



Disability Studies/Not Disability Studies

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ABSTRACT *The growing interest in and increased visibility of the field of Disability Studies raises questions about the field's logical borders and valid dimensions. This essay looks to guiding principles from the field itself as the basis for delineating a robust liberal arts-based inquiry into disability, distinct from traditional interventionist models. The former is described in this essay as Disability Studies, the latter endeavor, in substance the medicalized applied fields and special education, is identified here as the Not Disability Studies. The essay begins with an overview of the problems found in the academic curriculum with respect to the study of disability, and proceeds to describe how the proposed liberal arts-based Disability Studies can redress those problems.*

As the field of Disability Studies is gaining momentum and broader visibility, it is timely to examine how the field is being defined and the various uses the term is being put to. The border between what is considered Disability Studies and what is not is fixed at different points by different authors. Although it is unlikely that anyone would suggest that there be an absolute boundary, efforts to circumscribe the domain and to anticipate the consequences of limitless permeability across the borders are worthwhile.

In this essay, I am concerned with providing a coherent rationale for marking a border, setting off Disability Studies as a socio-political-cultural examination of disability, from the interventionist approaches that characterize the traditional study of disability. I position myself as an advocate for the creation of a robust liberal arts-based inquiry into disability, and as a disabled woman with an investment in increasing the equitable participation of disabled people in society. The delineation proposed here is consciously rendered to serve those interests, and the interests of validity and reliability which my social science training has schooled me to attend to.

The delineation between Disability Studies, and what I am describing here as the 'Not Disability Studies', has specific consequences for both scholarship and for disabled people's lives. The field of Disability Studies arose, in part, in response to the omissions and distortions in the traditional curriculum's[1] approach to disability. In one sense, the development of Disability Studies is a remedial endeavor, redressing the sins of omission and commission in the cannon. Yet, in a significant

way, Disability Studies moves beyond the corrective. It is the socio-political-cultural model of disability incarnate. It provides an epistemology of inclusion and integration, formulating ideas that could not have been imagined from the restrictive thresholds of the traditional cannon.

It is timely to mark this border, as the name 'Disability Studies' has begun to crop up around the United States and Great Britain to describe graduate and undergraduate programs in everything from the training of health care workers and occupational therapists, to courses in literary criticism examining representation and metaphor. The health and occupational therapy programs' appropriation of 'Disability Studies' compromises the integrity of a field designed to explicate disability as a social, political and cultural phenomenon. In this essay, I am labeling those applied approaches the 'Not Disability Studies'. For reasons to be described here, I name them as such not to denigrate their function, but to explain how the appropriation of the term compromises the validity and utility of a separate liberal arts-based inquiry.

In considering here how we might delineate Disability Studies, I'd like to begin by outlining the limitations or problems in the dominant or traditional curriculum's presentation of disability. This is a list of the faults and fault lines; that is the more clearly observable misrepresentations, as well as the covert problems in the academic curriculum that determine how disability is studied. Each of the problems is presented as a motivating force for the establishment of a discrete field of Disability Studies, grounded in the liberal arts and set apart from the applied fields. Then, each of the 'faults' will be examined to determine how to best redress it through the development of Disability Studies.

Faults and Fault Lines

1. A major problem is that the current presentation of disability, predominantly in rehabilitation and in special education, individualizes disability—the curriculum fosters the idea that disability is an individual's or at most a family's problem. Furthermore, the curriculum behaves as if disability is an isolable phenomenon, and ideas about it relate only to itself and to people who have particular conditions.
2. Another problem is the view that disability is, perforce, a problem. The construction of disability as problem interferes with viewing disability as an issue, an idea, a metaphor, a phenomenon, a culture and a construction.
3. A third problem is the absence of subjectivity and agency of disabled people. The absence of the voice of the disabled subject is evident in a review of standard curricula in history, in psychology, in women's studies, in literature, in philosophy, anthropology, and on and on. Moreover, the absence of disabled people's perspectives in the broader culture compounds the problem.
4. A fourth problem is the objectification of disabled people in scholarship. In part, this is a consequence of the absence of subjectivity and of the active voice of disabled researchers, but objectification is also fostered by the dominance of empiricism in the study of disability, by the large number of stereotypes and

simplified versions of disabled people's experience presented across the disciplines, the absence of critical analysis, the pathologizing of experience and the use of diagnostic categories or other means of labeling. These are among the mechanisms that further objectify disabled people in the knowledge base.

5. Across the curriculum, but particularly in the social sciences, and in the applied fields, essentialist and deterministic explanations of disability abound.
6. Another major problem with the traditional cannon is the medicalization of disability. As a result of medicalization, there is a pathologizing of difference, the individualization of disability (as described above), a loss of self-definition and self-determination, and a forced assignment of the roles of patient, client and consumer. Related to this is the conflation of impairment and disability—lack of recognition that impairment and disability should be addressed predominantly in two separate realms of discourse (Abberley 1995).
7. There is an overemphasis on intervention at the individual level, in what Trickett *et al.* (1994) have spoken of as "... person-fixing rather than context-changing" (p. 18).
8. Across the curriculum, there is a preponderance of information on disability in the applied fields. Sequestering the study of disability in the applied fields is restrictive because there is a narrow band of content covered in those fields and a restricted range of methodology brought to bear on the subjects.
9. Within the applied fields, there is inadequate attention to the interventions, the medical and educational solutions, that the disabled community has asked for.
10. A related problem is that the study of disability is marginalized in the humanities, and throughout the liberal arts.
11. Throughout the curriculum there is insufficient attention to disabled people as minority group, and the cultural, political and intellectual meanings of that status. Furthermore, diversity initiatives and multicultural curriculum endeavors have, for the most part, ignored disability as a category of analysis.
12. Finally, the curriculum is missing what I call an epistemology of inclusion. There does not exist a broad-based body of knowledge, an intellectual rationale for the incorporation of disabled people as full and equal members of society.

What is Needed

Given these problems, what is the most logical organization of the study of disability in the academy?

I think there should be a well-developed, interdisciplinary field of inquiry, grounded in the liberal arts, called Disability Studies, designed to study disability as a social, political and cultural phenomenon.

I think that separate from that, the applied fields should develop more valid and useful approaches to the presence of impairment in the population and disability in society, and respond to disabled people in a less deterministic and in a more integrated way than the applied fields ever have. Although the focus of the applied fields is on individual interventions, research and curricula should carefully examine the contextual variables that shape experience. Arokiasamy (1993) states that "(t)he

ultimate purpose of rehabilitation is the achievement of individual autonomy by the client ... (and) in its pursuit of this purpose, rehabilitation should use a holistic approach to treatment ... including the social, economic, political, cultural, and legal contexts in which people with disabilities find themselves" (p. 81).

These revised applied approaches should be informed by the intellectual traditions inherent in Disability Studies and by the political commitments adhered to by the Disability Rights Movement. Teaching in the applied fields should support inclusion, self-determination and self-definition. Based on those tenets, and informed by current research in education which supports inclusion, the programs should be revised to prepare professionals to work in integrated settings. I advocate the refiguring of special education and rehabilitation, which have traditionally over-determined disability as an explanatory variable and which prepare people to work in segregated settings, exclusively with disabled people. However, no matter what revisions are made, the curriculum and body of research that supports intervention should remain in the category of the 'Not Disability Studies'. For reasons that are elaborated below, the maintenance of two separate domains has both intellectual and political significance.

Rationale

Let's return now to the list of problems with the traditional curriculum outlined earlier and consider the validity and utility of differentiating between Disability Studies and 'Not Disability Studies'. Obviously, the applied approaches need a new name or multiple names. I am naming it as the null hypotheses, not because it is devoid of substance, but because it remains not fully articulated as a distinct field. Special education, rehabilitation and other disability-related fields were and remain more clearly a reaction to social need than fields determined by a set of principles and ideas. While social need is a reasonable basis for developing curricula, the perpetuation of these fields needs to be reevaluated in light of current research and social imperatives. Arokiasamy (1993), writing on the need for a theoretical basis for rehabilitation, notes that "... rehabilitation as a profession and as a specific field ... emerged largely out of legislative mandate ... and in response to a series of practical needs ... (which) has contributed to making rehabilitation a pragmatic, technique-driven profession without a sound theoretical base" (p. 77). The medicalized fields, such as rehabilitation and even special education, which adopts the organization of knowledge used in medicine, have historically presumed dominion over all knowledge on disability. Therefore, for the purposes of this article, it is useful to center the Disability Studies model, from which standpoint the remaining study of disability is peripheral.

1. *Recall that problem one is the individualization of disability.* Maintaining the distinction between Disability Studies and applied approaches underscores that individual responses are appropriate for impairment, but misdirected for disability. The individualization of disability, while logical in the applied fields, has spilled over into all other curricula on disability.

2. *Disability as a problem*: while disabled people have problems, and those may be addressed by individual interventions, maintaining a separate liberal arts-based Disability Studies would reinforce the idea that the society creates many of the problems disabled people experience and the society has a responsibility to address them.

There are, of course, problems that are a direct result of impairment. Pain, suffering, frustrations and anxiety often accompany impairment, and no amount of social change or theory will take those away. Even though pain, and even less extreme kinds of discomfort are mediated by social and political contingencies, they remain intensely personal experiences. While I believe that discourse on the social, cultural and political meaning of disability can and should take these issues on, Disability Studies has not yet been successful in doing that. Paul Longmore, in a personal conversation in 1996, described this gap in the literature as ‘... the need to theorize about impairment.’ It is incumbent upon Disability Studies theorists to articulate these elements of experience as they are relevant to many areas of inquiry, from literary criticism to anthropology, from clinical psychology to cultural studies.

Disability Studies theorists do need to grapple more directly with ‘impairment’ and recognize that it is as nuanced and complex a construct as ‘disability’. The problem may be that we have been hesitant to go in a particular direction in the development of theory—that is toward grappling with the actual pain, and limitations that we experience. It may be the manifestation in theory of a personal denial of the impact and consequences of impairment. Yet it may also be the tremendous difficulty in articulating impairment in ways that do not essentialize disability or do not reduce it to an individual problem. I think we recognize that outside readers might be likely to latch on to ideas about impairment, and that would deflect attention from the more socially demanding issues such as civil rights or oppression.

It would be helpful to look to writing in related domains for assistance. For instance, Morris (1991), in *The Culture of Pain*, has done some interesting work theorizing about pain, something which is usually thought of as a distinctly biological event. He comments that ‘... traditional Western medicine—by which I mean not so much individual doctors and researchers as an entire scientific-medical worldview that permeates our culture—has consistently led us to misinterpret pain as no more than a sensation, a symptom, a problem in biochemistry’ (p. 5). He closes the Introduction to his book by promising to elaborate on the meanings accorded to pain: ‘Pain on this new ground will ... [be understood] ... as an experience that also engages the deepest and most personal levels of the complex cultural and biological process we call living’ (p. 7). Morris’s work is not a simple ‘mind over matter’ orientation to pain, nor a palliative for people who experience pain to help them find meaning in their suffering, it is an entreaty to those too willing to be reductive in thinking about pain. He also makes a case for reconsideration of Western medicine’s domination over the meanings accorded to pain, a point that Disability Studies scholars make repeatedly about medicine’s claimed authority on disability and on impairment. In reducing pain or impairment to something that needs to be ‘fixed’ and medicine as the remedy to that stated problem, medicine succeeds in cornering the market on knowledge about these phenomena.

Although I have raised the issue of impairment apropos of ‘problems’, the explication of impairment should in no way be confined to experience that has a negative valence. A phenomenological approach to the study of impairment will yield the rich array of descriptions of experience that one is likely to overhear in the corridors at a Society for Disability Studies conference, or the back rooms of an independent living center: the insiders’ experience of body, and sensory, emotional and cognitive functioning that is expressed most openly within disability circles.

One research domain that is yet to be fully explored from the perspective of disabled people is the kinesthetic, proprioceptive, sensory and cognitive experiences of people with an array of impairments. For instance, because I use a wheelchair I utilize my upper body for mobility, and rock back and forth as I propel myself forward. My height when I am vertical differs from my measured height horizontally, and my impairment influences my height relative to objects in the world and to other people. Each of these experiences has an impact on my sense of my body in space, and affects the information I am exposed to and the way I process sensory information.

Given that my experience or the experience of someone who is blind or deaf, or someone who has mental retardation has been underrepresented across the disciplines, we are missing the constructs and theoretical material needed to articulate the ways impairment shapes disabled people’s version of the world. Even as I write this I am struggling to find the words to adequately describe these phenomena. It is particularly difficult to find language to describe my experience that is not relational, meaning descriptions that do not measure my movements in relation to non-disabled norms. The fact that impairment has almost always been studied from a deficit model means that we are deficient in language to describe it any other way than as a ‘problem’.

The work of Oliver Sacks comes to mind as someone who has attempted to reframe the discourse on impairment. Unfortunately, there is a clinical overlay to his material and an assumption of a doctor–patient configuration that compromises his project. Particularly in the theatrical presentation of his work in *The Man Who*, where ‘doctors’ costumed in white laboratory coats interviewed ‘patients’, the disabled persons’ experience was not depathologized, but rather their quirks were turned into objects of aesthetic interest, and the doctor’s competence in diagnosis and interpretation was valorized. Sacks and others, such as Thomas Szasz and R.D. Laing, do attempt to dissociate ‘disability’ from ‘problem’, but to the extent that their work fails to account for the authors’ relative power and for their claimed authority for their subjects’ experience, it is an incomplete endeavor contributing more to the appropriation of disabled people’s experience, than its elucidation. Furthermore, Sack’s work, although hailed as a literary achievement, fails as a Disability Studies project because it does not contribute to self-determination or self-definition of disabled people, and does not explicate a socio-political-cultural understanding of disability. As Tom Shakespeare (1996) said, in a review of *An Anthropologist on Mars*, ‘Oliver Sacks, the man who mistook his patients for a literary career, violates every existing principle of disability equality ... He describes himself as “making house calls at the far border of experience”, but he is more like a

colonialist than a general practitioner' (p. 139). Given these criticisms, it is important to consider whether, in fact, his essays do succeed as literary works in that they are unlikely to stimulate the reader/audience to view disabled people in their complexity, as sentient, purposeful people. All of this to say, just because material on disability emerges in the liberal arts, it is not necessarily Disability Studies if it does not challenge the notions that disability is an individual condition and a problem needing medical solutions.

3. *Absence of subjectivity in scholarship*: the voice of disabled people should be present in both Disability Studies and in applied approaches to disabled people, but the voice takes different form in each. The influence and direction of disabled people should permeate the applied field. If rehabilitation professionals really believe in self-determination for disabled people, they should practice what they teach by adhering to an active affirmative action program in their own departments and universities, adopting the books and essays of disabled people into their curricula, and by demanding that disabled people are in leadership positions in conference planning and on the platform at conferences. Meanwhile, in the liberal arts, the active voice, the creative voice, the narrative, can be articulated in the humanities, and in qualitative and interpretative research in the social sciences.

Women's Studies has demonstrated the scholarly potential of personal narratives, by mapping the way to interpret the personal as the political and as the scholarly. Feminist scholarship has also turned the entire academic curriculum inside out to reveal the epistemological consequences of the androcentric biases in the knowledge base. Disability Studies scholars are also explicating the political and scholarly antecedents and consequences of personal experience. Now, scholars of all stripes must recognize their moral and intellectual obligation to evaluate the gaps and faults in the knowledge base they disseminate to students which are a result of the missing voices of disabled people.

4. The fourth problem, *the objectification of disabled people*, can be redressed by developing scholarship from the position of the disabled subject, developing alternative methodologies to the empiricist approaches that have dominated the study of disability, developing the active voice in the humanities, and by breaking down stereotypes through the analysis of metaphors, images, and all representations of disability in the academic and popular cultures. The overwhelming majority of scholarship on disability, either utilizes or implies the third person plural: 'they' do this, 'they' are like that, 'they' need such and such. This contributes to the objectification of disabled people and contributes to the experience of alienation disabled people so often report.

5. As with much of the transformative scholarship on race and gender, Disability Studies serves a remedial function, necessary to correct omissions, inaccuracies and faulty logic. Two particularly pernicious ideas that need to be revoked are *determinist arguments* that explain human behavior and achievement in terms of biology, and those that explain achievement or failure in terms of individual psychological makeup.

Feminist Studies, Disability Studies and African-American Studies, among others, challenge the notion that biology is destiny. Each elaborates on the mutability of human behavior to counteract essentialist arguments and to demonstrate that there are few human practices that are inevitable. Specifically, Disability Studies challenges the assumption that the social and economic status and assigned roles of disabled people are a result of their 'natural' inferiority. However, '(U)nlike other minorities, ... disabled men and women have not yet been able to refute implicit or direct accusations of biological inferiority that have often been invoked to rationalize the oppression of groups whose appearance differs from the standards of the dominant majority' (Hahn, 1988, p. 26).

Yet, even when biological arguments for difference in social position are discredited, there remains the persistent belief that the cause of social disadvantage is within individuals and that change is dependent on personal transformation. These psychological explanations have a prominent place in traditional curricula explaining the behavior and social position of members of minority groups. For instance, across the curriculum, the meaning most often accorded to disability is that it is a personal condition, rather than a social issue; an individual plight, rather than a political one. When individuals with disabilities fail in education, employment or in love, the failure is attributed either to the disability, itself considered an obstacle to achievement, or to the individual's psychological weaknesses or lack of resiliency, their inability to 'overcome' their misfortune.

These explanations foreground the individual and give little consideration to the barriers, discrimination, negative imagery or lack of opportunity which shape experience. Within this framework, it seems more logical to help individuals cope with and adjust to their personal tragedies than to expend resources to alter the social terrain. To further cement this myopic view of the experience of disability, news stories about disability are invariably human interest tales of individual accomplishment, dense in the rhetoric of 'overcoming'. These are narratives of personal triumph over adversity, rather than analyses of needed social change.

Education, clinical psychology and other social sciences have been particularly influential in reinforcing these deterministic views. These fields conceptualize disability as deviance from the norm, as pathological condition and as deficit, and concentrate their efforts on the evaluation of these individual characteristics. Such evaluation requires the creation of an ideal standard of physical, psychological and sensory functioning from which any disability is considered a deviation. This is remarkably similar to the traditional evaluation of women, described by Carol Tavris (1992) in *The Mismeasure of Woman*. Her book describes the way research has often measured women against some idealized male norm, and attempts to explain women's behavioral differences in terms of perceived biological or psychological differences, rather than differences in power and circumstance. Thomson (1990), in discussing the position of disabled people in society, reminds us of the power differential between nondisabled and disabled people, reinforced because 'the dominant group defines itself as normative' (p. 239). Analyses such as these are essential to help focus attention on the processes that center and privilege non-disabled people and their characteristics.

Scholarship that relies on individual explanations of social phenomena is also used to explain racism, sexism and ableism. Adolph Reed (1995) notes that the development of psychological explanations of racism came about in the late 1930s when an '(E)lite commitment to scientific racism, rooted in biologicistic defenses of inequality, was eroding. Reed believes that Gunnar Myrdal's study, *An American Dilemma: The Negro Problem and Modern Democracy* (1944) ushered in a period of describing '... racism in individual, psychological terms rather than in relation to state action'. Myrdal's framework '... reduced racism to the level of *beliefs* that whites held about blacks' (p. 506) (emphasis Reed's).

A similarly individualistic explanation pervades the vast literature on attitudes toward disability which examines nondisabled peoples' personality variables as these characteristics relate to acceptance or rejection of disabled people as friends, classmates or lovers. However, the social explanation of disability found in the Disability Studies literature broadens the investigation of ableism to include social conditions that mediate responses to disability. These conditions include the economic and social structures that affect the relative position of and interactions between disabled and non-disabled people. These conditions also include the nature and quality of representations of disability in all curriculum domains and in cultural products. Of course, the degree of integration in living arrangements, educational institutions and cultural and social environments are essential components of this analysis, as are the political climate and legislative safeguards that influence social interactions.

Therefore, to counteract deterministic narratives of disability, the field of Disability Studies should focus on the social, political and cultural context in which these 'individual' responses occur. This shift affords a more comprehensive view of society and human experience, and the attribution of significance to human variation. This type of analysis challenges the biological as well as the individual/psychological explanations of human experience, achievement and behavior.

6–8. Other problems listed include the *medicalization of disability*, *overemphasis on intervention* and *the disproportionate amount of information on disability in the applied fields*. All of these can be helped by delineating between Disability Studies and the applied approaches. Because there has been so much emphasis on the applied approaches to disability, with their medicalized version of disability, these ideas tend to spill over into all other inquiry into disability. In housing the social, political, cultural inquiry into disability in a separate liberal arts-based domain, namely Disability Studies, and making the field robust, the medicalized paradigms can be used only where appropriate, and the political, social and cultural paradigms can be understood as valid organizing tools for knowledge on disability.

9. Within the applied fields, there is *inadequate response to the educational and medical interventions the disability community deems important*. While I am advocating in this essay for a liberal arts-based Disability Studies, the applied fields would benefit from an infusion of Disability Studies scholarship and Disability Rights perspectives in their work.

To begin, it is essential that leadership and control of disability-related services be in the hands of disabled people. In both the academic and community response to the educational and health care needs of disabled people, disabled people are relegated to the patient, student or client role, and rarely get to be the professor, the teacher, the clinician or clinic director. Furthermore, the model of inclusion currently being applied in a number of elementary and secondary educational settings, where full integration of disabled and non-disabled children is taking place, should be applied to health care services as well, so that disabled people are not restricted to rehabilitation facilities and other specialized services for their health care needs.

The leadership and influence of disabled people on the practices in the applied fields can take many forms. Clearly, professors and professionals with disabilities would be extremely important. Collaborative projects with community organizations is another. In addition, students should learn about the history of their practice, and about the social and political issues that frame their work. Provision of this type of contextual material will help students evaluate the impact of the dominance of the medical profession, almost exclusively non-disabled, on the types of interventions designed for disabled people. The issues of control, self-determination and self-definition can be discussed within such a framework.

Poetry, film and other creative products can also be used to introduce disability perspectives into the applied fields. The voice of disabled people can be brought into professional programs in the applied fields through such vehicles. I teach a course in a rehabilitation program, although officially titled 'Social and psychological aspects of disability', it is a basic liberal arts survey course in Disability Studies. We read fiction, literary criticism, view popular films with disabled characters, discuss current issues in the Disability Rights Movement, read anthropological and historical materials, and review psychological theory, with a disability reading of that theory. Because students don't obtain a liberal arts education in disability, nor a political education in disability, anywhere else in their education, I think it is critical to provide that within the professional programs. It is hoped that each of these strategies will help future practitioners remain alert to the rights of disabled people, and alert to disabled people's authority and knowledge, and it is particularly important for disabled students in these programs to have this exposure.

10. *The liberal arts, particularly the humanities, have barely noticed disability.* The tools of inquiry in the humanities have, until recently, rarely been applied to understanding disability as phenomenon. Even in the social sciences, the study of disability is cordoned off into courses such as the sociology of deviance, abnormal psychology and medical anthropology, which assume the logic of the medical view of disability as deficit, as pathology and as problem.

11. There is *insufficient attention to the minority group status of disabled people, and the cultural, social and political meanings of that status throughout the curriculum.* While advocates in the applied fields have often worked toward political change for disabled people, and hopefully always will, those actions do not emanate from the knowledge base and approaches used in the applied fields—their actions stem from

personal and moral commitments to improve the lives of disabled people. Arokiasamy (1993) writes that ‘... the rehabilitation practitioner, neither by training nor job role, is suited for activism of such macro proportions’ (p. 84). My purpose here is not to discourage political activism, indeed the more committed those in the applied fields are, the better. However, we need to recognize that these actions have no basis in the curriculum that students in the applied fields are exposed to.

In both the applied fields and in Disability Studies, there are a number of places where ideas about and information about disabled people’s social and political status could be covered. In the applied fields, course material can cover the history, and current status of the field’s practice, with particular attention to the relative power and privilege of health and education practitioners, even those who are disabled, as compared to the disabled community they serve. Courses in Disability Studies would, of course, cover the political issues involved in the disability rights movement and the independent living movement, as well as the factors that impede political change.

Before turning to the final problem on the list, and explaining how differentiating between Disability Studies and ‘Not Disability Studies’ can address it, there are a few other related issues to keep in mind.

First, consider how the distinction between the terms ‘disability’, and ‘impairment’ has benefitted the development of scholarship on disability, and has benefitted disabled people. That differentiation has focused attention on the social and political contingencies that shape disabled people lives. In developing curriculum, we should follow the logic of those semantic distinctions and utilize the term ‘Disability Studies’ solely for investigations of disability as a social, cultural and political phenomenon.

Similarly, Deaf scholars have made the distinction between *Deaf*, to identify those who share a language and a culture, and the lowercase *deaf* to identify those with the audiological condition of not hearing, in order to focus attention on the cultural construction of deafness. As Padden & Humphries (1988) write, the ‘... knowledge of Deaf people is not simply a camaraderie with others who have a similar physical condition, but is ... historically created and actively transmitted across generations’ (p. 2). Yet the study of deafness in most institutions remains mired in a medicalized, interventionist discourse and the study of Deaf culture rarely appears in the liberal arts curriculum. A recent advertisement in the New York Times for an academic position, listed an opening for a ‘Deaf Studies Instructor’. On the next line it said ‘Duties: Teaching American Sign Language and other human services courses ...’ I am not arguing here for the elimination of human services courses, although I frequently, and with little provocation, argue for a change in their form and ideological underpinnings, I am making a point about the use of the terms Disability Studies to describe them. The adoption of the term ‘Disability Studies’ by the applied fields as a hip way of labeling curriculum they’ve always taught does a disservice to those scholars working to establish the validity and internal consistency of this field.

Looking at the history of Women's Studies we can see similar struggles. The field early on differentiated between the meaning of 'sex' and 'gender'. Recognizing that gender is socially constructed does not preclude understanding or responding to sex as primarily a biological event. Similarly, creating Women's Studies to describe the meaning and function of gender in all its manifestations does not obviate the need for an academic response to 'sex'. Therefore, as gynecology can be thought of as an academic response to sex, rehabilitation can be thought of as an academic response to impairment or audiology to deafness. In the same way that Women's Studies has influenced the training and delivery of service in gynecology, Disability Studies can and should influence the curriculum and practice in rehabilitation education, and Deaf Studies can influence audiology.

A second point is that disabled people and allies have fought to delineate disabled people as a minority group. The continuum approach—the idea that there should be no distinction made between disabled and non-disabled people—doesn't wash when you observe the specific treatment of disabled people in society. Therefore, articulating the ways that disabled people are a minority group is a strategic endeavor to focus on the social construction of disability and the treatment of the named minority group. There are also epistemological consequences of explaining the ways that disabled and non-disabled people are distinct groups. If, throughout the curriculum, disability was recognized as a minority group status and as a marker of identity, it would have an impact on the entrenched view that disability is a problem and an individual, medical problem. Furthermore, the marked category would help organize knowledge on representations of the group and focus attention on the absence of voice from the perspective of members of the group. The move to secure the distinction between Disability Studies and the applied fields' response to disability is consonant with the distinction between disabled and non-disabled, and between disability and impairment. The need for a distinct field of Disability Studies is premised on the belief that disability has been socially constructed and that construction serves a variety of intellectual and social ends. The facets of that construction can be illuminated by alterations not only in the content of the curriculum in each field, but by a shift in its placement within the curriculum.

A third rationale for delineating between Disability Studies and the applied fields is uncovered by tracing the history of Women's Studies and comparing it to the trajectory of Disability Studies. While it is understandable that some of the early work in Disability Studies came from within the applied fields, where disability has traditionally been studied, it is time to separate the two areas and illuminate the boundaries between them. In the history of feminist inquiry, the 'applied fields, most notably applied ethic were the first areas in which feminist work was published'. There is a logic to that because '... feminism is first and last, a political movement concerned with practical issues. At first, the more abstract areas of philosophy seemed distant from these concrete concerns.' Feminists began to realize that they could address social problems not only through the applied fields when they saw '... the problems produced by androcentrism in ... the "core" areas of epistemology' (Alcoff & Potter, 1933, p. 2), in other words in the more abstract philosophical inquiries. I note this to point out an important distinct: that the

‘applied fields’ in feminism’s history—e.g. applied ethics—are not focused on individual, biologically-derived problems of women, but on social/cultural ones and so it was a logical place to address the social ‘problems’ that feminism was concerned with.

People concerned with the practical problems of ableism will have to work broadly across the disciplines to unearth how and where discrimination against and marginalization of disabled people can be studied. There are few tools available in the *medicalized* applied fields that can do that and the paltry representation of disability in the liberal arts have made such investigations difficult. Furthermore, as Messer-Davidow (1991) notes, ‘... the *making* of social change does not exist as an academic inquiry.’ She goes on to say that it is more typical to ‘study *what* gets changed and *when* it gets changed, but not *how* it changes ... Studies that do focus on these processes often are regarded as ‘popular’ rather than scholarly and thus dismissed by the academy’ (p. 293).

A fourth issue before returning to the list of responses to problems in the traditional curriculum. A question that is heard in Disability Studies’ circles, and has been for years in Women’s Studies, Lesbian and Gay Studies etc., is who should teach and write in the field? Whether disabled or non disabled people create scholarship has particular consequences for the scholarship produced and for disabled people’s lives. Both disabled and non-disabled people can perpetuate or work to ameliorate, the objectification of disabled people, the lack of subjectivity, the absence of voice, and the absence of self-definition and self-determination. I don’t assume that disabled people are exempt from the tendency to stereotype or objectify, after all, disabled people and non-disabled people have both been schooled in the same ableist discourse. Non-disabled people, though, have a particular responsibility to consciously and deliberately engage with these issues in their scholarship and teaching to avoid contributing to the problem. I think that it is incumbent on non-disabled scholars to pay particular attention to issues of their own identity, their own privilege as non-disabled people, and the relationship of these factors to their scholarship.

Analyses of the specifics of one’s identity or status as it affects scholarship should not be thought of in reductive terms such as ‘identity politics’ or the even more obfuscatory ‘politically correct’. In any way that scholarship can be influenced by identity, social position, experience, sensory acuity, cognitive functioning, physical configuration and functioning or other characteristics, scholars need to account for or control for that influence. In the same way that social scientists have always been taught to control for variables that might influence their research, all scholars should account for the influence related to experience and point of view as it directly relates to the research at hand. Furthermore, as I mentioned earlier, the articulated or implied third person ‘they’ which is pervasive in scholarship on disability, increases the objectification of disabled people. That, along with the absence of subjectivity has an impact on self-determination and self-definition—so critical to disabled people’s lives.

Stating one’s position relative to the subject matter is of theoretical importance and it is also of political importance. Stating that one identifies as disabled or

nondisabled calls attention to the absent voice of disabled people in scholarship and illustrates that the reader may tend to make the assumption, although probably not consciously, that the writer is non-disabled. Feminist, African-American, and Lesbian and Gay Studies have followed this convention for a long time, marking the female, Black, lesbian and gay voice. It is interesting that recently the male, white, heterosexual identity is being marked more systematically and theorized, with essays on 'whiteness' appearing with the most frequency (Hill, 1996). I am suggesting that non-disabled and disabled scholars working in Disability Studies follow that tradition, and discuss their subject position, and the consequences for their scholarship in similarly complex and meaningful ways.

Furthermore, those writing in Disability Studies can challenge the minimal presence of disabled scholars in their institutions. They can examine in scholarship the history and consequences of discrimination in education and employment, the absence of affirmative action guidelines for disabled people, as well as the failure of institutions of higher education to evidence a commitment to disabled people and disability issues, other than that mandated by law. As scholars we can use the tools of our trade toward shifting this trend. Furthermore, both disabled and non-disabled scholars can review their commitments to the tenets of Disability Studies, and to the disabled community by considering how they engage disabled people within and outside the academy in their work. As an example, Carol Gill, a disabled woman, a psychologist and Director of the Chicago Institute on Disability Research, reported in a paper prepared for the 1996 Society for Disability Studies conference an incident that demonstrates the failure of commitment that some researchers evidence toward the disabled community and toward equity. She reported the following:

A team of health professionals announce their commitment to participatory action research in developing an educational video on a disability topic. They characterize their project as 'inclusive' ... They say it is guided by our perspective. In fact, the only role given to people with disabilities is the opportunity to serve on a 'consensus panel'—a kind of continuing focus group whose aim is to teach the researchers what they should cover in the video. Of course, people with disabilities also serve as the interview subjects in the film. For their efforts, the consensus panel members get snacks, no money. The interview subjects get \$50 each. The health professionals are highly offended when I tell them this is not inclusion. They refuse to hire a professional with a disability to give substantive consulting services. They also refuse to share authorship with a disabled collaborator. Yet, they hound me for weeks to serve on the consensus panel with the other 'consumers'.

In the paper, Gill cited three more incidences of disregard for the expertise and authority of disabled people. Two years ago I was similarly confounded by the behaviour of faculty members engaged in disability research. I learned that a group of faculty was organizing a major conference that was being designed to present the

University's work across a range of disciplines in disability research. The conference was being planned as a precursor to establishing an institute or center on disability research at that university, and therefore the nature of the conference and the choice of the personnel involved had long-term consequences. I began to ask questions about who was on the planning committee, and learned that of the ten or so people, not one was a disabled person. They had been meeting for some time and apparently no one had made an issue of this. A group of disabled people initiated a series of meetings with the steering committee and the president of the institution, protested the composition of the committee, and a group of us were then allowed to join the planning committee. Those of us who joined, were, by the way, members of the faculty and staff already engaged in research on disability, but not included in the initial committee. We attended a number of long planning meetings, significantly shifted the focus of the conference and, to my mind, improved its scope and vision considerably. We then received brief letters saying that the conference had been cancelled indefinitely, and despite phone calls and letters to the conference organizers, we have never been given a satisfactory answer as to why it was cancelled.

These examples are included to point out that Disability Studies is an intellectual, as well as a political endeavor and that they are reciprocal enterprises. Oliver (1992) has written about the need to change the 'the social relations of research production', (p. 106). He sees it as not simply a matter of switching from positivist models of research to interpretive methods, but more significantly a need to understand the power relationships '... which structure(s) the social relations of research production' (p. 110). Oliver's work points to the need to consider the contextual variables that shape what we study and how we study it.

Returning now to the final entry in the list:

12. The last problem listed was that within the traditional curriculum there is not a well developed epistemological foundation for an inclusive society. What is needed is a broad-based liberal arts, interdisciplinary inquiry into the function and meaning of disability in all its manifestations. This inquiry should be similar in structure to Women's Studies, and Lesbian and Gay Studies, and as such would be informed by the political movements that generated the field, by cultural studies, and by the traditional disciplines. It should go beyond analysing the exclusion of disabled people from society and of disability from the epistemological traditions in society, to chart the peoples' and the subjects' place in the civic and academic cultures. That is Disability Studies.

NOTE

- [1] The terms 'traditional curriculum', 'academic curriculum' and 'the curriculum' are used throughout the essay. While curricula vary to a degree from institution to institution, these terms refer to the domain of knowledge generally taught in institutions of higher learning

in the United States. Although there have been changes in the past few years in that body of knowledge due to the incorporation of new scholarship, particularly feminist inquiries, a number of authors have remarked that those changes have only been additive, and that we have yet to witness a true transformation of the curriculum (Gorelick 1996; Minnich, 1990; Schuster & Van Dyne, 1985).

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