

## Infusing Disability Studies into “Mainstream” Educational Thought: One Person’s Story

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**Abstract:** The purpose of this article is to explore how ideas from disability studies can inform “mainstream” educational practice. In this autoethnographic narrative I describe a personal journey of planning, teaching, and evaluating a 3-hour “in service” presentation for high school principals. In my account of this event I alternate between a description of the content, my personal reflections, and participant reactions. I demonstrate how the content and format of this kind of presentation can serve as a formalized context for generating a much needed dialogue between disability studies and current practices in the field of education.

**Key Words:** Education and disability studies, in-service, secondary education

### Introduction

“They’re in another world.”

“They need to come down from the ivory tower.”

“It’s been so long since they’ve been in a school – if they were ever in one.”

“Some of their ideas are great – they just wouldn’t work with my staff.”

“They wouldn’t last five minutes in my classroom.”

“Courses in education do not prepare you for the reality of teaching in a school.”

These are typical of the comments I have heard about university instructors from teachers and administrators over my fifteen-year career in education. Each comment reflects the disparity between what is taught at the university level and what is needed to survive and flourish in a school setting. As a professional development specialist in a large urban school system, I have often been required to promote mandated policies and locally-chosen instructional initiatives. Much of my work has been to support “change,” and I am always intrigued by people’s acceptance of, or resistance toward, change.

As a part-time doctoral student, I am no exception when it comes to contemplating the usefulness of theories taught at the university level. I often ask, “How can I make what I learn practical for school staff? How can I teach administrators, teachers, paraprofessionals, and other school personnel new information that assists them in working with students?” In short, “How can I link theory and practice?” My own ongoing attempts are, in part, a result of my dual identity as student of education who is interested in theory, and as an educational practitioner interested in creating social change.

The purpose of this article is to explore how ideas from disability studies can inform “mainstream” educational practice. Within the “mainstream” field of education, scholars, policy makers, and educators have long conceived disability within narrow and oppressive frameworks that unquestioningly uphold dominant paradigms of thought. While scholars of disability studies acknowledge this, and offer different paradigms, noticeable silences exist about the field of education within disability studies. Conversely, in the field of education, silence exists around studying people with disabilities in a multi-dimensional, interdisciplinary manner. Though these dilemmas are underdiscussed within and across both fields, they are inextricably connected.

By introducing “mainstream” educators to disability studies in professional arenas, long-resisted conversations I am interested in pursuing are orchestrated. In focusing on one such event, I desire to share a story that reflects the struggle to bridge theory and practice. Through personal narrative, I capture my journey of planning, constructing, presenting, and evaluating a 3-hour “in service” presentation for school personnel. As such, this methodology is an example of what Richardson (1994) calls “a highly personalized, revealing text in which an author tells stories about his or her own lived experience” (521).

### Potential Significance

This article is about fostering dialogue between advocates of academic disability studies and practitioners of K-12 education. As Corker and Shakespeare (2002) write, “Theory has to be conceived as a means to an end, rather than an end in itself” (15). Originally, I felt it was a risk to create an “in-service” that incorporated disability studies because of the entrenched attitudes about disabilities held by most able-bodied school personnel. Like teaching the concept of “whiteness” to whites, it evokes an emotional response that implies a complicity in the status quo of dominant discourses that shape societal practices. In brief, the presentation was designed to make people conscious of that which is often relegated to the dysconscious or “uncritical habits of mind” (King 1991, 131). Nonetheless, I now believe that disability studies is a powerful tool in destabilizing traditional thinking within “mainstream” education venues. Furthermore, I hope that the structure, format, and information I chose to include can serve as an example of a change agent model that could be utilized by others.

### Questions

In planning the project, I posed two questions to contemplate and asked myself why they were important to me. The first is “How can I infuse disability studies into ‘mainstream’ educational thought?” Though I work with hundreds of educators, I have never had a conversation about disability studies with any of them unless initiated by me. Is that surprising? I did not know about disability studies until fairly recently. This is ironic given that I have considered myself to be within the field of special education for my entire professional career, despite questioning the majority of its practices. I am therefore led to ask, why is disability studies not addressed in “mainstream” academic journals, most universities, and in actual schools? Clearly it is a conflict of interest with almost all publications and educational institutions operating within the institutionalized special education-general education dichotomy. Given this dilemma, what then is the best way to liberate voices that appear continually silenced within and outside of academic thinking?

The second question is, “How can disabilities studies be introduced and used to challenge entrenched belief systems and attitudes towards the education of students with disabilities?” I have supported the notion of inclusive education<sup>1</sup> since I came into contact with it in the early 1990s. I have spent years working with general and special education teachers and administrators, many of whom have resisted the integration of students with disabilities into general education classrooms based upon their self-conviction that current practices are in the best interests of students. However, I have always been disturbed that the dual system allows educators to conceive of two “types” of human – one general and one special, thereby actively participating in transforming students with disabilities “into a breed apart from other students”

(Karagiannis 2000, 129).

### Why Disability Studies?

After working for years in special education I came to question school structures that segregated students classified as disabled, causing them great emotional and psychological pain. As I began to read literature by people with disabilities written from a disability studies framework (Rodis, Garrod, and Boscardin 2001) and research that actively sought out their usually silenced voices (Ferri, Keefe, and Gregg 2001; Gabel 2001), I developed an increasing awareness of *their* insider perspectives and interpretations of school experiences as students and as teachers. Many had internalized a sense of failure by virtue of being placed in special education classes (Varenne and McDermott 1998), some conveyed school as a site of oppression (Reid and Button 1995), while others expressed anger at their isolation (Piziali 2001; Vee 2001).

Foucault (1977) called attention to “the indignity of speaking for others” (209), yet the field of special education is traditionally comprised of non-disabled people making profoundly life-shaping decisions for people with disabilities. School structures are microcosms of the macro-culture, and as such they influence each citizen’s understanding of the *place* and *value* of disabled people. As they stand today, most school structures still support the placement of students with disabilities in *separate* locations from “mainstream” peers.

Disability studies challenges such structures and the assumptions on which they are founded. Instead of perceiving disability as a deficit (physical, sensory, emotional, or intellectual), disability studies scholars assert that disability is caused “by the failure of society to remove its disabling barriers and social restrictions... in other words, disability is something wrong with society” (Oliver 1996, 129). Wendell (2001) criticizes the non-disabled’s obsession with prevention and cure that “focus public attention on the medical model, which leads us to ignore the social conditions that are causing or increasing disability among people with impairments” (31). The claim is clear: people are not inherently disabled. *It is society that disables them.*

The dominant paradigm that medicalizes disability is directly challenged by advocates of the social model who have sought new ways of conceptualizing disability. The former paradigm has reigned since the rise of the medical profession in Western society (Foucault 1994), while the latter is ideologically located in a framework of social change akin to the Civil Rights movement pioneered by African-Americans in the 1950s (Hampton and Fayer 1990).

In many respects disability studies is a relatively new discipline, exploring different ways of thinking about the world in relation to the phenomenon of “disability.” As such, disability studies does not claim to be a unified field of inquiry, but rather reflects multiple perspectives simultaneously. And while the social model is the primary conceptual framework within the emerging canon of disability studies, its own hegemony is challenged from within. Shakespeare (1994) feels the social model is overly simplistic and needs a more complex definition that considers various social phenomena because “people with impairment are disabled, not just by material discrimination, but also by prejudice. This prejudice is not just interpersonal, it is also implicit in cultural representation, in language and in socialization” (296). While concurring material societal barriers exist, Shakespeare also raises questions about *attitudes* toward people with disabilities and how *attitudes are formed*. Wendell (1999) points out that in their haste to challenge the medical model, some disability scholars may contribute to replacing one restrictive paradigm with another, minimizing the complexities of disabilities, and neglecting the medical

connection altogether – which is, in fact, a large part of reality for many people. She writes, “We must learn how to live with the suffering body, with that which cannot be noticed without pain, and that which cannot be celebrated without ambivalence” (332).

However, these conversations typify discussions in the emerging field of disability studies, reflective of a common desire for multidimensional and critical understandings of disability, hitherto neglected in dominant scientific-medical paradigms. People with disabilities have reason to mistrust traditional research methodologies and conceptual frameworks of disability, characterizing them as “at best irrelevant, and at worst, oppressive” (Oliver 1996). Prevailing scientific-medical notions of prevention and cure associated with disabilities deflect attention from the actual lived experience of disabled people, while simultaneously fostering strong associations of pity and patronization thereby effectively furthering oppression (Shapiro 1993).

Disability studies is therefore an academic discipline invested in challenging traditional thinking. At its core is an increasing number of people with disabilities – be they scholars, research participants, or both – speaking from center stage, with and without able-bodied allies. This central positioning gives rise to opportunities for the non-disabled to establish “a permanent relationship of dialogue with the oppressed” (Freire 1970). In redefining “disability” and “normalcy,” scholars in disability studies challenge the presumed hegemony of the non-disabled; the namers are now questioned by the named. As hooks (1994) points out, the privileged act of naming:

“...Often affords those in power to access modes of communication and enabled them to project an interpretation, a definition, a description of their work and actions, that may not be accurate, that may obscure what is really taking place” (62).

What takes place in our schools is an example of the subjugation of the disabled by the non-disabled. It is these pervasive and seemingly taken-for-granted policies and practices that scholars in disability studies actively seek to transform. The reasons or justification of this subjugation and its results will be addressed and challenged throughout the course of this article.

### Theoretical Framework

A disability studies lens is valuable because it seeks to actively challenge societal practices in and out of the academy. As Linton (1998) notes, “The enormous energy society expends keeping people with disabilities sequestered in subordinate positions is matched by the academy’s effort to justify that isolation and oppression” (3). She also claims that “the term *disability* is a lynchpin in a complex web of social ideals, institutional structures, and government policies” (10). In untangling and illuminating parts of the web, I seek to bring a more complex understanding of disability – including social, cultural, and political ramifications – for those who are identified with this label.

### Method: The Value of Story

This study is a personal narrative; a story by and in part about me and the people with whom I came into contact. I chose personal narrative as methodology for several reasons. First,

narrative inquirers often work in a particular context and “on a small scale” (Elba-Luwisch 1997). For these reasons, namely “the study of the unique and the contextual,” Gudmundsdottir (1997) concurs that “narratives have succeeded where other methods have failed” (1). Because I describe a highly contextualized specific event, I believe narrative a fitting choice. Second, this presentation is a seemingly ordinary occurrence in which the power of narrative can be demonstrated because I seek to “capture events and phenomena in such a way that we are [I am] able to bring them ‘up close’ as opposed to ‘out there,’ distant and abstract” (Gudmundsdottir 1997, 1). Fairbanks (1996) believes that narratives yield a particularly valuable form of knowledge. He explains, “Analyzing the complexities of the ordinary through the stories individuals tell us or the events they experience together in light of theoretical concepts is one of the primary means of constructing knowledge through narrative” (327). Third, narrative is inextricably meshed with the *act* of teaching itself, as “teaching can only be known through story” (Doyle 1997, 93). As a presenter I knew I would encounter audience members with stories they needed to share, tales of self, family, school, etc. I also knew I would engage in swapping some stories, and recognizing their stories as part of *my chosen material*. As Anderson (1997) notes, “Knowledge communities provide bridges between theory and practice and are ‘seeding grounds’ for competing stories that may lead to meaningful, enduring, educational change” (132). Fourth, it is this very process of dialecticism that is part of narrative research. As a method, it “redraws the distinction between public and private, holding the materials of one’s personal life as essential to an understanding of one’s work, and particularly so, when one’s life and work are concerned with education” (Elbaz-Luwisch 1997, 81).

As a *personal* narrative, this article can also be viewed as autoethnographic. Bullough and Pinnegar (2001) have asked the question, “Shouldn’t teacher educators study their own practice, since one’s practice is... who we are?” (14). I agree with Ellis (1997) when she writes, “Autoethnography should be self-absorbed” (122), and the autoethnographer “... also needs to be absorbed within the world she inhabits and the process she finds herself a part of, which also work their way into one’s identity” (123). Furthermore, I believe that autoethnography is not self-absorbed in a merely narcissistic manner. Rather, it allows the author to be the prism through which meaning is being made. In this article, I am not saying look at me, but rather *look with me* and *look through me*. Researchers must be self-reflective about their own knowledge and beliefs, and the relationship these play in the constant reshaping of our own identities. We must remember our “... stories we bring as researchers are also set within the institutions within which we work, the social narratives of which we are a part, the landscape on which we live” (Clandinin and Connelly 2000, 64). With such knowledge, claim the authors, comes responsibility and the need to act on beliefs because, “We are complicit in the world we study... [and therefore] we need to... offer up research understandings that could lead to a better world” (61).

The pursuit of a better world can mean questioning established practices. As a methodology, autoethnography contravenes an accepted notion of social science, that of separating subject and researcher, thereby rejecting objectivism and what Johnson (1987) calls its “god’s-eye view about what the world is really like” (x, cited in Clandinin & Connelly 2000, 36). This study is a text I have created, and I readily acknowledge it as “a construction rather than realist interpretation, one version of reality rather than the only version” (Tierney 1997, 25). As Lincoln (1997) has attested, “all texts are created from partial perspectives, and that furthermore, that is the best we can hope for” (37). My partial perspective, therefore, has been framed through the use of autoethnographic narrative in which I am:

“An object of inquiry who depicts a site of interest in terms of personal awareness and experience; it utilizes the self conscious or ‘pervasive nervousness’ referred to by Geertz (1988) to reveal subjectively and imaginatively a particular social setting in the expressions of local and grounded impressions” (Crawford 1996, 167).

## Background and Context

In this research I describe and reflect upon a presentation I did during the spring of 2002. First, I will describe the context from which it evolved. This information is important because it demonstrates how educators can be proactive in introducing disability studies by seeing new opportunities in familiar situations. Originally, I was asked to present “The First Year of Implementation of The New Continuum of Services” to 50 counselors, educational evaluators, school psychologists, and teachers of speech (many of whom prefer to be referred to as “clinicians”). This “new” continuum is the response of the Board of Education to the Reauthorization of the Individuals with Disabilities Education Act (IDEA) (1997). Having presented on the same subject for the same group twice the year before, I was wary of having little more to say than in previous times. After deliberating, I agreed to do it if I could spend fifty percent of the time on “increasing disability awareness” before I delivered the content of the workshop presentation, as described in the originally proposed title. I informed the administrator that I wanted to introduce new material and would take risks that may intrude upon people’s comfort zone. Despite trepidation – I did it. According to my own impressions, and the written feedback, the presentation went well. However, I noticed by reading facial gestures, body language, and covert exchanges that it *was* discomfoting at different times for different people.

The following month I was asked to present to two groups of principals on the topic of team teaching. As I co-planned each session with representatives from their groups, I suggested a slight modification of the presentation on disability studies already developed to be an equally weighted piece preceding their targeted content. I explained that this would generally deepen their understanding of (re)integrating disabled students into general education classrooms.

For the second presentation I was a guest speaker in a different school district, but the third presentation I was on “home ground.” My narrative in this article will focus on the third presentation, although I refer to other sessions occasionally. I drew on material from a variety of sources, most notably my Advanced Seminar in Disability Studies at Teachers College.<sup>ii</sup> Other sources included film clips and videos I have used in previous staff development sessions or graduate courses, along with materials I constructed.

I am aware that I cannot capture three hours of an interactive event within a few pages, so I have taken some liberties. I write the following section in the present tense, which draws readers into the text, making them feel more like they were there. The section weaves the content of the presentation with audience responses. I convey this information as text, rather than dialogue, although, I recognize that in doing so, I lose the excitement and immediacy of discussion and debate in which knowledge is constantly (re)contested and (re)appropriated (Bakhtin 1986).

I have included my thoughts in italics. This reveals – among other things—my decision-making, personal reflections on the way we operate as schools in a society, and my hopes for new ways of thinking. I acknowledge that there is a risk of these two devices becoming blurred,

but hope this serves not as a distraction, but rather a way to convey a richer, more complicated text.

To avoid interrupting momentum, my narration moves between sections without stopping to introduce each one. However, for those who may wish to utilize the format or a variation of it, I have also outlined the presentation in a linear manner, as shown below:

1. Popular Notions of Special Education.
2. Framework: Reconsidering Disability as Private Citizens and Public Employees.
3. Objectives of Presentation.
4. Choosing and Using the Lens of Disability Studies.
5. Calling on the “Minority Model.”
6. Listening to “The Disabled.”
7. “What does it mean to be ‘able’?”
8. “What is meant by ‘disability’?”
9. Foregrounding Privilege.
10. Challenging the Status Quo.
11. The Politics of Exclusion: Contemplating *Brown v. Board of Education* (1954) and the Reauthorization of the Individuals with Disabilities Education Act (1997).
12. Issues of Access and Integration in Schools.

Note that each segment is of a different length, depending on the overall flow of the workshop. Different methods of instruction were utilized to facilitate the process of information. Each presentation fluctuates depending on what needs to be stressed. In section 11 it may be interesting to target different “minority” groups to explore similarities and differences.

I used different methodologies within the presentations to promote active participation. These took the form of individual reflections (silently or in writing), frameworks for guided note-taking when watching videos, interactive dyads, conversations in small groups, and whole group discussions.

### Presentation

The title of the presentation is “Students with Dis/abilities: Team Teaching as an Option in The New Continuum of Services.” One of my aims is to challenge (and derail) the way principals think about disability. I purposely do not use “Special Education” in the title, as that concept has ossified into signifying a segregated place, rather than a service. The “/” in “dis/ability” serves to disrupt expectations. Though the term may appear awkward, it is designed to jar initial associations non-disabled people have in relation to the word “disability” which is to immediately emphasize what people cannot do, over what they can.

*I had many concerns before this presentation. It is has been my experience that principals dread meetings about special education that they see as overly bureaucratic, self-consumed with regulations and mandates, and view as “kids with problems.” Most issues are immediately deferred to the assistant principal for special education. I also know that principals are extremely busy, overwhelmed people with incredibly difficult jobs. I was going to take them into areas many had previously resisted.*

*My superintendent and a host of other high-ranking administrators would be there. What if the presentation didn't go well? What if it was too ambitious, too jarring, too "off-putting"--perceived as disconnected from their schools? These thoughts were always at the back of my mind, yet I convinced myself that mine was the right approach, no previous strategies over the years had created the change I had hoped to see by this time.*

For the opening section, I have chosen a clip from the television show, *The Simpsons*. In this two-minute snippet, Bart arrives at his new school, and instantly becomes popular with his classmates. However, when the teacher calls upon him to read cursive script, Bart is unable to do so, never having been taught it—this results in his being escorted to the “Leg Up” program. His peers here include a student who speaks another language and is assumed to be slow, a girl who bumped her head one day and woke up in the program, and a boy who starts fires. The teacher asks students to take out a safety pencil and a circle of paper, to “finish work on the letter ‘a.’” When Bart asks, “Let me get this straight – I’m supposed to be in the 4<sup>th</sup> grade, and I’m going to catch up by going slower? Goo-goo.” The entire class begins to chant “goo-goo, goo-goo.” Soon, Bart looks dejected as he half-heartedly joins in a game of musical chairs (in which none are taken away), and the teacher claps her hands to proclaim, “Everyone’s a winner!” Once the clip is over, I pose two questions for participants to discuss in groups--What did you see? What is the message?

*The Simpsons clip is a good “opener” because, through exaggeratedly comic stereotypes, it clearly illustrates a school in which: (a) there is a place to put students who do not meet grade-level expectations; (b) that place is filled with other stigmatized children; (c) they exist in a land of perpetual remediation with a deceptively artificial reality (is everyone a winner--or a reject?). To substantiate this critique, I relate a personal anecdote about a recent school visit I made to a special education class. A student said she wanted to sit out of sight from people passing in the hallway, for fear she would be identified as retarded. When the teacher said, “You’re here because you’re special,” the student replied, “Bullshit.”*

I transition to articulate that we are going to contemplate “disability,” not “Special Education” *per se*. To do this, I ask audience members to think in dual terms for the entire duration of the presentation--along one track for themselves as individuals (who they are, what they believe, and why they believe) and along another track as an employee (working within bureaucratic parameters, legislative issues, and other buffers). I want to acknowledge the tension between both “situations” and have a discussion that is not only confined to schools, but encompasses how non-disabled people generally view the disabled.

*I think everyone is connected to “disability” in some way. For those not personally disabled, a family member or friend connects them to the issue. The duality of thought that I want to encourage helps me ease people’s thinking between educational practices and societal practices at large. It needs to be highlighted that further access to classes for the “general” population is only one step in the larger struggle for access in society.*

At this point I explicitly state my objectives--participants will: (a) compare the implications of being labeled “disabled” v. “non-disabled” in school and society; (b) examine and analyze their individual knowledge and belief system about people with disabilities; (c) hear the perspectives of people with disabilities (d) explore team teaching as one option to support the increased integration of students with disabilities.

*The agenda is heavily frontloaded with disability issues, yet their application to classroom experience will be demonstrated when I shift the presentation to the practicalities of*



*team teaching. It is important to connect practice to theory throughout, and especially to partake in conversations about classroom practices.*

I now bring their attention to the important point that this presentation will be using the lens of dis/ability Studies. I ask rhetorically, “Why have I chosen this lens?” I share my impression that the skin around special education is extremely thick, yet needs to be penetrated in order to reach a place in individuals where they can begin to see what is not usually seen, and that what we take for familiar can be seen as something else. Sharing my belief that the framework of disability studies affords me this opportunity, I make clear that our conversations will not be about business as usual; we will be taking risks. I introduce them to Linton (1998) and the notion of seeking to re-conceptualize disabilities:

“Disability studies has arisen in the past twenty years to focus an organized critique on the constricted, inadequate, and inaccurate conceptualizations of disability that have dominated academic inquiry. Above all, the critique includes a challenge to the notion that disability is primarily a medical category” (2).

*I decide not to problematize the notion of the social model. For most, if not all, participants it is their introduction to the notion. Recognizing the asymmetry of knowledge and therefore power (Foucault 1980), I consciously decide to aggressively emphasize the social over the medical model in order to make an impression.*

For the purpose of this presentation, I next suggest people think of disability within a “minority model.” For some, it is useful to picture people with disabilities as a “minority” similar to people of color, women, gays and lesbians, Latinos, Native Americans, Asian-Americans, I lead a discussion on how minority groups came to be formed, how various disciplines of study have evolved and are represented in many academic departments. I ask people to privately identify with one or more “minority,” and to keep that identification at the forefront of their thoughts for the balance of the presentation.

*I know almost everyone can relate to some aspect of being minority. I want to connect emotionally with people, to make personal these issues of exclusion and powerlessness, to acknowledge how marginalized people with disabilities are in our society. In using this ongoing analogy, I hope I do not make anyone too uncomfortable. However, I believe a certain amount of discomfort and tension in pedagogical practice can serve as an opportunity to grow (Kumashiro 2000).*

I ask that we be always mindful of the question, “Who is speaking?” I explain that one of the things that attracts me to disability studies is the opportunity to listen to the voices of people considered disabled. If we think of how the minority with whom participants have identified are portrayed or described without members of the group having a voice in proceedings – how do they feel? People in such positions often get angry, feeling “wrongly” portrayed and stereotyped. I know that if I want to learn more about a particular group that is not like me, I have to go to the source. I either talk *with* “them” or read books *by* “them.” Scholars and research participant in disabilities studies have described being systematically kept out of mainstream dialogues. I ask, “When do we listen to the voices of the disabled?” People slowly concur that in most situations rarely, if at all. For this reason I have brought their voices with me. I proceed to share overheads of quotations from young adults with disabilities who have gone through school systems and survived. Marshall (2001) describes, “As a child, it was very shameful to be in the Learning Disabled classes or be considered ‘retarded’ in any form... Having a learning disability

is only a small part of who I am” (120). Pelkey (2001) claims, “... I was taught to hate myself... my foundation for hating myself grew out of my much noted shortcomings and lack of abilities deemed positive... I became less than” (18). In challenging the negative associations with having a disability, O’Connor (2001) seeks to redress the imbalance and provide a more accurate description:

“There are so many positive aspects of ADHD. For example, I can do many things at one time successfully... My main goal is to be able to control my ADHD in certain settings, and to use it as an advantage, rather than taking drugs to suppress all my creative energy... The problem is that most of the literature about ADHD is written by people who do not have ADHD. They generalize... and say the symptoms are concrete. This is extremely offensive to me... [As] my situation can be totally different from another person with ADHD” (71).

What do these quotations tell us? In contrast to Marshall’s (2001) description of his LD, we are all too familiar with the label of disability coming to dominate the school identity of a child. Pelkey (2001) describes how her abilities are de-emphasized until the picture she has of herself is that of a person lacking something, making her less valuable than others. O’Connor (2001) conveys the annoyance of having a meaning made by others imposed on her, when she knows differently, knows better.

Together, these three testimonies convey the stigmatization, shame, and misunderstanding experienced by students with disabilities in schools. Almost all quotations I use are from people with disabilities and/or disabilities studies scholars. I want to turn the tables, and invite participants to hear some points of view that do not usually get much attention.

Bearing in mind we have established that people with disabilities often perceive schools and society quite differently from the dominant group, I now move to how people with disabilities primarily stress the problem of social barriers. Furthermore, a stress on social barriers deemphasizes, and ultimately rejects, the medical model of disability. A quotation from Wendell (2001) is shared:

“Prevention and cure both focus public attention on the medical model, which can lead us to ignore the social conditions that are causing or increasing disability among people with impairments. Moreover, given the history of eugenics, there is a reason to be skeptical about whether prevention and cure are intended primarily to prevent suffering or eliminate ‘abnormalities’ and ‘abnormal people’” (31).

This is a simple but fundamental idea that is capable of moving people’s thinking. However, people seem so invested in the “objectivity” of science as the ultimate “solution” to “problems.” Mitchell and Snyder (2000) link the responsibility of science to how it has shaped widespread thought, casting various “groups” of people as inferior and/or undesirable:

“Physical or cognitive inferiority has historically characterized the means by which bodies have been constructed as “deviant”; the Victorian equation between femininity and hysteria; the biological racism that justified slavery and the social subordination of racial minorities; psychiatry’s categorization of homosexuality as a pathological disorder; and so on” (2).

Scientific beliefs and practices can and should be questioned. Scientists have been mobilized at various times to defend practices in the interest of dominant groups. They have supported female biological inferiority, people of African descent being valued as three-fifths of a Caucasian, and the electrocution of gay people as “aversion therapy.” It seems we still struggle through the damaging vestiges of 19th century medicine. I wonder, for what oppressive practices will our society be remembered?

I turn the tables, by asking “How do the disabled view the able bodied?” This is a provocative question, akin to more familiar (though arguably equally discomfoting) notions of “How do blacks perceive whites, women perceive men, gays perceive ‘straights’?” I reveal Morris’s (2001) opinion to them:

“Generally, non-disabled people are undecided about whether they want a society which contains people who look different, who need support, who need to make changes to make buildings and houses more accessible to them, who need more resources for education and health, etc. In a lot of situations they would rather we weren’t born, or were ‘allowed to die’” (12).

This is a visceral statement and is included because it strikes a chord. I am able to remind people that the disabled were the first to be systematically killed in Nazi Germany. Referred to as “useless eaters,” “Nature’s mistakes,” and having “lives not worth living” (Proctor 1995), they were eliminated by the hundreds of thousands, yet are rarely commemorated in Holocaust museums. I also ask about contemporary issues such as amniocentesis, and how any suspicion of an abnormality in the fetus usually means pressure on the mother to terminate. I probe, even if we do not take Morris at face value of literally “dead,” then what about symbolically? Do not many “able bodied” people want the disabled out of sight--in institutions, special facilities, special schools, and special classrooms?

*After this discussion, can the audience still be so sure that Morris’s sentiment is too strong? I do not want people to be overcome by guilt or feel defensive to the point that they are no longer receptive, but I do want to show how everyone is implicated in these issues—and how we must weigh our complicity or resistance. There are so many sources from which to draw, and many points to make, however, I chose the quotations above because, together they make a powerful statement that cannot be ignored; the disabled are systematically discounted and marginalized by the able bodied, including in institutions of education in which we all work.*

I now link this train of thought to special education. Linking special education as it is currently configured with broader issues of accessibility, I share Skrtic’s (1991) comment that “Special Education...[is] the profession that emerged in twentieth-century America to contain the failure of public education to educate its youth for a full political, economic, and cultural participation in a democracy” (24). I ask a series of questions--Is it democratic to remove students from access to the same instruction as their non-disabled peers? In the case of high school – how do we justify placing students who must take rigorous exams into classes not taught by content area specialists? How many people in the room would like their own child placed in high school special education classes, knowing they had to be as prepared as the next student for the world beyond school?

*The questions, in turn, provoke a series of discussions. I believe linking access to democracy and highlighting the absurd illogic of mandating examinations for everyone but not*

*requiring everyone be taught by content-certified specialists confronts current inequities that are deliberately ignored within current school systems. The last question also hits a nerve because they know, and I know they know, the inferior education the majority of students receive in segregated environments. Part of me winces when I push this question, yet I feel it is making the emotional connection I desire by calling forth acknowledgement in our complicity in oppressive school structures. However, what ultimately propels me are the sentiments expressed by Delpit (1995); such classrooms are acceptable for “other people’s children” and “those with power are frequently least aware of—or at least willing to acknowledge—its existence” (24).*

In wanting to link the asymmetry of power between those considered able and disabled, I now ask groups to discuss the question, “What does it mean to be able?” I ask this because I want to see how (or if) people come to reflect upon what they assume is “normal”. The question is puzzling to some, intriguing to others. I decide to share with them some written responses I had collected from a previous version of the presentation with “clinicians”. They read, to be “able” means:

- To be free from prejudice.
- To have access to all places.
- To be able to help others.
- Not to have needs or behaviors that others find annoying.
- To be within the group.

I ask, “What do these statements tell us about the able reflecting on being able?” In short, they do not have to concern themselves with (ableist) discrimination; they can go where they want when they want; they are in a position to be magnanimous; they do not annoy people through their differences; and perhaps most of all – they belong on the “inside;” they are part of society.

Once we have contemplated different versions of what is meant by able-bodied, it is necessary to contrast that with the question, “What does it mean to be disabled?” To facilitate this, I show an image of a five-piece jigsaw. The middle piece reads “Disability.” Others contain the words “Physical,” “Sensory,” “Emotional,” “Cognitive/Intellectual”. I encourage an open discussion. What exactly is it that unites these words with the lynchpin of “disability”? We inevitably arrive at the concept of “normal,” which is critical to our thinking. As we gravitate to the topic of “normal” I ask - “What is normal? Where did it come from? Who gets to decide? What happens as a result of these decisions?” I watch and listen as small groups and sub-group conversation spin off in multiple directions.

Now that I have participants troubling the concept of “normal,” I ask them to focus on a quotation by Davis (1995), “When we think of bodies in a society where the concept of the norm is operative, people with disabilities will be thought of as deviant” (29). We now broaden the conversation about the mythical norm and its relationship to the concept of average. By virtue of having a norm, we must also consider those that fall outside of it in terms of physical, emotional/behavioral, sensory, and cognitive differences. In terms of the latter, two standard deviations from the norm in scientifically sanctioned IQ tests means you do not belong to the “average” group. In the subsequent segment, I attempt to draw from our previous discussions on ability, disability, and the concept of “normal” through asking, “What kind of privileges do the non-disabled have, and by implication, what are some of the privileges that the disabled do not have?”

*I wonder if the frankness of this question is off-putting for participants? If so, why? This question is indirectly asking, “Who labels who? What benefits do the labels bring--to the labeler*

*and the labeled?” I contend that it is demeaning for students to be designated as belonging to special education. As witnessed by the student who wished to stay out of view of her passing peers, this is a form of public humiliation that remains deliberately unrecognized by educators who work with students labeled with various classifications.*

I remind people that my interest in creating and delivering this presentation is to challenge the status quo of the perceptions of people with disabilities. I ask them to contemplate some commonplace practices that disability studies scholars believe harm individuals, including the idea of normalcy and its relationship to IQ tests (Davis 1995; Linton 1998). I briefly paraphrase the history of the Bell Curve and its origins in astrology (Gould 1996) – noting how it became transformed from the “error curve” to the “normal distribution curve,” thereby supporting the wholesale theory of innate intelligence. A frightening part is the still widespread use of such tests in evaluating students for disabilities. Parents are often informed that their child “is” literally a number as if fated to be cast in fixed digits (Valle and Aponte 2002).

*Though I question how much we can change the monolithic structures embedded within our education system, I would rather challenge them than work without questioning them. However, I have noticed that they appear as a given to many colleagues. At a previous session, I asked psychologists and educational evaluators to reflect upon the origins and history of the tools of their profession—particularly notions of IQ and the Bell Curve and share their knowledge with others present in the room. I was met by what I can only describe as “stunned silence,” as if I had crossed an invisible line by asking them to say why they believed in what they were doing on a daily basis. This reticence to question and reflect on one’s professional epistemological stance, confirms my belief that many professionals accept their role as “willing agents in their own discipline” (Allan 1999, 24). In doing so, they absolve themselves of complicity in current practices, regardless of the damage done to those labeled (Gartner and Lipsky 1987; Karagiannis 2000; Lipsky and Gartner 1997; Skrtic, 1991.)*

In order to bring into focus the actual experience of segregation, I associate disability issues regarding access with what I call “The Politics of Exclusion”. By this, I mean systematic efforts by institutions to “contain” a group of people perceived as markedly different from the norm; the difference regarded as grounds to deny social inequality. In the next segment I ask participants to contemplate *Brown v. Board of Education* (1954) and the Individuals with Disabilities Education Act (1997). I ask how justifications for exclusion been made? What can we learn from examining them? I am careful to note that I do not conflate disability with race. However I do want us to contemplate connections and differences to deepen our thinking. I show a video clip from the television documentary series *School* (2001) that vividly portrays life for students and teachers in segregated settings, how parents mobilized to fight for access to better conditions for their children in a country deeply divided on issues of race, and the passing of legislation that led to major social changes.

*I do not wish to offend African-Americans by incorporating this segment. It is powerful to examine moral inequalities, and contemplate why they were segregated in the first place, and who benefited from maintaining exclusionary practices. “Separate is inherently unequal” is a phrase that is clearly articulated in the video. I have noted other connections between exclusionary practices such as labeling, segregation, attitudes, fear, dependency, value, behavior, language, and access to school supplies. There have been connections between disabled and moral “minority” groups throughout the literature for decades (Oris and Landers, 1984). In contrast, one disconnection is the provision of Least Restrictive Environment (LRE) in IDEA that stresses the option of placements on a continuum of services, thereby not*

*guaranteeing general education classes for all students. Martin, Martin, and Terman (1998) have noted that, "There is a persistent tension between the requirements of appropriate education and least restrictive environment" (35).*

In many respects, the concept of LRE has been interpreted to justify segregation. As we are approaching the end of the first segment, I ask how integrated students with disabilities are in the schools of the principals in attendance? Though this question may appear outmoded, in my experience the overwhelming majority of schools still have separate staff, classrooms, and locations (often attic, basement, or wing) for students labeled disabled. I ask why are schools vehicles where integration is supposed to take place? Disability studies supports the civil right of the disabled to have access to life among the able. Is public schooling representative of the way the nation is envisioned at large?

*In the group discussions that follow, I wonder how people describe their schools to peers.*

*Schools vary so much – the ones that opened in the early 90s are mostly inclusive, while the older and larger schools have experienced a two-steps-forward, two-steps back approach during the last decade. I wonder to what degree the principals are moved, or unmoved, by this presentation. I also wonder what might they do to improve the quality of experience for students with disabilities?*

At this point, we take a break. When I invite the participants back, I link these philosophical and theoretical conversations to practical matters by demonstrating how team teaching is one way of supporting students with disabilities in the general education curriculum. I also shared a synthesis of recent findings about principals and inclusion and distributed self-made materials designed to help them create and nurture team teaching arrangements. At the very end of the session, I distribute a short feedback form consisting of three questions: (a) What did you think was useful? (b) What questions are still circulating in your mind? and (c) What pieces need to come together to make this [inclusive practices/stress on team teaching] work?

### Discussion of Audience Response

The information I have chosen to analyze is the principal's engagement in and reaction to the presentation. Comments made during the event, along with anonymous written feedback, and personal anecdotes are discussed. As I was packing my materials to leave, one principal said, "What you are doing is trying to change the way people think." That was true, but how successful was I?

### Epiphanies

Among the 26 responses from principals, some tapped into the direct challenge posed by disability studies. One wrote that s/he appreciated my "effort to affect the belief system of the solidly bell-curve/innate paradigm [of intelligence]." Another wrote, "[the] discussion on personal thoughts/beliefs was powerful." Many commented upon the opportunity "for exchange of thoughts," especially one who shared that inclusive practices are "a special challenge in our building." One wrote of the need, despite the odds, to attempt "changing the mind sets of some adults that are suspended in time." Several thought it "helpful seeing the bigger picture," and one claimed "all of the analogies dealing with 'separate but equal' helped to better understand the way segregating students with disabilities should be perceived." These comments suggest that some participants were provoked into contemplating familiar terrain through a new lens.

## Resistance

At one point in the presentation, my supervisor whispered to me, “It sounds as if you are beating up on medicine.” I was, I preferred to think, challenging the objectivity of science, and the unquestioned reverence it receives. Several people spoke defending science and the progress it has made to help many disabled and ill people. This gave me the opportunity to reassert that I was consciously using the voices of the disabled in their critique (and distrust) of medicine. What good is a “cure” if you are comfortable with who you are? Do “cures” negate those that already exist in their specific incarnation, reinforcing their devaluation? Do telethons and other fund-raisers actually improve the *participation* of people with disabilities in society? If a particular condition, such as atypical craniofacial characteristics for a person who has Down Syndrome, or the removal of a breast due to cancer, a common response is plastic surgery. This often involves procedures that can be ongoing, expensive, and painful. However, surgery is a medical response to what is in essence a social issue: the intolerance of non-disabled people toward people with physical differences, be they congenital or acquired.

Another principal wrote, “How can we get students to behave in accordance with school rules so that they learn society cannot/will not provide the same support?” This question is problematic for several reasons, as it assumes students with disabilities are rule breakers, and their actions inherently wrong, while failing to ask schools to reflect on pedagogical and structural practices that are not necessarily in the best interests of students with disabilities (who often know this). It is clear that the notion of students in special education inevitably having behavior problems is a pervasive byproduct of the bifurcated system.

On another note, a principal wrote, “Not everyone thrives in full inclusion. This needs to be addressed as well.” Though I understand this point, believing – due to particular contexts and circumstances – students and their families should have the choice of non inclusion in general education classrooms for all or part of the day, my thoughts are foremost with students currently segregated with little or no choice. Justifying exclusionary placements would have been counterproductive.

I have noticed that a shift from “we cannot do this” or “do we have to do this?” to “How can we best do this given our resources?” and, “What else might we need?” Still, there is ambivalence and misunderstanding that exists at this level. One principal commented that in inclusive classes in her school, “you can’t tell the difference between who is and who is not a ‘special education’ student.” As Sapon-Shevin (1996) points out, it is the expected assimilation, the homogenization of normality that needs to be questioned.

## Intersections

It is noteworthy that two female African-American principals expressed discomfort in considering the analogy of legislation giving access to “mainstream” schooling according to categories of race and disability. One said within earshot (but not to the entire group) “I thought this was supposed to be about special education.” Clearly, the connection was not explicit to everyone. However, the other had moved beyond her initial reticence by end of the presentation, asking me to repeat it with her school staff. Analysis of intersectional ties of multiple markers of identity such as ability, race, class, gender and sexuality, can complicate how we understand existence by adhering to categories often assumed as independent.

One restraining force that pervades most people's thinking is the medical model of disability. In challenging the primacy of this model, audience members experience a jarring of entrenched beliefs. One participant vehemently defended the use of Ritalin as it has helped his disabled son adapt to college life. This sparked a rich discussion of the use of drugs to control people versus examining the environment and tasks individuals are expected to perform within it.

### Reflection on Practice

While one administrator described the presentation as “theoretical, philosophical, and practical,” the majority of responses debated the pragmatics of seeing the video examples of team teaching and documents about lesson planning. In examining responses to “What questions are still circulating in your mind?” several comments stand out. One principal asked, “When will the State Education Department understand that ‘one size does not fit all’?” Is this a cry of frustration at the restrictive options imposed by the state or does it absolve principals from promoting increased integration of students with disabilities and changes in teaching methodologies and curricula? Another wrote, “Will they change? Will they be more accepting of kids in general ed?” These are commonplace thoughts, but they are also formulated from a passive stance. Could the question be phrased actively as, “How can I promote and support change? How can I influence teachers to accept diversity within the classroom?” The original response prompts me to ask how ready, willing, and able are administrators? Equally important, how can they be supported in their efforts?

### Re-imagining Education for All Students

Can the invisible lines between general and special education be re-imagined for the benefit of everyone? One principal wrote, “General educators need to be taught to be special educators. Special educators need to be taught to be more assertive and participatory.” This indicates the belief that this blurring of lines is not just possible, but preferable. The same person also asked, “How are students taught to be their own advocates?” This is an extremely important question, as it conveys the need to shift how we think about and work with students to facilitate self-empowerment.

One principal asked, “If we were to mainstream more kids, what would happen to our special ed. teachers?” This is interesting for several reasons. It echoes the concern from the *Brown v. Board of Education* video clip, that many of the African-American teachers in the dual system did lose their jobs. Perhaps more realistically, many special educators are currently reevaluating their role as they become increasingly connected to inclusive practices within the general education classroom. Probably, this question exemplifies how the able-bodied population is supported by the management of those labeled disabled, and the interests of the former often appear to supercede the concerns of the latter.

In responding to “What pieces need to come together to make it [increased inclusive practice] work?,” many principals wrote of common planning time for staff, professional development, and financial support. Several did address the notion of how best to change perceptions. One principal believed s/he needed “open minded teachers and ritualized reflection around instruction,” while another wrote, “viewing a heterogeneous classroom as beneficial to all students.” In these comments it is possible to see an understanding of disability as diversity. Can this belief be internalized by an entire staff? Many feel the need to have a common belief system



among staff. One principal described the problem of “changing the mind sets of some adults that are suspended in time,” while another stressed that “exceptionally strong, open-minded staff must be selected.”

### Personal Feedback

Finally, several people talked to me after the presentation. One told me I “was a little opinionated” but he liked that. Another described how my passion and sincerity for these issues came through, making it hard to imagine someone else presenting the same material. Yet another principal complimented me on a good job saying, “You managed to include revisionist history, the Holocaust, and abortion – all topics people avoid in after-dinner conversations.” How should I interpret these comments? Regarding being opinionated... who is not? Even those who resist change embody an opinion that the status quo is the preferred state. I recognize that aspects of disabilities studies are controversial, but *every* position is ideological. Regarding passion... I am glad it shows. Disability studies has enabled me to access new tools to further ideas I have held. I think the embrace of human difference is desirable in a heterogeneous society and disability *is* part of difference. As for including material that may trouble some... we need to be challenged to see things from multiple vantage points. Historical treatment of people with disabilities and contemporary practices *must* be discussed among others to create a greater understanding of these constructs as well as their connections. Together, these three comments from participants invoke the need for disability studies: (a) to criticize dominant ableist discourse, (b) to challenge oppression, and (c) to achieve a just society.

### Conclusion

I have narrated my journey of using theoretical concepts within disability studies to serve practical ends in the field of education. Returning to my first question, I asked, “How can I infuse disability studies into “mainstream” educational thought?” For the duration of the presentation I believe I purposefully challenged entrenched attitudes toward the education of students with disabilities. I cannot say for sure how many had a “turning point” (Titchkosky 2002, 103), and there were more signs of resistance than epiphanies, but I did witness struggles in people’s adjustment to this information. I will optimistically align myself here with researchers who claim *resistance is engagement* (Ellsworth 1989, Lather 1992). I believe my strategically chosen points started the audience into *beginning the examination of their deeply rooted beliefs*.

My second question was, “How can disability studies be used to challenge entrenched belief systems and attitudes toward the education of students with disabilities?” This narrowed the theoretical breadth of the first question to a specific area of practice. In connecting powerful ideas from disability studies to the practical needs of the school district, a space was created to engage in issues with depth and seriousness I had not witnessed before. Lines between personal and professional melded as schools and educational practices were contemplated.

Despite my satisfaction with the presentation, I am mindful of its singular venue. In the world of professional development significant change does not result from a “one-shot,” unless it is followed up and such practices are incorporated within school cultures (Guskey and Huberman, 1995; Sparks, 1994). However, I am confident that the push to re-conceptualize disability in this and future, “in-service” presentations contains seeds of change. Ultimately,

disability studies introduces the possibility of a re-imagined educational landscape in which human diversity is not weeded out, but cultivated and celebrated. The growing number of schools contemplating how best to reintegrate students with disabilities can find ideas from disability studies as they restructure their classrooms. This is the juncture where we now find ourselves.

### Postscript

What needs to be done in order for disability studies to be embedded in teacher discussion groups, school-based action research projects, curricula-writing groups, Parent-Teacher Association agendas, and cabinet meetings of administrators? As Ware (2001) has demonstrated, “daring” to do disability studies is essential, in schools, universities and in-service staff development. Though theories circulate in universities, if they are to become reality, they must continue to be propagated among educators and in schools. By mutually developing means for the implementation of theories educators at both university and school levels can collaboratively *demonstrate* a commitment to change. Let us not wait and only hope for the better world envisioned by Clandinin and Connelly (2000); but create more dialogues that will bring it about.

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## Endnotes

<sup>i</sup> It cannot be automatically assumed that those who consider themselves disabilities studies scholars believe in educational inclusion for all students with disabilities.

<sup>ii</sup> Taught by Beth Ferri at Teachers College, Columbia University during the spring 2002 semester.