (p. 43), then disability studies in education would invite many important opportunities to provide students with the opportunity to "study larger social issues through multidisciplinary perspectives" (p. 43).

In the section that follows, I describe one aspect of such a project situated in a high school creative writing class in which the teacher and I created a curriculum informed by humanities-based disability studies. This research builds on previous research with secondary teachers in general and special education, many of whom questioned why, despite compliance to IDEA, greater numbers of students remain excluded from the educational mainstream (Ware 1995, 1998, 2000d). Although the official data reports otherwise, the fact remains that while students may be relocated into the educational mainstream in "a rush to inclusion" they often remain excluded in many complex ways that defy a simple body count for compliance purposes. The section that follows describes how one teacher realized the subtle contradictions at play in his own inclusive classroom.

15.7 Writing, Identity, and the Other[6]

> As I understand the concept of the "other," it involves two essential processes: When we make people 'Other,' we group them together as the objects of our experience instead of regarding them as subjects of experience with whom we might identify, and we see them

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[5] One such project is underway at the University of Rochester funded by the National Endowment for the Humanities. "A Collaborative Inquiry on Understanding Disability in Secondary and Post-Secondary Settings" is attempting purposeful linkages with education, humanities, and medicine.

[6] This research served as a pilot project for a

> primarily as symbolic of something else—usually, but not always, something we reject and fear and project on to them. To the non-disabled, people with disabilities and people with dangerous or incurable illnesses symbolize, among other things, imperfection, failure to control the body, and everyone's vulnerability to weakness, pain, and death (Griffin, cited in Wendell 1996, p. 60).

With an emphasis on identity and "othering," a veteran language arts teacher, Tom Painting and I developed a curriculum unit we titled, "Writing, Identity and the Other" for his ninth grade creative writing class. The class consisted of typical students and those with learning, emotional, and physical disabilities (ages 13–15). The unit aimed to promote understanding of disability as part of the human experience drawing from disability studies literature and first person accounts of living with disability. Having had no prior awareness of disability studies, Tom hoped the content would cohere with his year-long theme for the class, writing for self discovery. After several meetings and the exchange of selected excerpts from the literature (e.g., Hockenberry 1995; Mairs 1986, 1996; Shapiro 1993; Shaw 1994), we discussed the value and applicability of this content for his students. Together we identified selections from the readings each of us was drawn to, including two disability studies film standards, *When Billy Broke his Head* (Golfus and Simpson 1994), and *Breathing Lessons* (Yu 1996). Tom relied upon me to propose a structure for the content and I relied upon him to develop the writing activities that would address the following goals for instruction and research.

- What can I understand about the identity of others who appear different from myself?
- What can I learn about my own identity through understanding the identities of others?
- Can disability ever represent anything other than a negative image?

Although, there were many questions we might have focused on, these three represented our initial interests in reimagining disability in the context of a high school language arts class.

15.7.1 Teaming with Tom

Tom is a veteran teacher who has taught for 17 years in the same district, a large urban, upstate New York system. Throughout our teaming, his tenacity and intuitive sense of his students amazed and intrigued me. His teaching is difficult to script as he literally seems never to miss a beat. Each morning, prior to the class, we met over coffee, and based on the previous days' instruction, set a general "target" for our teaching. Classroom interactions were something akin to "trading fours" as I played sideman to Tom and his students. I learned early to follow their lead, or when necessary, to move completely out of the way. The students (ages 13–15), having declared creative writing their major at this arts magnet high school, were in their second year with Tom. This familiarity provided an easy atmosphere in the classroom, one that did not begin with roll call nor did it end at the sound of the bell. Early in my classroom observations (prior to coteaching), a group of his students described their teacher as suffering from "HPD."

"HPD?" I asked with hesitancy, fearing I lacked the vernacular for navigating urban New York schools—or that the DSM-IV I had conjured yet another diagnostic category.

"Haiku psychosis disorder" the students laughed, given Tom's intense appreciation and collection of haiku—a simple, image driven poetry form. True to his diagnosis, on Day 2 of our teaching Tom arrived with an overstuffed folder full of haiku, beaming with the comment, "I found some really great stuff on disability that I didn't even know I had!"

Throughout our teaming, Tom remarked on his growing disability consciousness informed by both personal history and that of his professional practice. He described his awkward encounters in the gym with a disabled man and his own uncertainty about engaging in conversation—a phenomenon that was quite uncommon for Tom. He also recalled experiences from his childhood and youth growing up with a brother who was physically disabled. Tom recalled these events in a stream of consciousness fashion, as though these prior experiences had long since been reflected on until we began teaming. His growing understanding about the cultural and material conditions of disability reminded me of the historian, Douglas Baynton (2001), who asserts, "disability is everywhere in history, once you begin looking for it, but conspicuously absent in the histories we write." (p. 46).

Day 1. We began the unit[7] with a quick review of the previously explored writing genres (e.g., autobiographical writing, poetry, and science fiction). Tom revisited the general goals he had developed for the class and invited student responses as he wrote on the board:

Writing for Self-Discovery
To know about ourselves.
The use of language—how it convinces us to see things a certain way.
To think about where we came from, like the Day of the Dead Stuff and the deaths we've experienced.
Culture.
The future.
The past.
Paying attention to dialogue.
Writing new plots from our lives.
Experiences—imagined & real!

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[7] Because Tom had extended the invitation to work with his class in mid-year, we were forced to work around the Christmas break, resulting in a noncontinuous block of twenty-two teaching days.

After summarizing what he wrote, Tom asked the students to hang on to these goals for their writing, as in our upcoming unit we would address these targets from a slightly different perspective. While still at the board, he marked nine points in a three-by-three array with directions to the students to connect the dots without touching any point more than once. This activity is often used in workshops to depict the value of thinking outside the box as a means to creativity when the only solution to seemingly complex issues is thinking outside the box. Tom engaged the students with the challenge, bribing those who knew the solution to allow their classmates to solve the puzzle on their own. Following an excited discussion of the task, Tom wrote "the Other" beside the image of the box. In the closing minutes of the class, Tom directed the students to: "write a brief definition of the Other. What do we mean by the Other? Who is the Other?" The following are examples:

> When I hear the word Other, I think of the bad. Not the norm. I don't try to think inside of the box but its easier to sometimes. The Other to me is the parts of life and society that people don't want to think about. Maybe because its harder. The other is unwantable.
>
> Different, not the same, something else to choose or pick. Not including one.
>
> To me the Other means all the stuff that I've never seen before or all the stuff that has a different opinion than me. The other is outside my arms length, outside my space and outside my habits.
>
> The other son, the other boy, the other tree outside of the "box," the other room outside of the box.

Days 2 and 3. Building off of their definitions of the Other, we led a whole class discussion of the free write responses that extended over two class periods. Among the key comments raised were those of identity that reflected cultural trends such as body piercing and tattoos, and issues related to sexuality. The exchange was difficult to predict, as topics cut across a range of issues and levels of awareness. Comments specific to homosexuality tended towards sensationalizing, until one student offered: "I have an uncle who's gay, but, in my family, he's not outside of us. I can honestly say that he's one of the best uncles I have." Another, in response to the disdain expressed by some of his peers, raised the ante when he expressed concerns for human rights and social justice, insisting, "if being gay is who you are, no one should have the right to make you feel bad about it." Another student wondered, " Is self-knowing is sometimes about not wanting to know?" Although there was no explicit reference to disability the students demonstrated the capacity to probe complex meanings ascribed to the Other.

The students' writing began with personal definitions that later shifted to society and who has the ultimate authority to define and judge normalcy. The term *normal* was their original descriptor, but given its attendant medicalized notions of the normal-abnormal binary, I introduced the term *normalcy* (Davis 1995) to underscore thinking about social justice. The students appreciated the distinction and were quick to grasp the hegemony of normalcy in a democracy. Our discussion of normalcy led easily into locating the influences on cultural awareness they had previously considered. We closed the day by summarizing where we get our ideas about normalcy. The students' list included "those closest to me—my family, my friends, church, schools, TV—and what I tell myself." Hegemony was thus easy to examine in the context of those judged to be outside normalcy, those we "other" in society.

Pedagogically, Tom's enthusiasm for the topic was significant as it complemented the disability studies material I introduced and it complicated the issues of disability and society. His willingness to include his own experiences in the conversation provided students the opportunity to consider multilayered and problematic analyses of "local histories and subjugated memories" and to express "open and honest concern for human suffering, values, and the legacy of the often unrepresented or misrepresented" (see Giroux 1996, pp. 50–52). However, it is important to stress that it was not our intention to lead students to any particular position as much as it was to consider experiences that might support ways to reimagine disability. Working from specific disability studies materials and first person accounts of disability the students approached the task as writers might—through images, language and expression. By the end of the first week, we were able to introduce the lived experience of disability through poetry as in the examples that follow.

Days 4 and 5.

My Place
I don't want to live in bungalow land
On the outer edges of the urban sprawl
In the places designed for people-like-us
Kept safely separate, away from it all.
I want to live in the pulse-hot-thick-of it,
Where the nights jive, where the streets hum,
Amongst people and politics, struggles and upheaval,
I'm a dangerous woman and my time has come.
(Napolitano 1998)

After providing a few minutes to read the poem in silence, Tom asked the class to read in rounds with each student reading one half of a line aloud and overlapping into the voice of the next student in a round of voices that read as one. The class repeated this for several readings. Then without discussion about the poem, Tom asked the students to "attend to the language of the poem" and to write at the board, the wor or words that "really fix your attention--what captured your imagination as you listened to the poem?"

Pulse-hot-thick-of-it
  outer edges safely separate sprawl
amongst urban sprawl bungalow land
    nights jive
a dangerous woman and my time has come

Students discussed the poem in small groups as we fielded questions about the seeming “archaic” language (e.g., upheaval, amongst, bungalow land, jive). The language of the poem and its juxtaposition to more contemporary language (e.g., urban sprawl, pulse-hot-thick-of-it, nights jive, dangerous woman) led many to speculate about the time period and its setting. Guessing whether the setting was in England, Australia, or Ireland, seemed for some, to be the sole purpose of the exercise. However, others began to speculate about the speaker and their curiosity slowly replaced the animated conjecture about the setting.

“I think the woman wants to get back into a place she’s been pushed out of,” one student offered.

“I think she’s just getting freedom—like for the first time, or something,” said another.

With an air of insistence, another explained, “She could still be struggling to get free—it’s not like she won’t go back to the other place.”

The students were perplexed by the poem unable to make much sense of the actual lived context of the speaker until Tom posed a few questions.

“Let’s think about this for a minute--who lives in places for ‘people-like-us?’” Pausing, he continued, “In our society, who do we keep ‘safely separate?’”

“The elderly?”

“Crazy people?”

“Or maybe, developmentally disabled people--people who can’t live on their own—they’re kept separate.”

Before, we could bring the lesson to closure, the bell signaled the end of class—but many of the students lingered over the question, Who do we keep safely separate in our society? One student paused on his way out of class to redraw the lines that Tom had enclosed in a box around their responses. “Hey, Mr. Painting,” he teased, as he erased the box that encased the words, “a dangerous woman and my time has come.” With a laugh he said, “Don’t you think this woman is probably outside the box?” Tom paused by the board and, with a wide smile, raised both hands wide open to the air and with approval replied, “That’s it isn’t it, Jose?”

When Tom and I met the next morning, he explained his hunch about where we might go after these first few days of introductory material. “Let’s not try to tie everything up too neatly for them. Let’s give them the space to enter where they feel comfortable.” According to his analysis, the students seemed anxious, perhaps, unclear about the purpose of the work, or they were anxious to begin the holiday break. Regardless, he did not want them to feel pressured. Tom then acknowledged his growing unease with the content, remarking, “I hope I know how to stay with them on this—it’s hard stuff.” His comments were quite unexpected. My sense was that the students were holding their own, and I thought Tom was too. I would later learn from Tom that content provoked personal issues—some he thought he had dealt with—and others he knew still needed his attention.

Later, in class, we did not return to the Napolitano poem, but instead began with a focused freewrite. Tom asked the students to define disability leading with the prompt: “Disability is … ” Everyone began writing at once, but when the designated time elapsed, several students asked for additional time. Before inviting the responses, Tom asked, “Did anyone feel frozen at first? I was surprised at how difficult it was to come up with the right words.” Many students agreed and commented about having written too many words or too few words. One student explained, “It’s weird because it’s something you know you know, but just don’t really think about it.” Others offered the following definitions.

> Disability is many things. It can be when you cannot work parts of your body or it can mean you cannot read well. To me, everyone can have a disability in some way even if you don’t see it.
>
> Disability is a problem that some people have that prevents them from living a life like able-bodied people. They may need a wheelchair, a walker, a cane, a seeing-eye dog, a tutor, or captioning and interpreting for all spoken words, or artificial machine-assistance to help them carry on their body’s normal functions. A disability may weaken a person physically, but their thoughts and emotions are just like all peoples *[sic]*.
>
> Something that causes a person to become unable to function the same way other people do. They may still be able to function normally, but in different way*[sic]* than people without a disability do.

Overall, their responses were a mix of objective and subjective descriptions that tied into the earlier conversations on normalcy and the range of visible and invisible disabilities. The exchange prompted Tom’s memory of a summer job in his college days as a home health care provider for a disabled adult—something he admitted he had not thought about in years. Tom recalled his reluctance to perform the job requirements, his inability to contend with personal feelings about dependency so starkly contrasted to his own youth and athletic accomplishment that framed his identity. All of these emotions so complicated the job that he resigned from the position in less than a week. The intersections of these very critical issues proved to be of great interest to the students as the tables were turned, and they probed their teacher’s emotions and attitudes.

As a researcher, I observed Tom’s easy exchange with the students despite his prior concerns about the emotional demands of the content. It is interesting that when when Tom and I initially planned the unit, he made no mention of his personal experiences with disability. However, since we both participated in the writing assignments along with the students, recounting our personal experiences was a given. On the one hand, it was valuable that Tom located himself in this inquiry with the same desire to understand disability differently, as did his students. Conversely, in his role as the teacher his vulnerability led to concerns about where our teaching would ultimately lead us. The challenge of teaching in the zone of the unknown was clearly becoming burdensome as we neared the Christmas break.

Earlier that day we had wondered how much could be accomplished given that we were at the end of the last full week of instruction prior to the holiday break. Knowing the following week would be marred by interruptions with holiday programs, early dismissals, and the general frenzy in high schools prior to a holiday, Tom made a quick decision to assign weekend homework. Despite the students' groans of protest, they were assigned an essay describing their first experience with disability. When the students returned on Monday, they had written varied accounts of family members and classmates with a range of disabilities, many provided loving descriptions of grandparents whose aging led to disability, others wrote about themselves. Karen, a student with physical disabilities titled her essay, "Telling about disability, telling about me." Her essay began with the following:

> My first encounter with disability was when I was born with spina bifida that affected my spinal chord. I wear leg braces (you probably noticed this). When I was little I didn't walk till I was 3 years old. My parents are very protective of me.

15.8 Reflecting with Tom

Although I felt that the first two weeks of instruction were a great success, the experience left Tom with new doubts about his teaching. He wondered why, prior to this unit, Karen and some of the other students had never written about disability. He was unable to recall a single student in all his years teaching who had ever written about disability. He wondered if he had somehow failed to create a place in which it was safe to examine this issue. As a consequence, he expressed doubts about whether the class, now halfway through their second year together, was really a community of writers. More important, Tom wondered if he had unconsciously avoided the topic of disability. His concerns surprised me, but they also provided the opportunity to discuss how schools silence particular discourses. Specifically, race, class, and sexuality are often cited in the educational literature as silenced discourses, but rarely is disability considered among the inequities resulting from the normalizing discourses of schooling. I explained that in the example of disability only certain professionals are sanctioned to broach the topic. That is, although conversations about disability occur in schools everyday, for the most part, they are restricted to procedural issues of identification, referral, and placement in special education, or they focus on related problems of staffing, curriculum and inappropriate student and parent behavior. This discourse of containment and control has failed to consider disability through a cultural lens or what it might mean to live with a disability over a lifetime.

As our teaching progressed, Tom recognized his reticence growing from a number of sources. He acknowledged his lack of familiarity with the materials I provided on disability and was surprised to find so many sources available to support disability studies. In addition, he was discomforted by the fact that he had not previously considered disability as an identity category. Relatedly, his lack of vocabulary to discuss disability with his students was discomforting. More important, he was slowly coming to realize that students with disabilities would not be likely to find themselves anywhere in the curriculum.

15.8.1 The Final Two Weeks

When we reconvened after the break, we began with Tom's package of haiku. In small group discussion, the students were asked to speculate beyond the moment depicted in the haiku and to flesh out a character with details of physicality and history by locating him or her in a scene. "Envision human attributes—a voice, a look, a story to tell." Tom urged.

a girl is wheeled in--
chatter ceases
in the ladies' room
Jocelyne Villenueve

MEN ONLY
door too narrow
for his wheelchair
Rebecca M. Osborn

Among their examples are the following:

> The girl is about 23, but why is she called "girl?" She has just been in a car accident and is paralyzed. She is hooked up to all sorts of devices attached to the back of the wheelchair.
>
> I see a little girl in a wheelchair that cannot go to the bathroom by herself. I think she is small and has brown eyes and is embarrassed a little too. I know how she feels too in some ways because I have a disability and sometimes I get a reaction similar to that.
>
> This man has been handicapped for a while now. He's depressed but still tries to get out of the house. He's alone and has a hard time. Even though he's a man he can't get in the men's room so it's like since he's handicapped he's not a human being. I picture he's overweight, 40 years old, tight blue shirt, messy hair, jeans.

Reviewing their writing, I noted patterns that might be characterized by themes of empathy/compassion, pity/knowing, self-knowing, and rescue/saving. I prepared a handout with excerpts from their writing along with the list of themes and asked the students to confirm these themes or to identify other emotions I may have missed. The students added "anger" and "resentment" and then realized the list comprised only negative emotions. In discussion of why this occurred some students seemed at a loss to explain. Others, like Jose, seized the opportunity to remind everyone about his earlier analysis of the cultural messages we receive about disability when the class discussed the Napolitano poem. This time, he expounded on the negative portrayals of disabled people in films:

> I still dislike they way they're portryed as angry, vengeful people like in films--Davros—in Dr. Who, or the Phantom in the Phantom of the Opera, but this story I like because it showed at the end that the Phantom had human emotions.

In response, another student insisted she had really heard many adults describe other adults with disabilities as girls or boys instead of women or men—as she had written in her characterization. She challenged Jose's analysis explaining that she had borrowed language from how people really talk about the disabled, and not how they talk in the movies. Students contributed to both sides of the debate raising issues about how we infantalize disabled people, how fear frames difference, and how, without thinking, we perpetuate negative media stereotypes. It was remarkable how much the students raised in their criticism generated by two haikus. From this point, it was easy to revisit an earlier conversation on the social construction of disability and the acknowledgement that they lacked sufficient experience with disability to aptly portray characters with disabilities. One student explained, "Its funny, that we don't really talk about disability in school. If it is just another way to live, then why don't we know more about that way?"

In our final activity we viewed the documentary, *When Billy Broke his Head … and Other Tales of Wonder* (1994). This award winning film introduces more than 20 activists who live with disability and view the experience as central to their identity. The narrator, Billy Golfus, a former radio journalist who was brain damaged after a motor scooter accident introduces the film saying, "This ain't exactly your inspirational cripple story." The students' final writing assignment was to develop characters informed by the individuals in the film. In contrast to their earlier writing, their characters—informed by the lives of the individuals they came to know in the documentary—were markedly more witty, complex, and humane.

15.9 Implications for Teachers

This research was designed to explore K-12 curriculum approaches informed by humanities-based disability studies as described in part one of this paper. Although I reported only a fraction of this classroom research, in this final section I will focus on the implications for teachers when attempting similar content to promote new understanding of disability. In many ways, one of the greatest challenges to teaching this content will be for teachers as they contend with personal issues that surface as they confront unexamined attitudes, assumptions, and beliefs about disability. Consider for example, Tom's realization of the absence of disability issues in his general teaching for over seventeen years. Obviously, this was a surprise and a disappointment given his espoused ideology and daily practice. That is, Tom attended individualized education plan meetings and worked individually with counselors, social workers, special education teachers and other team members on behalf of his students with disabilities. Among his colleagues, he was known to be an inclusive practioner, and yet disability-related topics were nowhere to be found in his curriculum. He explained this in an interview after we completed the unit: "I felt that I lacked the authority to talk about disability; that was someone else's job." In fact, because the discourse on disability in public education and society is so entrenched in the medical model, by most standards, Tom did lack the credential to address disability in his teaching. Professionals from medicine, rehabilitation, psychology, psychiatry, social work, and special education inform the discursive community on disability, which results in a normalizing discourse that informs the collective view of the disabled as diseased, weak, tragic, and too often deserving of their fate.

However by introducing disability as a cultural construct with the purposeful goal of reimagining disability, Tom was more than qualified to introduce these issues. By examining disability through a cultural lens he tapped into prior experiences to inform his insights and practice in a reflective teaching approach. Curiously, this aspect of our teaching was not addressed when we planned the unit. I shared my background as a parent of an adult son with physical disabilities and as a former special education teacher and administrator. However at the time, Tom did not realize the importance of his personal experiences to his teaching of this content, and I did not assume it was necessary to inquire about his lived experience. In retrospect, this proved to be somewhat ironic in that my work with pre-service and practicing teachers is focused on acknowledging prior experience in the formulation of our constructs about ability and disability. As our teaching evolved, the importance of personal reflection when teaching this content became readily apparent. Now that I have expanded this project to include five new teachers along with Tom, the project teachers began with a journal assignment similar to that which I use in my teaching and workshops, titled, My First Memory of Disability."

15.10 Conclusion

If teacher educators accept the challenge of reimagining disability we must begin by problematizing disability through a cultural lens. This approach will necessitate new alliances with colleagues in the humanities and new conversations informed by humanities-based disability studies. Teacher education must recognize that purposeful links between general and special education have failed to occur in most teacher education programs. Although some universities have taken the lead in this enterprise, notably, Syracuse University (Blanton et al. 1997) and the University of South Florida (Paul et al. 1993), many teacher preparation programs are institutionally sanctioned to perpetuate educational apartheid. Turf wars and age-old disputes about professional credentials for educating students with special needs remain unresolved and serve to silence more important conversations about disability as a political and discursive entity. Among these issues are those which Tom and I addressed in his class including identity, education, representation, access, employment and strategies for empowerment and activism, and most significantly, personal meanings of disability. By no means is this list exhaustive, as important related concerns include issues of sexuality, spirituality, religion, and the genocidal aspects of the human genome project. In sum, consideration of these topics would dislodge the silence buried deep inside the uninspired curriculum that restricts teacher and student imagination about disability in both secondary and post-secondary education.

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