

Disability Studies: What Is It and What Difference Does It Make?

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The academic field of disability studies has expanded rapidly over the last two decades or so. With that expansion has also come some growing ambiguity about exactly what is meant by the term “disability studies.” This article reviews the history and evolution of disability studies as an interdisciplinary approach to research and scholarship. While acknowledging the broad range of interests and approaches that can fall under the umbrella of the “disability studies” label, we argue that it may be useful to present a set of core themes or beliefs that seem central to disability studies as a field if it is to fulfill its promise as a truly different way of exploring the meanings of disability in society. Finally, we argue that disability studies should be of special interest to members of TASH and others with particular interest in the lives of people with significant intellectual and developmental disabilities.

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Over the last decade or so, the term “disability studies” has become a familiar usage throughout all areas of inquiry and scholarship involved in the study of issues affecting people with disabilities. Yet, the question arises as to whether the writing and research emerging from this still new and evolving area of study have any special relevance to those whose strongest interests are improving the lives of individuals with the most significant intellectual and developmental disabilities and their families. This article—as well as the others in this special issue—tries to demonstrate why that question should be answered in the affirmative. The purpose, then, of this article is threefold. First, we provide a brief history of the emergence and evolution of the broad range of scholarship and inquiry that falls under the field called “disability studies.” Second, we identify and briefly discuss what we see as at least some of the core concepts that underlie the relatively new field of study. Finally, we argue that, as a field of study, disability studies has particular salience for those interested in the development of research and policy in support of people with significant intellectual and developmental disabilities.

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Certainly, if one goes simply by frequency of usage, the practice of “disability studies” has gained ample currency within academic settings of the humanities and social sciences (Cushing & Smith, 2009; Taylor & Zubal-Ruggieri, 2009). In such a context, disability studies is often compared with similar approaches to human difference that have a somewhat longer history, such as Gender Studies and Race/Ethnicity Studies. In its broadest terms, then, disability studies might initially portray itself as the interdisciplinary study and representation of the concepts, cultures, and personal experiences of disability in all its variations. Equally important, of course, is the implication that just as we have come to understand race and gender as complicated and shifting mixtures of the physical and the cultural—the personal and the public—so must we place disability and impairment within a social and historical context.

Yet, at the same time that the term “disability studies” has come into more and more common usage, it has also become less clear as to what exactly the term refers. As the introduction to this special issue outlines, the meaning of “disability studies” seems to many to have become more diffuse just as the term’s adoption has become more popular. Others may feel confident that they understand well enough what the term means but that it ultimately has little relevance to the more urgent questions of reforming policies and improving practices in all of the contexts that affect the lives of people with intellectual disabilities and their families. This analysis explores both of these issues. We describe our understanding of what is, admittedly, a diverse and changing field. More importantly, we argue that the teaching and research emerging from this field do, indeed, have important implications for people with the most significant disabilities and the professionals trying to provide them with support.

Some History

It is probably impossible to pinpoint an exact date for the beginning of disability studies as a distinct field of academic scholarship.¹ The Society for Disability

¹ In the United Kingdom, some of the key early writing came from Vic Finkelstein, Mike Oliver, and others as part of a growing advocacy movement in the 1970s (Shakespeare, 2006). However, our focus here is on developments in the North American context.

Studies—the oldest academic organization explicitly dedicated to this area—traces its beginning to 1982 (see the brief account at <http://www.disstudies.org/about/history>). However, even before that date, there were isolated examples of individual researchers or even entire programs that helped create the foundations of this radically different approach to the study of both the concepts and the experiences of disability. Perhaps the simplest way to think of this emergence is to identify disability studies as the academic side of the disability rights movement. The political theorist Michael Walzer has succinctly characterized “social criticism” as “the educated cousin of the common complaint” (Walzer, 1987, p. 65) to make his argument that effective social theory must never move too far from the very real problems faced by everyday people. So, it should be with disability studies. Born of the protests and growing self-advocacy of ordinary people in the 1970s (Shapiro, 1993), disability studies reflected the efforts of scholars with disabilities (and some nondisabled colleagues) to conceptualize and interpret the common complaints of people with disabilities and their families. What had been the sporadic and often unconnected work of isolated researchers and theorists began to coalesce around a set of core ideas and shared experiences.

Fields within the social sciences were perhaps the earliest disciplines in the United States to present research that seemed to capture some of these new assumptions about the cultural meaning of disability. As early as the 1960s, sociologists such as Erving Goffman (1961, 1963) and anthropologists such as Robert Edgerton (1967) were using the social construct of stigma to explore the phenomenological and cultural experience of disability. In the 1970s and 80s, the medical sociologist Irving Zola illustrated how the study of disability could usefully employ the methods and concepts of the social sciences to place the personal experience of physical disability within a social context (Zola, 1982a, 1982b). In 1980, Zola began publishing a newsletter that was to become what is now the *Disability Studies Quarterly*, the oldest academic journal devoted specifically to works representing “the full range of methods, epistemologies, perspectives, and content” embraced by this interdisciplinary field of study. At Syracuse University, Burton Blatt recruited social scientists and policy analysts (e.g., Robert Bogdan, Steven Taylor, and Douglas Biklen) to blend vigorous advocacy with scholarly rigor in exposing the institutional abuses that were the daily experience of hundreds of thousands of people with intellectual disabilities (Biklen & Bogdan, 1977; Bogdan & Biklen, 1977; Bogdan & Taylor, 1976; Taylor, 2006). In 1982, four young sociologists² from various parts of the country came together at a conference of the Western Social Science Association to form a special

section for the “Study of Chronic Illness, Impairment, and Disability.” By 1986, the group became a separate organization called the Society for Disability Studies (SDS), soon having separate conferences and publishing proceedings (e.g., Kiger & Hey, 1989).

As noted before, since these early rumblings in the late 1970s and 1980s, disability studies has grown exponentially. At least in its North American context, disability studies has moved well beyond its origins in the social sciences, developing entire subcategories of work in history (e.g., Baynton, 2001; Carey, 2009; Kudlick, 2003; Longmore & Umansky, 2001), humanities (Davis, 2010; Garland-Thomson, 2009; Mitchell & Snyder, 2000; Siebers, 2008; Snyder, Brueggemann, & Garland-Thomson, 2002), and the arts (Crutchfield & Epstein, 2000; Hevey, 1992; Lubet, 2010; Sandahl & Auslander, 2005). In both North America and Europe, work has emerged in interdisciplinary fields such as feminism (Hillyer, 1993; Thomas, 1999), bioethics (Kittay & Carlson, 2010), and Queer Studies (McRuer, 2006). Powerful memoirs reflecting on the meanings and experiences of disability from a personal perspective served as critical testimony to the generations of voices that had been largely silenced or ignored both in the sciences and the humanities (e.g., Ferguson & Asch, 1988; Finger, 2006; Fries, 1997; Johnson, 2005; Linton, 2006; Sherry, 2006). Equally important for our purposes here, groups of researchers within the traditional fields related to disability began to identify their work as part of disability studies. The label of “disability studies in education” became used by some to denote a newly critical stance toward the traditional assumptions of the more familiar “special education” (Connor, Gabel, Gallagher, & Morton, 2008; Danforth & Gabel, 2006; Gabel, 2005). Psychologists were challenged to reconsider “the relationship between disability studies and psychology in ways that contribute to the emancipation - rather than the exclusion - of disabled people” (Goodley & Lawthorn, 2006, p. xvii). Policy analysts and human service professionals began to talk about how a newly theorized understanding of disability could change approaches to both policy and practice (Devlieger, Rusch, & Pfeiffer, 2003; O’Brien & Sullivan, 2005; Schriner, 2001).

Out of all of this diverse scholarship, the description of disability studies adopted by the Society for Disability Studies comes perhaps as close as anything to an “official” definition of this new, interdisciplinary field of study:

Disability studies recognizes that disability is a key aspect of human experience, and that disability has important political, social, and economic implications for society as a whole, including both disabled and non-disabled people. Through research, artistic production, teaching and activism, disability studies seeks to augment understanding of disability in all cultures and historical periods, to promote greater awareness of the experiences of disabled people, and to advocate for social change. (Society for Disability Studies, n.d.)

² The four founders of the Society for Disability Studies were Darryl Evans, Gary Kiger, Stephen Hey, and John Seidel. They quickly joined forces with Irving Zola to gain both visibility and credibility for the new organization.

Still, despite such attempts at official definitions, it is probably not surprising that a certain messiness came to characterize the usage of the term "disability studies." It became somewhat unclear whether disability studies could be framed as a coherent and definable, if multidisciplinary, field of academic endeavor. As more and more academic programs began to spring up using the label of disability studies, disagreements began to emerge about who could and could not make legitimate use of the term.

A growing list of questions came to accompany almost any introductory discussion of this new approach. Did "real" disability studies have to be based in a nonclinical or applied setting (e.g., in the humanities or social sciences) or could certain programs in the rehabilitation sciences or in special education also lay claim to the term as well? Could it be used in a medical or health care setting of any kind or was that a contradictory juxtaposition of the medical and social models used to approach disability in drastically different ways? Was it an approach that worked for certain disability categories such as physical disabilities or deafness but not for others such as significant intellectual disabilities (Anastasiou & Kauffman, 2011)? Did the field have any connection to actually improving the lives of children and adults with disabilities or was it just an over-theorized distraction from the types of applied science needed to find out what works and what does not in the prevention, cure, or remediation of disabilities of all kinds? What was the role of people without disabilities in the doing of disability studies? The fact that these questions of use and definition arose, of course, was a marker of success and maturation of the field itself. The term "disability studies" became contested precisely because of the power and insight found in the growing body of research and commentary that popularized the term.

What disability studies is not

In her influential introduction to disability studies (Linton, 1998), Simi Linton has a chapter titled "Disability Studies/Not Disability Studies." In the chapter, she makes an extended argument for "setting off disability studies as a socio-political-cultural examination of disability from the interventionist approaches that characterize the dominant traditions in the study of disability" (p. 132). For Linton, it is important to have boundaries about how and where legitimate disability studies could be done. Despite that argument, as we have noted, the use of the term "disability studies" to characterize many new or restructured academic programs and research initiatives based within those "dominant traditions" (e.g. special education, health care, and human services) has continued to grow over the last decade or so. While we worry that some uses of the term have more to do with image than substance, we also are reluctant to restrict the term to certain areas of knowledge and inquiry. A lively debate over definitions and appropriate usage can be a healthy activity that energizes the field.

Nonetheless, it is easier in many ways to begin our discussion of where we locate the core of disability studies by making some broad comments about what disability studies is *not*—or at least should not be—rather than what it is. It should be clear from what we have said so far that the term "disability studies" should not be allowed to become little more than a synonym for special education or rehabilitation sciences. Nor should the term become interchangeable with research into community support and inclusive education (even though most scholars in disability studies would probably agree in general with these orientations). Finally, disability studies is not the same as disability rights, although again the two are closely related. Disability studies may be many things to many people, but if its full potential to reshape the way that society understands people with disabilities is to be realized, then it must avoid being seen as simply a new bottle for old wine.

Some Core Concepts of Disability Studies

If there are some elements or characteristics that we can say are arguably not part of what most scholars in the area would identify as central to disability studies as a field, then it is equally true that there are other features that we would regard as core concepts. These are themes or contentions that we find so basic to the theory and practice of disability studies as to be at the heart of any discussions about its relevance for any specific program or content area. Our argument here again is not to set up some sort of purity test for what is—and should be—a messy, interdisciplinary field. However, the following five concepts strike us as a minimal set of arguments with which to put some flesh on to the bare bones of rhetoric about what is different and important about disability studies.

Concept 1: The study of disability must be social

Just as gender is more than chromosomes and race is more than skin color, disability is more than an individual impairment. This simple statement is one version of what is, perhaps, the one concept closely associated with disability studies that has gained the greatest familiarity and even acceptance within the academy: the so-called "social model" of disability. Usually contrasted with something called the "medical" or "deficit" model, the social model has become one of those umbrella terms—indeed, much like the term "disability studies" itself—that has a broad recognition and understanding, while also being constantly debated by those who find one or another of its usages problematic (Anastasiou & Kauffman, 2011). Our purpose here is not to settle—or even enter into—those debates. Rather, it is to point to the concept as the single idea that most people would cite as one of the most influential contributions to the theoretical study of disability in the last 40 years. Even the World Health Organization (WHO) in its current version of the *International Classification of Functioning, Disability and Disease*

(WHO, 2001) acknowledges the importance of this idea and tries to "merge" it with the more traditional medical model. The WHO definition of this concept summarizes the most common understanding of the social model:

Disability is not an attribute of an individual, but rather a complex collection of conditions, many of which are created by the social environment. Hence the management of the problem requires social action, and it is the collective responsibility of society at large to make the changes necessary for full participation of people with disabilities in all areas of social life. (WHO, 2001, p. 28)

What the WHO definition leaves implied but unstated is that the concept of the social model requires not merely social "action" but social analysis as well. The importance of the social model as a core concept of disability studies is not only that disability is more than individual pathology and deficit but also that its meaning is more than a personal problem. Disability must be studied in its social, cultural, and historical context as much as the personal conditions of impairment and functioning must be studied in their medical and educational contexts.

This does not have to be an either-or proposition. Most scholars in disability studies readily acknowledge the personal reality of impairments. Studying the social history of intellectual disability does not mean that the personal experience is irrelevant. Indeed, much recent writing has urged renewed attention to the "embodiment" of disability (Finger, 2006; Shakespeare, 2006; Siebers, 2008). Nor does the emphasis on the social model negate the importance of medical and educational research on diagnostics, assessments, treatments, and interventions. Even with these more traditional approaches to the health and education of individuals with specific impairments, however, disability studies can contribute a social perspective from which to view and interpret scientific findings. Indeed, for most disability studies scholars, this is not really a choice. All research, all knowledge exists unavoidably in a cultural and historical context. The only choice is in how openly that context is acknowledged and explored.

Concept 2: The study of disability must be foundational

It is certainly the case that scholars in disability studies argue that their approach to disability and impairment is fundamental to deepening our understanding of how that status is experienced in society. However, disability studies also makes the argument that perhaps the most important reason to explore the meaning(s) of disability is not to understand disability itself but to understand other categories of human difference. In other words, the study of disability (and the *concept* of "disability") is at the foundation of our understanding of the social

construction of race, gender, class, and other ways in which we differentiate ourselves from one another. It is essential, in short, to our understanding of how we see ourselves as same and different (Devlieger et al., 2003).

It would be difficult to find professional preparation programs these days in special education or rehabilitation sciences that did not pay some attention in their curriculum to issues of race, class, gender, and other social categories. The issue of disproportional representation of racial minorities within at least some categories of special education has certainly received growing attention over the last several decades (Artiles, 2003; Harry & Klingner, 2006; Losen & Orfield, 2002). Virtually every future special education teacher, rehabilitation therapist, or adult services professional at least learns the rhetoric—if not always the deeper convictions—of culture competence and reciprocity. However, the difference between this welcome growth of attention to cultural issues within applied disciplines and the concept of disability as foundational that is brought forth by disability studies remains important. Disability studies is arguing that the issue is more than the distortion of science by social intrusions of systemic injustices such as racism, sexism, and poverty.

Throughout history, the label of "disability" has functioned as an accusation more often than an assessment. In a review of how discrimination against African Americans and women has been justified at various times in American history, the historian Douglas Baynton makes this claim overt: "Not only has it been considered justifiable to treat disabled people unequally, but the *concept* of disability has been used to justify discrimination against other groups by attributing disability to them" (Baynton, 2001, p. 33). In the opposition to suffrage and women's rights in the early part of the 20th century, male politicians and others would cite the feebleness and instability of women generally as reasons to "protect" them from the responsibilities of voting, running for political office, or learning a profession (Baynton, 2001, p. 42). The medicalized racism of the same era was used to bolster the rise of Jim Crow laws and policies in the South and anti-Mexican laws in the West (Molina, 2006). The imagery of disability has always been used to symbolize the dangerous and inferior. The concept of disability is used to hide what scares us, to remove what repulses us, and to medicalize what shocks us. The logic was irrefutable. Disability was the ultimate "other" (Kudlick, 2003).

In many ways, disability continues, by definition, to be a lesser state of being that justifies paternalism at best and extermination at worst. To apply that label to the LGBT community, to the homeless poor, and to those who do not speak English is to justify the practices of exclusion and neglect that are still tacitly understood as a legitimate corollary of the disability status. In opposition, those being labeled often challenge the accuracy of the attribution but seldom challenge the logic behind the accusation. In discussions of current social issues such as the overrepresentation of certain racial groups

in special education, the problem is analyzed primarily as an instance of systemic racism without an equal review of the negative assumptions about disability that make the concept understandable as source of exclusion. Disability—and the concept of disability—must be part of the very foundation of attempts to understand what is different as well as what is normal.

Concept 3: The study of disability must be interdisciplinary

If disability is social and foundational, then our efforts to understand the experience and concepts behind that status must cut across traditional academic disciplines. Disability studies demands that the study of disability be as broad as culture itself. We must draw upon the tools and traditions of all our ways of knowing about the world. Again, in many ways, the best analogy here is to similar interdisciplinary fields such as women's studies or race and ethnic studies. Just as these more established fields have drawn upon the history and sociology of women and the concept of femininity or the cultural and literary representation of African Americans, so does disability studies look for ways to explore the meanings of disability as it emerges in all of our in academic departments.

In its early days, this core feature of disability studies was focused on the need to bring the study of disability into the arts and humanities, and areas of the social sciences other than psychology. In making that case, the impression was sometimes given that disability studies could *only* exist within these non-applied disciplines. Efforts to legitimize the study of disability outside of applied fields such as special education and social work, sometimes led to attempts to delegitimize the practice of disability studies within those same traditional fields. In part, this was an understandable response to the traditional domination of those traditional fields in the study of disability. Special education and rehabilitation sciences had been seen by many as "owning" the topic of disability in a way that disability studies scholars wanted to challenge. At the same time, many academics within the applied sciences associated with disability would often see calls for interdisciplinarity as meaning that general education experts should interact with special education experts. History, literature, philosophy, art, and other fields within the humanities are seen as supplemental interests to the main goal of learning how to teach and how to support individuals with disabilities. The worry, then, by some within the humanities and social sciences was that allowing the mantle of disability studies to be assumed by these same professional schools would co-opt the truly reformatory potential of this newly critical approach. Those worries remain, and the disciplinary tensions that accompany those concerns will also continue. At this point, we believe that truly interdisciplinary (and not just multidisciplinary) disability studies can only flourish if the orientation and insights it makes possible are available to all parts of the academy.

Concept 4: The study of disability must be participatory

This concept is one that is probably familiar and endorsed by virtually all members of *TASH* and other progressive disability research and advocacy organizations. Still, the call for increased participation and influence by people with disabilities and their families with what is taught and explored about disability is one that disability studies has greatly emphasized, if not originated. The call for participation, of course, is not just about what questions get asked, but about who gets to ask the questions (Ferguson, Ferguson, & Taylor, 1992). The point is not just to have new types of research and teaching about disability but that scholars with those disabilities should be prominent among those doing that research and teaching.

However, this concept becomes somewhat more contentious when taken beyond superficial rhetoric. What does "participation" truly mean in terms of scholarship? More specifically what might participation mean for people with intellectual disabilities (Docherty et al., 2005)? Should disability studies research always be action-oriented (as with Participatory Action Research) or can it sometimes be primarily analytical or historical in focus? Is "participation" enough, or does disability studies research have an obligation to be "emancipatory" in effect (Mercer, 2002; Seelman, 2001)? In part, this touches on one of the central tensions in disability studies scholarship: What is or should be the role of the non-disabled researcher/teacher within the field of disability studies (Barton, 1996)? Just as it would be odd if women's studies programs were led primarily by men or European Americans were the most prominent faces in African American scholarship, so it would be surprising only if those within disability studies took no notice of the disability status of those whose voices were most prominent. At the same time, the brief history of disability studies is full of examples of scholars without (visible) disabilities making significant contributions to the field. The principle of participation raises as many questions as it answers, but as long as people with disabilities remain underrepresented in our colleges, universities, and research institutions, then the issue must remain central to the field.

Concept 5: The study of disability must be values-based

This principle is also one that is familiar to the members of *TASH*. One of the changes that has occurred within the various domains of teaching and research is that the notion of values-based research has become widely accepted, even within the hardest of sciences. It is now standard practice to use and report social validity measures within traditionally quantitative and behavioral research (Wolf, 1978). Within disability studies, there have come more dramatic claims for advocacy as inseparable from progressive scholarship of any kind (Oliver, 1992, 1993). At either end of this spectrum

of research practice, the legitimacy of some consideration of ethical implications within all approaches to knowledge about people with disabilities is accepted by most scholars.

As with the principle of participation, however, the emphasis on values-based research quickly becomes complicated. For many within disability studies, the overt values base takes the form of significant critical analysis of traditional disability-oriented programs and professions. If "special education" and "rehabilitation" are not exactly "four-letter words," they are at least viewed skeptically by some as signifiers of a formal service system that is known mainly for its oppression and pathologization of children and adults with disabilities (Heshusius, 2004; Ware, 2005). For those living their professional lives in the midst of these systems, critical of the failures while striving for reform, such a blanket dismissal of the helping professions can seem dismissive of the real needs of real individuals for the sake of ideological purity. At the same time, the history of failed reforms and continued disempowerment of people with disabilities and their families by the health and education systems makes the prospects of decades more of such incremental change somewhat disheartening for many within disability studies.

What Difference Does It Make?

Learning how and why to "imagine disability otherwise"

We use this phrase, borrowed from Ware (2003), because it represents the *possibility* of what the range of work in disabilities studies can offer us: a way to "imagine disability otherwise." In her piece, Ware documents her collaborative work with a group of high school teachers who used writing from humanities-based disability studies to reflect on and expand their knowledge about disability, and—perhaps more importantly—how to carry this knowledge into their own teaching practice. Ware's use of the phrase intended to make the point that the range of analyses and representations in disability studies scholarship offers "ways of knowing" and theoretical insights with which disability service providers can examine individual and societal attitudes, beliefs, and assumptions. It is this kind of critical reflection, Ware argues, that is required to shift the dominant narrative of disability in society that is reflected in person-fixing practices in the helping professions.

Historically, the difference associated with disability was seen as something that could be "remediated away" or fixed. Interventions in the applied fields have often responded to the "problem" of disability and disability's interaction with classroom environments, community living, and work places. However, work in disability studies approaches the construct that is labeled "disability" as multifaceted and complex. Interdisciplinary work in the field thus can allow us to develop a deeper and much broader understanding of disability as a part of our shared, human experience, as well as position disability

as a difference that is a potential source of interest and intrigue. These new and re-conceptualizations frame disability as a social construction and seek to address the social, cultural, historical, and material aspects of disability while at the same time acknowledging the physiological aspects of impaired function (Baglieri, Valle, Connor, & Gallagher, 2010). The shift in focus—to the limitations of attitudes, environments, contexts, and practices (from that of individuals)—allows disability-related professionals to actually reposition and redefine the "problem" traditionally associated with disability (see Biklen, 2007; Biklen & Burke, 2006; Nusbaum & Rodriguez, 2010) and support an understanding of disability as a natural part of the human experience.

Creating a cultural context for inclusive education and community support

Changing how societies (and ourselves!) think about and respond to disability can create the cultural space in which inclusive approaches to education, employment, living, and community can flourish. Inclusive contexts are not going to flourish if we do not actively strive to support the individuals with and for whom we work to live the best lives of their choosing (something the TASH community is very familiar with), as well as do this within a framework that views the label or demarcation of disability in very different ways. Therefore, inclusion and community support cannot be based solely on "what to do on Monday" and are not just a program or set of practices. The project of societal inclusion requires all involved to engage in (rather than avoid) difficult questions about the nature of disability and the practices surrounding the phenomenon of disability as well as to identify and challenge the sites of exclusion for individuals with disabilities within our schools, workplaces, and communities (Allan, 2008; Brantlinger, 1997; Mintz, 2009; Slee, 2001; Slee & Allan, 2001).

Scholars in disability studies, whose work is situated in education, use the analytic tool of deconstruction to expose exclusionary forces that exist within "inclusive" practices and programs. Through deconstruction (e.g., Slee & Allan, 2001), scholars argue that the dialogue necessary to ask critical questions about the nature of "inclusive" practices is created. In their 2001 article, Slee and Allan ask if a "theory of activism" (p. 185) could facilitate new types of research and knowledge production. Their question opens a dialogue in which the roles of researchers without disabilities, activists, and individuals with disabilities are examined and the political nature of inclusion can be more fully explored. This type of dialogue is directly relevant to the TASH community, whose constituents cohere around a disability rights agenda, which is inherently political. Furthermore, disability studies scholars working in education (e.g., Allan, 2008; Graham & Slee, 2008; Slee, 1997; Slee & Allan, 2001, among others) conclude that the creation of inclusive contexts is dependent on, first, deconstruction

and, then, reconstruction of inclusive practice so that new ways of understanding disability can inform theory and research—and thus create the cultural contexts for inclusive and community-based practice.

An example of such work is Mintz's (2009) unpublished doctoral dissertation, which used methods consistent with critical ethnography to uncover how teachers at an inclusive elementary school conceptualized "inclusive education." Mintz found that participating teachers' conceptualizations of inclusive education were largely linked to the technical implementation of a set of practices. Furthermore, teachers' ideas about inclusivity allowed them to situate the educational segregation of some students at their school within their ideas about what inclusive education "was" (the site of data collection had been inclusive for over 10 years, but was required by district mandate to create a separate classroom to serve some students with disabilities in the year of data collection). Mintz concluded that inclusive education needs to be taught as both an ideological commitment, as well as understood in terms of the technical implementation of research-based practices. Finally, a general educator teaching in an inclusive classroom in the documentary "Including Samuel" eloquently supports our point about inclusive communities by stating: "Inclusion doesn't create community. Not having inclusion takes away from community" (Habib, 2008).

Infusing the curriculum with disability studies

Scholarship in disability studies provides a vehicle to examine social attitudes, beliefs, and assumptions about disability as well as understand disability as a social and political category versus something to diagnose, identify, and label in individuals. Importantly, as Connor (2010, 2011) articulates, this scholarship interrogates conceptions of "normal" and in doing so "seeks to engage everyone—teachers, practitioners, policymakers, scholars and researchers...to rethink our perceptions of difference and response to those differences" (p. 31). Thus, work in the field not only broadens the knowledge base about disability but also expands the epistemological boundaries of how this knowledge is produced. Situating the study of disability within and across a range of curricular areas and including the lived-experience of disability allows disability-related practitioners to engage with others in ways that go beyond acceptance or tolerance and that can foster critical reflection and understanding of the disability experience and the social phenomena of disability.

In teacher education, disability is situated in programs specifically designed to *respond* to disability (such as communication disorders or special education credentialing programs). General education teacher preparation programs often address disability in a course using a "disability-of-the-week" approach. This assumes that the categorical markers and characteristics of various disability labels are the most salient ways of knowing about student disability in schools versus understanding struc-

tural, institutional, pedagogical, and attitudinal constraints that prohibit students from accessing social and academic experiences in schools (Young & Mintz, 2008). Brantlinger (2006) critiqued "the big glossies" (her term for the mainstream textbooks used in the kinds of courses previously described) and the reliance on a standard, categorical approach in most of these texts. Both textbooks and teacher education courses that focus on disability categories, characteristics, and labels potentially reinforce notions of disability as disorder or deficit and reinforce traditional educational practices that respond to these markers of difference by trying to *fix* them so that students with disabilities may become more like their non-disabled peers (Young & Mintz, 2008). They are founded on the belief that these categories and characteristics are the most salient features of the disability experience and the most meaningful way to understand the position of disability in schools. Brantlinger instead argues that teacher education should adopt texts that address student difference in multidimensional, interdisciplinary, personal, and critical ways.

In contrast, Connor (2009) used narrative analysis represented in political cartoons to convey the self-realizations about academics, social, and personal demands of three students labeled as learning disabled in their transition to college. Ferguson (2009) and Valle (2009) both situate the perspectives and experiences of parents of children with disabilities within a historical context to more thoroughly understand the experience of families with the special education system and professionals in the field. Both authors discuss the power of professional and institutional discourse in the identity shaping of students with disabilities and the tensions and suspicions on both sides of the professional/family relationship. In her 2001 piece, Ware asks the question, "Dare we do Disability Studies?" In this work she describes her efforts using humanities-based scholarly work in disability studies with high school teachers to support their dialogue and critical reflection and begin to explore status quo assumptions about disability that underpin the educational system. Collins (2003) and Smith (2007) are examples of critical investigations into institutional structures and pedagogical techniques that can either support or inhibit "ways of knowing" about student disability and difference that sit in contrast to those found in mainstream texts.

Employing a disability studies perspective also offers tremendous richness in K-12 curriculum and creates multiple avenues to trouble the normal-abnormal binary, which is central to problematizing the status of disability in many societal contexts. Addressing disability as curriculum and infusing disability into existing curricular areas is central to the task of "imagining disability otherwise" (Ware, 2003). The Center on Human Policy at Syracuse University (<http://www.disabilitystudiesforteachers.org/>) offers a number of resources for teachers seeking disability studies curriculum. Examples of how this might happen

include (a) the disability rights movement as a part of teaching in the social sciences about the civil rights movement; (b) the role of American and German eugenics in disability history, and (c) disability as a meaningful and powerful analysis tool in literature and art courses. The Center on Human Policy's Web site offers lesson plans and curricular resources that connect disability to standards in various academic content areas as well as include lesson objectives, questions, resources, and other materials. In their guide for teachers and teacher educators, Valle and Connor (2011) address the question "how do I talk about disability in my classroom?" and encourage educators to actively and specifically challenge normalcy by making disability and its representation a specific topic of conversation in K-12 classrooms. The authors talk about the power of silence around the topic of disability and offer some challenging questions to prompt educators to address disability, *itself* (rather than only the pedagogical practices one should use to *respond* to it). Valle and Connor argue that by addressing "the elephant in the room" (p. 190), conversations about disability have the potential to dispel discomfort and shift the perspective about disability from deficit or disorder to part of natural, human variation and the foundation of a truly inclusive school community. Situating disability within and across K-12 and higher education curriculum can further support the contribution of multidisciplinary work from disability studies to the efforts of inclusion across social contexts—specifically classrooms and education communities where students with and without disabilities learn together.

Creating critical and reflective helping professionals

Baglieri et al. (2010) revisited a 2000 article in *Remedial and Special Education* that identified five key differences between traditional special education scholars and those who saw special education as needing "substantial reconceptualization" (Andrews et al., 2000, p. 258). The fifth of the key differences between these two groups in the original article identified the need for more self-reflective teachers who used ethical decision-making in their work as being a key step in improving special education. The kind of critical and reflective practice encouraged by those seeking to "reconceptualize" traditional special education and, by extension, other applied, disability-related professions goes beyond considering questions like "did the lesson I taught go well?" Rather, becoming a critical and reflective practitioner requires that we ask ourselves hard questions that attempt to get to the social meaning and social consequences of our work with individuals with disabilities. Ware (2003) characterizes this kind of reflection as "belief in action," which requires that first we understand/know our beliefs about disability and thus can begin to explore how our individually held ideas are carried out in unconscious ways in our work with individuals with disabilities. This also requires that we (those of us who identify as nondisabled) willingly examine our nondisabled privilege and power

and actively utilize strategies to release the power given to us because of our "expert" and/or nondisabled status to undo the ableism that is pervasive in the applied, disability-related fields. Finally, Ware (2001) offers three questions for disability-related practitioners that can begin the process of critical reflection:

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? (p. 114)

Scholarly, interdisciplinary work in disability studies provides many vehicles with which practitioners and scholars can begin to develop new meanings about disability and critically examine issues of access, employment, education, sexuality, and representation as well as to utilize strategies for disability empowerment and activism. By infusing both professional and K-12 curriculum with these new and re-conceptualizations of disability represented in disability studies, questions such as those posed by Ware might begin to be answered.

Disability studies needs the TASH community

Thus far, much of our focus has been on the contributions that disability studies can make to efforts to reconceptualize policy and practice within traditional fields of special education and human services. We strongly believe that progressive organizations such as TASH need to incorporate the new generation of scholarship that is emerging from interdisciplinary research and conceptual analysis in disability studies. TASH needs disability studies. However, we also strongly believe that disability studies needs TASH. Or, at least, the inquiry within disability studies needs to be confronted with the issues and experiences of an organization with a specific interest in people with significant intellectual disabilities.

While the situation has improved over the last decade or so, it is still true that certain types of disability identities are less commonly the focus of disability studies research. Among those categories of impairment less well represented within the disability studies literature is intellectual disability generally, and significant intellectual disability more specifically. The reasons for this imbalance are multiple and debated. Simplistic descriptions of social construction both inside and outside disability studies have made it seem somehow less applicable to people with the most significant cognitive impairments. People with physical or sensory impairments led the way in early demands for recognition and inclusion in all branches of research on the experience and meaning of their disabilities (Fine & Asch, 1988; Oliver, 1992, 1993). Critics of social construction (Anastasiou & Kauffman, 2011), on the other hand, often use the seemingly overwhelming impairments of significant intellectual disability as the best example

of an objective reality trumping whatever cultural contingencies might contribute to the meaning of less pervasive disabilities. Disability studies, from such perspectives, may have something to contribute to the exploration of other disabilities, but not to those where the limitations are so clearly individual rather than social.

Members of TASH know better. It is essential that their familiarity with the experiences and contributions of people with significant intellectual disabilities to our deeper understanding of human differences be brought to a larger audience of disability studies scholars who have little contact with such individuals. The process has already begun. Parent narratives by scholars within the humanities have started to illustrate how their life experiences can make valuable contributions to the disability studies literature (Berubé, 1996; Gabbard, 2011; Kittay, 1999; Savarese, 2007). Beyond such accounts, however, disability studies needs to learn more about the possibilities of inclusive policies for those with even the most significant disabilities. Notions of supported employment, self-directed services, natural settings, and informal supports need to be shared with an approach to policy analysis that concentrates on concepts of independent living and personal attendant care. TASH needs to help disability studies as a field to expand and invigorate its conceptual purview beyond its earliest interests and concerns.

Teaching the Tensions

We would like to conclude this paper with a brief discussion of the complications that are created when a disability studies perspective is introduced into disability-related applied fields, such as special education or rehabilitation. We argue that this space—the place where the complications and tensions lie—is the place where it becomes possible for disability to achieve truly full inclusion into our society. For example, contrasting disability studies with theory and practice in traditional disability-related fields allows us to understand the tension between giving students the services they need, while not subscribing these students to a future of social and economic dependence (Young & Mintz, 2008). This place of tension between the goals of traditional, disability-related fields allows us to ask questions:

Is it possible to minimize impairment by focusing on ability and celebrating disability?

Can we achieve both full inclusion in all aspects of life, and at the same time foster a positive disability identity?

Disability studies and the enormous range of work in the field—historical, literary, artistic, philosophical, sociological, and beyond—attempts to make visible the aspects and nuances of disability that remain largely invisible within the applied professions, in their focus on reducing evidence of disability within an individual student or

client. The tensions exposed by disability studies help us shift the conversation from being “about” an individual’s impairment to an understanding of disability through the range of lenses that exist in such a multidisciplinary field.

Finally and importantly, scholars in disability studies believe strongly that the voice of individuals with disabilities is a necessity in the production of research and scholarly work and is central to the epistemology of disability. As a field, disability studies recognizes and privileges the knowledge derived from the lived experiences of people with disabilities. Whenever possible, scholarly work in the field conducted by nondisabled researchers adheres to an emancipatory stance, meaning that researchers work with participants as coresearchers (“participant-researchers” rather than “subjects”; Connor, 2009). Young and Mintz (2008) point to one of the tensions; then, inherent in employing a disability studies perspective on research about disability in the applied fields by asking, is it possible to respect the knowledge gained by expertise while at the same time critiquing the way expert knowledge is used on a day-to-day basis (p. 500)?

We end with an articulation of these tensions—questions that are not easily answered and that perhaps are best left open for revisiting through our work. How can the principles and perspectives of constructivism and behaviorism interact with each other in the support of children and adults with significant intellectual disabilities for shared goals of social justice and inclusive communities? Can pluralistic approaches to research acknowledge and appreciate the different traditions of inquiry while sharing goals of rigor and merit to evaluate our varied claims to generate knowledge? Can an intellectual home be found (or created) where abstractions and theoretical analysis are juxtaposed with policy and practice without either claiming priority of place over the other?

It is our belief that TASH is uniquely positioned to provide a constructive context within which to explore these questions. It can be a professional context within which different perspectives can rub elbows rather than bang heads. That, to us, is the ultimate promise of disability studies to people with significant disabilities and their families.

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