

**BODIES OF KNOWLEDGE AT EVERGREEN:
TEACHING, LEARNING, IMPAIRMENTS
AND
SOCIAL DISABLEMENT**

A Position Paper

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TEACHING, LEARNING, IMPAIRMENTS AND SOCIAL DISABLEMENT

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CONCEPTUAL SUMMARY¹

Because learning is enhanced when topics are examined from the perspectives of diverse groups and because such differences reflect the world around us, the college strives to create a rich mix in the composition of its student body, staff, and faculty, and to give serious consideration to issues of social class, age, race, ethnicity, (dis)ability, gender, religious preference, and sexual orientation.

“Evergreen’s Mission” (Evergreen State College)

INTRODUCTION TO THE SUMMARY

My overall point is this: As an institution and a community, we at Evergreen do not “give serious consideration to issues of . . . (dis)ability,” or to the undeniable presence and experiences on Evergreen campuses of d/Deaf,² ill and disabled students, staff and faculty. In fact, institutional focus on material (physical) access – a focus made myopic by disregard of the cultural dimension of disability experience – has resulted in a number of specific and perennial problems. The problems include

- active instances of direct discrimination including exclusion from campus events,
- staff and faculty unprepared, and occasionally unwilling, to deliver their individual expertise accessibly and to address relevant cultural factors,
- overloaded student support services,
- unnecessary crises and resultant extra work for staff and faculty.

The final section lists five suggestions for beginning to address these issues.

Though this document is a position paper, my intent in what follows is informative rather than polemical; I would rather spark a process than a fire. I am more concerned with framework and conceptualization than with anecdote. My comments throughout are based in my own observations, research undertaken while planning several Evergreen courses and programs, two conference presentations I have prepared and delivered with Evergreen students living with disabilities (and without), and relevant concerns expressed by Evergreen faculty in numerous

¹ This is the condensed version of the longer paper. As will be clear, the focus here is on abstract concept. The full paper moves more slowly, developing positions and concepts with more explanation and illustrative detail.

² I rely on Lennard J. Davis’ definitions of “Deaf” and “deaf,” indicated here with one word. Davis writes “The Deaf are that community of deaf people who share language, cultural values, history, and social life. The deaf are simply those who do not hear” (“Deafness” 882).

informal conversations and at two summer institutes I attended in 2004. I've taught at Evergreen for ten years, and worked in healthcare and public health for six.

CONSTRUCTING DISABILITY: AN INTRODUCTION

Disabled Students and Employees at Evergreen

Evergreen's reported proportion of disabled students – 6 percent (in Fall of 2004, 263 students of an enrollment total of 4,046) (Washington State Office of Financial Management) – is well below the national mark. However, Evergreen's method of gathering information from students may result in a significant underestimation of actual prevalence, as indicated by contrasting methods used in the National Postsecondary Aid Study (NPSAS). When U.S. undergraduates were asked questions without the word “disability” (a stigmatizing label) in them, 9.3 percent indicated that they live with physical, mental and emotional conditions impacting learning (Horn 17). Just 3.6 percent of the same students answered “yes” when asked “Do you consider yourself to have a disability?” (Horn 17).

According to Evergreen's Human Resources Office, in 2003 some 3.7 percent of employees had provided documentation of a disabling condition, and 1.1 percent were disabled veterans (Governor's Affirmative Action Policy Committee 13-16). Washington State's Department of Personnel states that 5.3 percent of the workforce in general government state agencies has formally disclosed an impairment, and that 1.3 percent qualify as disabled veterans.

Approximately 20 percent of civilian and non-institutionalized Washington State residents live with impairment resulting in at least one functional impairing condition affecting a major life function such as breathing, walking or working, a figure mirrored nationally according to the 2000 U.S. Census (Kinne 5, Waldrop 2).

Distinguishing Between Impairment and Disability

In acknowledgement of the constructed and contingent nature of disability, the Americans with Disabilities Act (ADA) defines “disability” as related to an individual's ability to function within her general environment, and to the way in which others regard her.

Disability³ is

³ Evergreen's “Reasonable Accommodation in Employment Policy” quotes this definition (Evergreen “Reasonable” Sec 4.C).

(A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (B) a record of such an impairment; or (C) being regarded as having such an impairment. (42 USC 12101-12213)

In other words, disability lies not in a specific diagnosis or condition – all people with hearing loss or all people with cerebral palsy – but in how one’s “physical or mental impairment” impacts specific functioning over time.⁴

Differentiation of “impairment” and “disability” grew out of work in the interdisciplinary academic field of disability studies, and has developed into a well-theorized and influential alternative to earlier conceptual models (as witnessed by the content of the ADA). The distinction matters, as we will see in looking at a common Evergreen classroom situation. First I’ll employ the *medical model*, which dominated U.S. public discourse during the 20th Century, and then the newer *social model*, which separates impairment and disability.

Say that a student with moderately impaired hearing, who wears hearing aids in each ear, enrolls in an Evergreen program. He cannot understand others’ spoken communication when there is background noise – side-talking, chairs scraping on concrete, people laughing out in the hall, music playing, two people talking at once, and so on – although he hears a single speaker very well when the rest of the room is silent. People responding from the medical model, which conflates impairment (reduced hearing) with disability and individualizes and privatizes the latter, would locate any difficulties in learning – such as not being able to hear workshop instructions or lectures – solely in the hearing-impaired student. Limitation, in other words, is understood to be inherent in an impairing/disabling condition, leading to general perception of impairment as automatically and essentially disabling, and to placement of obligation for response to disability solely with the impaired/disabled person. Since the goals of intervention in impairment/disability under the medical model are first cure and then the impaired person’s “adaptation” and “adjustment” to her surroundings, the student who proves unable to learn adequately under “normal” (noisy) circumstances is considered “unable to learn” or

⁴ Washington State’s Department of Health more fully characterizes impairments as “the *loss or abnormality of body structure or of a physical or psychological function*” and adds the important note that impairments can be physical (cancer, paralysis), emotional (depression), cognitive (intellectual disabilities) or functional (elsewhere termed “sensory” – loss of sight is one example) (Kinne 5; emphasis in original). What is and what is not considered “impairment” in a particular culture rests in social construction of the concept.

“inappropriate” for the situation. In effect, she or he is ultimately denied access to meaningful education, at least in that situation.

The same situation analyzed through the social model leads to a different conclusion. Here is made, as Elizabeth J. Donaldson writes, “distinction between . . . the material body [impairment] and the socially-constructed body [disability]” (111). Proponents of the social model would think of the student with moderately impaired hearing as functionally disabled (unable to perform one or more major life activities, in this case hearing well enough to understand others’ communication) in a room in which there is background noise, but *not* disabled (though still hard of hearing) when the room is silent except for one person talking. The student is unable to participate fully only if others refuse to alter the environment by reducing background noise, meeting in a quieter location, amplifying their voices with a microphone, relying on communication methods other than voice, etc. Let’s say that they do refuse, despite his requests. The *impairment* in that event remains simply the reduced hearing (which the student has already improved as much as is technically possible, with hearing aids). The accompanying *disability* – the hearing impaired student’s inability to function and participate given the (constructed) circumstances – rests entirely in other program members’ failures to acknowledge and take seriously the student’s situation. He has been socially-disabled, by others’ choices and actions.

To put it another way, in the social model disability is contingent on setting, broadly defined.⁵ Disability occurs in degrees along a continuum, when it appears at all. A person may live with a chronic *impairment* that nevertheless does not disable him in particular surroundings (including specific cultural expectations), but he may experience reduced capacity to function, loss of opportunity and resultant cultural disadvantage (*disability*) elsewhere, among a different group of people, or if surroundings change. Disability as such is not chosen by the impaired individual or inherent in her impairing condition; disability is both imposed and shaped from without. One additional tenet of the social model: The goal of intervention into disability is to reduce or eliminate socially-constructed barriers to activity and meaningful participation, including barriers presented by attitudes and values.

⁵ Disability can be thought of as impairment interacting with any one or more of these socially-constructed environments: physical/architectural, cognitive, affective, sensory.

Power, Privilege and Justice: Disability as Critical Modality⁶

“Disability,” or “social-disablement” as I will now refer to it, is a weighted term in most U.S. cultures, one that carries emotional, legal and moral implications. Social-disablement grows out of prevailing arrangements of power and privilege, arrangements keeping in place inequities rationalized by socially-determined (and hence mutable) values and structures. Privileges persist and become codified or institutionalized through social arrangements resulting in unequal access to power, which I define here as does Carolyn Heilbrun: “Power is the ability to take one’s place in whatever discourse is essential to action and the right to have one’s part matter” (18).

In her book *Justice Interruptus*, Nancy Fraser describes two “broadly conceived, analytically distinct understandings of injustice” (Fraser 13). First is the socioeconomic, composed of “exploitation, . . . economic marginalization . . . and deprivation” (13); these are “distributive injustices requiring redistributive remedies” such as “increas[ing] the consumption share of economically disadvantaged groups” and, more radically, “transforming the political economy” (19, 20, 25). The second domain is the cultural or symbolic, where injustice is “rooted in social patterns of representation, interpretation and communication” (14); these are “injustices of misrecognition requiring remedies of recognition,” such as “accord[ing] positive recognition to a devalued group” – and “transforming the underlying cultural-valuation structure” (19, 20, 24). The action of remedy in both injustice domains presupposes acknowledgment of “the equal moral worth of persons” (25, 26). An important point relevant to our work here is that efforts toward justice in one domain might not affect or address the other.

STRAND ONE: TEACHING STUDENTS/TEACHING CONTENT

The most pressing overarching concerns I see for Evergreen faculty, related to teaching students with impairments, are three:

- the inadequate nature and amount of institutional attention paid to the issues of teaching and learning with impairment (including Evergreen’s over-reliance on formal accommodation as a single response), and the too-limited support provided to faculty and students as a result;

⁶ I borrowed the phrase “critical modality” from Lennard Davis, who uses it in reference to what he calls “the deafened moment” in literature (“Deafness” 882-883).

- absence of informed discussion and theorizing, and information about Disability Studies, that would help faculty consider how impairment and social-disablement both query and enrich our current teaching and learning practices; and
- lack of relationship on this issue between student support services staff and the faculty as a whole, including the lack of discussion and proactive, on-going technical assistance.

Teaching Students Living with Impairments

Federal law “protect[s] students with disabilities from discrimination” and requires that “students with disabilities have *equal access* to information and to the avenues of communication” at U.S. colleges and universities (Grossman; emphasis added). Students living with impairments must “meet the ‘essential’ ‘academic’ and ‘technical’ standards of the college or university” and legal cases have established precedents to guide the interpretation of these terms (Grossman).⁷

Evergreen relies almost exclusively on an individualized, disclosure-based accommodation procedure in teaching and learning settings. This single-path approach has historically created a number of problems for both faculty and students (and, I would guess – without any data whatsoever except anecdotes from other institutions – unnecessary expense). There are sound legal reasons why faculty should not act as “gatekeepers” when students request accommodation, and why institutions should not expect them to do so. The resultant path of formal accommodation, however, may wend through request, confirmation of need, identification of and finally even experimentation with appropriate technology or procedures.

But bureaucracy aside, disclosure-based accommodation as the sole strategy for inclusion rests on a fatal error. Given prevailing social arrangements related to impairment, disclosure means risking unpleasant consequences, including exclusion. Past experience or an accurate reading of attitudes and behaviors may provide solid reasons why Evergreen students don’t disclose impairing conditions. And at Evergreen, that means their presence in classrooms and on campus is too-rarely noted or taken seriously.

Stories about Evergreen experiences told by two recent graduates (recounted and theorized in Strand One of the longer version of this paper) make it clear, too, that

⁷ Legal requirements for K-12 and postsecondary education of students with impairments differ in many respects. A short and easily accessible discussion of these differences can be found in “Universal Design for Instruction: A New Paradigm for Adult Instruction in Postsecondary Education” (Scott, McGuire and Shaw 370-371).

accommodations addressing only one of Fraser's aspects of injustice, that of access to resources (the socioeconomic domain, broadly defined), aren't enough. When accommodation is seen as a shoehorn-the student-into-the-classroom approach practiced to "normalize" individual deficits (the common, medical model, understanding of formal accommodation), misrecognition and its destructive "social patterns of representation, interpretation and communication" (Fraser) go unaddressed. And while those involved may acknowledge the necessity to address interaction of impairment with physical/material environments, they may ignore requests related to cognitive, affective or sensory settings.

Methods of Engagement: Teaching Content

Classroom communities and teacher-student relationships frequently repeat a version of larger social arrangements of power and privilege unless conscious attempts are made to intervene (Gutierrez; Wilson and Lewiecki-Wilson 306). In Strand One (longer paper). An Evergreen alum tells of a situation in which a faculty adopted the same broad working approach suggested in Evergreen's Mission, that of taking seriously students living with impairments *as knowers*. Here I will touch on two additional interventions, one focused on program content (relevant to Fraser's cultural domain) and the other on teaching practices related to distribution (material access to learning resources).

Program and Course Content: Disability Studies

As a relatively new interdisciplinary field in academia, disability studies builds from feminist, postmodern and post-colonial theory to articulate and theorize the lives and knowledges of people living with various impairments (Wilson 150). Several U.S. universities offer formal programs in Disability Studies, including a Ph.D. at University of Illinois at Chicago. A number of articles suggest ways to use disability studies components in classes in a wide variety of subjects. Appendix 2 contains a list of resources for faculty interested in Disability Studies.

Universal Instructional Design

Choices related to content transmission and learning activities play a big role in determining who can fully access learning. What can faculty do to optimize learning opportunities for all, while retaining the autonomy to manage teaching strategies and also avoiding unnecessary work?

One answer is an integrative instructional approach loosely adapted from building and product design, called Universal Instructional Design (UID). Universal instructional design in classrooms is about proactively designing learning environments, materials and activities for equitable use (access) and meaningful participation by people from a wide range of diversities. From being singled out, impaired students move into becoming an integral part of the classroom community, for the simple reason that everyone has choices about how to participate and how to evidence their learning. If all handouts are posted online, for example, students with a variety of needs for manipulating or voicing text – and anyone who missed class – can take care of business.

Common sites for application of universal instructional design are the class “culture” (ideally, one of hospitality and awareness); and three aspects of information delivery that are often referred to as UID’s “essential qualities”:

- representation (delivery of content via several modalities),
- engagement (student choice of flexible routes of engagement with program/course materials), and
- expression (an array of methods for assessment/demonstration of learning) (Izzo and Murray 32).

The resources in Appendix 1 provide additional information about UID.

As a practice, UID dovetails perfectly with the social model of impairment; as three University of Minnesota faculty point out in an article discussing their own classroom innovations, “Universal Instructional Design is an outgrowth of an interactional, social constructivist approach to disability issues . . . [UID] explores how individuals interact with the environment to construct knowledge” (Higbee, Chung and Hsu 14).

STRAND 2: FACULTY AND STAFF LIVING WITH IMPAIRMENTS

This strand has the flavor of a case study, as the dearth of public information about the work experiences of Evergreen employees living with impairments led me to start with the specific. The experiences of people living with environmental sensitivities/Multiple Chemical Sensitivity (ES/MCS) provide a particularly clear illustration of the ways in which social arrangements of privilege and power interact with impairment to construct disability at Evergreen. After a brief explanation of ES/MCS as impairment (not repeated in this summary), the rest of Strand 2 relies on both generic and specific experiences of people living with this condition, to examine and represent the lives and concerns of Evergreen employees rendered “disabled” by environment/impairment interactions.

People socially-disabled by the narrow ranges of air or water quality⁸ considered “acceptable” and “healthy” – the 12 to 16 percent of the general population (Caress, Steinemann and Waddick 432) with medical histories and past experiences that tell them even minimal exposure to diesel exhaust or to cigarette or wood smoke will bring on an asthma attack or hives, for example – don’t have the luxury of inattention to their surroundings (or of waiting for quantitative evidence of a problem). If our reactions are severe and we are to participate in community life, in other words, we must proactively minimize our exposure to these substances. And we must often do so despite the fact that not-sensitive people don’t perceive – or believe – there is a problem.

Because so much of modern air pollution is human-made, and the result of choices made for expediency or comfort rather than true necessity, it is quite difficult for chemically sensitive people to think of these situations as anything other than deliberate exclusion. An exile, that is, so often made “necessary” not by reactions to chemical substances – *which their bodies don’t manifest unless the triggers are present* – but by other people’s generally unreflective and often casual choices to release these substances into the air. Their choices to “misrecognize” – disbelieve, disregard and deny needs of ES/MCS people (cultural injustice) – leads to the forced exclusion of ES/MCS people from physical and social environments, including those connected with their work (material injustice).

⁸ People living with ES/MCS react to chemicals in and on air, water, food, clothing, paper, plastic surfaces, personal products, etc. Air, water and food are the most common sites of communal tension. For example, Lacey recently decided to add chlorine to city water, an action that may force a number of people to move.

But if it is social practices, not physical necessities – and often the practices of not-impaired people acting without sufficient understanding of or care for others – that result in disability, then whose responsibility *is* disability and its amelioration? The common sense, business-as-usual answer to this question is “the disabled people, of course.” But that’s privilege and the medical model talking. When disability is caused by the actions of others, then changes in those actions are what will correct it. Accommodation as it is usually thought of is vital in specific cases, but is not necessarily a useful solution by itself, or for all. In my experience and that of others, most Evergreen employees living with impairments either do not need formal accommodations, or do not request them for fear of one of several types of reprisal. And yet formal accommodation based in disclosure of need and documentation of impairment is in effect Evergreen’s sole avenue of communal response to employee experience of impairment and social-disablement.

TOWARD EVERGREEN AS KNOWLEDGEABLE BODY: HEALTH IS MEMBERSHIP

“Is it possible for the College to accommodate itself to these unprecedented conditions . . .” (Keller Pt.II)? Helen Keller asked this question of Radcliffe College in 1900; four years later, she graduated as the first DeafBlind person to earn a B.A. Keller’s question to her college summarizes my question to mine. Can Evergreen as institution and community take students, staff and faculty living with impairments seriously enough to enter with us into authentically reciprocal relationship? Research has long revealed that people are healthier when they are involved in social relations (House 76). And communities themselves are more robust when human connections are actively valued, and felt obligations and opportunities for mutual goodwill mesh into active reciprocity, as both Robert Putnam (in *Bowling Alone*) and Lewis Hyde (in *The Gift*) have shown.

Wendell Barry’s provocative observation that “community . . . is the smallest unit of health” (90) suggests a new paradigm for thinking about inclusion, a paradigm that moves well beyond legalistic requests. Humans live not alone, but in “an interinvolvement with other bodies and other creatures, living and unliving, that is too complex to diagram or describe.” (95). There it is: We’re all connected.

Summarized Recommendations⁹

- I. Acknowledge the historical, social and institutional natures of exclusion and discrimination on Evergreen's campuses, and the undeniable presence of people living with impairments. Training all staff and faculty in their legal responsibilities toward people living with impairments, in the inadequacy of legal requirements as the sole gesture toward community, and in practical ways to include proactively and then to respond to specific requests for inclusion might be one effective way to begin this.
- II. As a matter of official policy, identify and act on ways to make all Evergreen settings (physical, cognitive, affective, sensory) more inclusive.
- III. Make widely available on all Evergreen campuses information about how and where students, staff and faculty can formally request accommodation, and how and where staff and faculty can refer students who may need assessment or support services.
- IV. Employ proven health promotion techniques to educate the campus community on TESC smoking and air quality (scented product) policies, and enforce policies restricting driving on campus. Require all people doing facilities work (cleaning, painting, remodeling, etc.) to post advance notice on the outer doors of buildings, and in the areas themselves. Attach real consequences to failure to demonstrate proactive awareness of others' needs.
- V. Establish a DTF or President's advisory group¹⁰ charged to actively examine institutional and community practices related to social-disablement on Evergreen campuses, and the experiences of working, learning and teaching with and about impairments.

CONCLUSION

There are no excuses for social disablement in a community that prides itself on collaboration and learning across significant difference – that is, in Evergreen environments of learning, working and teaching.

⁹ See the longer version of this paper for supporting detail.

¹⁰ Official committees advising administrators are active on a number of higher ed campuses in the U.S. A quick search over the WWW found these names as a start: UCLA, UC-San Francisco, Michigan State University, Columbia University, and the University of Wisconsin system.

FULL POSITION PAPER

INTRODUCTION

Because learning is enhanced when topics are examined from the perspectives of diverse groups and because such differences reflect the world around us, the college strives to create a rich mix in the composition of its student body, staff, and faculty, and to give serious consideration to issues of social class, age, race, ethnicity, (dis)ability, gender, religious preference, and sexual orientation.

“Evergreen’s Mission” (Evergreen State College)

This paper addresses three aspects of Evergreen faculty experience related to deafness, illness and disability: 1) teaching d/Deaf¹¹, ill and disabled students; 2) teaching disability-related content; and 3) working as an Evergreen employee living with impairment. After a section establishing a conceptual framework and the numbers of d/Deaf, ill and disabled community members at Evergreen, the paper splits into two strands. The first focuses on issues related to teaching and learning in Evergreen programs and courses (combining aspects 1 and 2). The second strand centers on faculty experiences related to job and Evergreen community life (aspect 3). The paper has been written so that readers can choose one strand to follow while skipping the other, although there is unique information (and minor overlap) in each. The two strands then come together in a closing section in which I suggest a new paradigm and make five recommendations for crafting an adequate response to the undeniable presence on campus of people living with physical, cognitive, emotional and sensory impairments.

My overall point is this: As an institution and a community, we at Evergreen do not “give serious consideration to issues of . . . (dis)ability,” or to the undeniable presence and experiences on Evergreen campuses of d/Deaf, ill and disabled students, staff and faculty. In fact, institutional focus on material (physical) access – a focus made myopic by disregard of the cultural dimension of disability experience – has resulted in a number of specific and perennial problems. The problems include

¹¹ I rely on Lennard J. Davis’ definitions of “Deaf” and “deaf,” indicated here with one word. Davis writes “The Deaf are that community of deaf people who share language, cultural values, history, and social life. The deaf are simply those who do not hear” (“Deafness” 882). To Deaf, “deafness is not a disability. They now see themselves as a linguistic subgroup like Latinos or Koreans. The Deaf feel that their culture, language, and community constitute a totally adequate, self-enclosed, and self-defining sub-nationality within the larger structure of the audist state” (“Deafness” 881-882). “Audist” is a word similar to “abelist,” but focused on oppression based in normalization of hearing.

- active instances of direct discrimination including exclusion from campus spaces and events,
- staff and faculty unprepared, generally unsupported and occasionally unwilling to deliver their individual expertise accessibly and to address relevant cultural factors,
- overloaded student support services,
- unnecessary crises and resultant extra work for staff and faculty.

These difficulties are eminently addressable, I think, because they stem from identifiable sources: an out-dated paradigm for thinking about illness, disability and deafness; and unexamined arrangements of power and privilege coupled with a one-sided understanding of justice.¹² These factors together have resulted in Evergreen's over-reliance on a single, necessary – and flawed – type of response to all disability-related concerns. The result is daily actions denying d/Deaf, ill and disabled people full participation in our various campus and learning communities.

Though this document is a position paper, my intent in what follows is informative rather than polemical; I would rather spark a process than a fire. I am more concerned with framework and conceptualization than with anecdote. For one thing, particulars about Evergreen staff, students and faculty living with impairments and their experiences on campus, including statistical counts, are difficult to come by. (So far as I have been able to discover, in fact, no one has researched or documented disabled students, staff and faculty experiences related to work, teaching and learning.) And for another, my ultimate goal is not vilification, but change. I want to work in fully accessible Evergreen environments, among Evergreen people who acknowledge and consciously practice human interdependence. My comments throughout are based in my own observations, research undertaken while planning several Evergreen courses and programs, two conference presentations I have prepared and delivered with Evergreen students living with disabilities (and without), and relevant concerns expressed by Evergreen faculty in numerous informal conversations and at two summer institutes I attended in 2004.

My standpoint in relation to issues of impairment and disability in higher education is as an (adjunct) member of the faculty who has taught mostly half time at Evergreen for 10 years, in addition to working for six years in healthcare and public health. Since 2000, I've taught three

¹² This paper's final section lists five suggestions for beginning to address these issues.

courses and two programs on the subject of chronic illness and disability experience. By rough count, in those classes alone I've worked with well over 75 ill and disabled Evergreen students, and perhaps 10 such alums, staff and faculty. In addition, I've lived for 15 years with impairments associated with myalgic encephalomyelitis/chronic fatigue and immune dysfunction syndrome (ME/CFIDS).

CONSTRUCTING DISABILITY: A CONCEPTUAL AND DESCRIPTIVE

INTRODUCTION

Social Construction of Disability Through Design of Environments
Distinguishing Between Impairment and Disability
Power, Privilege and Justice: Disability as Critical Modality
People Living with Impairments at Evergreen

Social Construction of Disability Through Design of Environments

The built environment constructs disability. Doorknobs, for example, require the physical capacities to grasp, turn and push or pull; their placement demands enough height and balance to do so at the effective angle. Once installed, doorknobs determine who can enter – that is, who can perform the function of opening the door.

Cultural environments also construct disability. And in architecture, the built and the cultural come together; in thinking about doorknobs, for instance, the effect of expectations becomes clear. If it is culturally considered “normal” for older children and adults to be able to open doors, then those who can't turn a doorknob are not normal. Such assessments carry cultural freight. Not only are the not-normals denied access to whatever is on the other side of the door, but their failure to meet cultural expectations may move them into a disempowered social position. Depending on their personal characteristics, the position might be that of “child”, or of “disabled”.

If, however, designers select a lever or push bar door opener, then people from a wider range of capability (although still not everyone) can perform the “normal” function of opening it without assistance. In this case, fewer people are disabled (unable to function, rendered

“abnormal”) by what after all was someone’s choice during the design and furnishing of the building – the choice of door opening technology.¹³

Choices made during the creation of environments that result in types of barriers other than architectural also construct concepts of “normality” and “abnormality,” and “ability” and “disability.”¹⁴ Davis lists additional barrier types as “affective, sensory, [and] cognitive” (*Bending* 41). Profound deafness, for instance, is often considered a disability because the deaf person does not communicate by hearing or (sometimes) speaking, dominant methods of human interaction. Yet members of the Deaf community sign with great fluency and nuance – communicating expertly. The issue here is not lack of the intelligence or motivation necessary to communicate (far from it), but simple absence of capacity to do so by the widely-favored method of talking and listening. Similarly, widespread tolerance for smoking in “public” places renders those same places inaccessible for use by people for whom tobacco smoke triggers breathing difficulties. One final example, this time of a cognitive setting: Teachers who design learning activities without at least one structured, linear option unintentionally may be making participation more difficult, even impossible, for students taking strong medications, or living with mental illness, learning disorders, depression, ADD or the after-effects of traumatic brain injuries.

Distinguishing Between Impairment and Disability

In acknowledgement of the constructed and contingent nature of disability, the Americans with Disabilities Act (ADA) defines “disability” as related to an individual’s ability to function within her general environment, and to the manner in which others consider her.

Disability is

(A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (B) a record of such an impairment; or (C) being regarded as having such an impairment.¹⁵ (42 USC 12101-12213)

¹³ This example is one I actually witnessed during eval week, Fall quarter, 2004. As I pushed the bar to open one of the outside glass doors near the program secretaries’ office in LAB I, a student standing huddled against the rain said “Thank you! I’ve been waiting a long time.” She physically did not have the strength and balance necessary to manipulate the door by herself, and the electric door opening mechanism was broken (as it often is). Nor is there a telephone nearby that she could have used to report the outage and ask for assistance.

¹⁴ It is worth noting here that “use of the word normal in reference to physical bodies appeared in English merely one hundred fifty years ago, coinciding with the birth of statistics and eugenics” (Davis *Bending* 38-39).

¹⁵ Evergreen’s “Reasonable Accommodation in Employment Policy” quotes this definition (Evergreen “Reasonable” Sec 4.C).

In other words, disability lies not in a specific diagnosis or condition – all people with hearing loss or all people with cerebral palsy – but in how one’s “physical or mental impairment” impacts specific functioning over time. Even the mistaken perception of the presence of impairment (as might be the case with disfigurement) is considered to be “disability.” To fall within the purview of the ADA, in employment situations

impairments . . . must substantially limit major life activities such as seeing, hearing, speaking, walking, breathing, performing manual tasks, learning, caring for oneself, and working. [For example], an individual with epilepsy, paralysis, HIV infection, AIDS, a substantial hearing or visual impairment, mental retardation, or a specific learning disability is covered, but an individual with a minor, nonchronic condition of short duration, such as a sprain, broken limb, or the flu, generally would not be covered. (U.S. Department of Justice)

Differentiation of “impairment” and “disability” grew out of social justice movements for disability rights, and from work in the relatively new academic field of disability studies.¹⁶

Elizabeth J. Donaldson compares this insight to earlier feminist work on sex and gender:

. . . distinction between impairment and disability [is the distinction between] the material body and the socially-constructed body . . . Like Gayle Rubin’s configuration of the sex-gender system – the process by which biological sex is transformed into cultural gender – the impairment-disability system is the process by which biological impairment is transformed into cultural disability. (111)

Sociologists have termed this new line of analysis the *social* model of disability.¹⁷ In the rest of this paper, I will rely on two definitions based in the social model:

Impairment is the lack of part of or all of a limb, or having a defective limb, organ or mechanism of the body [or, I would add, the perception of “defective,” such as accompanies facial disfigurement in much of U.S. society]. **Disability** is the loss or limitation of opportunities that prevents people who have impairments from taking part in the normal life of the community on an equal level with others due to physical and social barriers. (Finkelstein and French 28; emphasis added)

¹⁶ An emerging and interdisciplinary field, “Disability Studies encourages perspectives that place disability in social, cultural, and political contexts” (Society for Disability Studies). I will discuss Disability Studies at more length in Strand I. I should also point out that there is debate in this field about the validity of completely severing conceptually the idea of “impairment” from “disability.” As Donaldson writes, “If impairment occurs in the body and disability occurs in society, then this posits an ideal, disembodied social subject who seems to remain intact, unaltered, even normal, despite physical impairment” (112). See also Wendell “Unhealthy.”

¹⁷ Donaldson also considers several limitations of the social model for thinking about severe mental illness (111-113).

Washington State's Department of Health (DOH) characterizes impairments similarly, as "the *loss or abnormality of body structure or of a physical or psychological function*" and adds the important note that impairments can be physical (cancer, paralysis), emotional (depression), cognitive (intellectual disabilities) or functional (elsewhere termed "sensory" – loss of sight is one example) (Kinne 5; emphasis in original).¹⁸ As we have seen, interactions between impairments and physical, sensory, emotional, cognitive – and hence cultural – environments can affect a person's activity (functioning) and participation. DOH defines participation as "involvement in life situations" (Kinne 5-6). A person unable to push open a door because of physical impairment may not make it to her eval appointment, thus being rendered "disabled" by her physical environment. Until someone happens along, or the electric door opener works.

To put it another way, in the social model disability is contingent on setting, broadly defined. Disability occurs in degrees along a continuum, when it appears at all. A person may live with a chronic *impairment* that nevertheless does not disable him in particular surroundings (including specific cultural expectations), but he may experience reduced capacity to function, loss of opportunity and resultant cultural disadvantage (*disability*) elsewhere, among a different group of people, or if surroundings change. Disability is not chosen by the impaired individual or inherent in her impairing condition; disability is both imposed and shaped from without. One additional tenet of the social model: The goal of intervention into disability is to reduce or eliminate socially-constructed barriers to activity and meaningful participation, including barriers presented by attitudes and values.

Here's a classroom situation I've encountered several times at Evergreen, analyzed through the social model and written generically. A student with moderately impaired hearing might be functionally disabled (unable to understand others' communication) in a room in which there is background noise (side-talking, two people talking at once, and so on), but not disabled – though still hard of hearing – when the room is silent except for one person talking. In addition, noise would functionally disable him in terms of only one type of communication, spoken; other methods of sharing information, such as written notes, PowerPoint slides and captioning on

¹⁸ I also add to this definition the caveat that impairments can be and are experienced as such, well beyond the medical industry's present capacity and willingness to detect and diagnose them. Historically, specific "conditions" have moved into or out of official compendiums of medical diagnoses, based on social or religious (not positivist scientific) factors; what allopathic medicine as practiced in the U.S. identifies as its purview and what members of society "medicalize" is due largely to the work of social and cultural construction. Homosexuality and Attention Deficient Disorder are two well-documented examples. The ADA itself does not list specific impairments, relying on limitation within environments as its yardstick.

videos, are of course still available. The student is unable to participate fully only if others refuse to alter the environment by reducing background noise, meeting in a quieter location, amplifying their voices with a microphone, relying on communication methods other than voice, etc. Let's say that they do refuse, despite his requests. The *impairment* in that event is the reduced hearing. The accompanying *disability* – the hearing impaired student's inability to function and participate given the (constructed) circumstances – rests in other people's failures to acknowledge and take seriously his situation. He has been socially-disabled, by others' choices and actions, and I'd like to suggest that the loss of opportunity – the disability – is two-way: the student with impaired hearing cannot learn adequately unless others make adjustments to the environment (including its affective aspects), and without those adjustments, other program members are denied his full participation in their collaborative knowledge-making and learning community.

Much of the discourse around impairment and disability in the U.S. (although certainly not all) rests in the *medical* model of disability. This second framework dictated professional and institutional responses to impairment during much of the 20th century, and continues to dominate standard training and expectations of professionals in the fields of medicine, psychology, rehabilitation, and the social services. The medical paradigm equates impairment with disability, and individualizes and privatizes disability within specific bodies and persons, as in "she is a disabled person." Disabled bodies and persons are characterized as "deficient" or "abnormal." Limitation is understood to be inherent in an impairing condition, leading to general perception of impairment as automatically and essentially disabling, and also a personal tragedy – a tragedy that must be borne, usually, by the impaired/disabled person (and perhaps her family) as a private problem. The goals of intervention in impairment/disability, under the medical model, are first cure, and then the impaired person's "adaptation" and "adjustment" to her surroundings, including the affective surroundings associated with what is thought of as "affliction."

To re-analyze the classroom situation above, this time using the medical model, any difficulties in learning – such as not being able to hear lectures – are situated in the hearing-impaired student rather than in the design and delivery of teaching and learning. If the student proves unable to learn adequately under "normal" circumstances (circumstances a proponent of the social model would recognize as highly constructed, and selectively privileging the abilities

to hear and to focus even with background noise present) then he is considered “unable to learn” or “inappropriate” for the situation – and in effect denied access to meaningful education.¹⁹

Power, Privilege and Justice: Disability as Critical Modality²⁰

“Disability,” or “social-disablement” as I will now refer to it, is a weighted term in most U.S. cultures, one that carries emotional, legal and moral implications. Although I can’t do more here than state this as fact, a number of scholars working in disability studies examine impairment’s cultural valences at some length. Donaldson, for example, attributes “cultural anxiety surrounding mental illness” to “an inability (or desire) to reconcile medical discourses of mental illness, which describe the symbolic failure of the self-determined individual, and competing discourses of democratic citizenship in which will and self are imagined as inviolable” (113). See Appendix 2 for a list of disability studies resources.

When in my programs we study lives lived with impairment, students usually say that denial and silencing of the facts of impairment, and of experiences of social-disablement in impaired people’s lives, grow out of not-impaired people’s fear, and perhaps their ignorance. There is truth in that explanation, but not the whole truth. Denial and invisibility are also two of a number of practices arising from prevailing social arrangements of power and privilege, arrangements keeping in place inequities rationalized by reference to socially-determined values and structures.²¹

In her widely-known work on the subject of racism, Peggy McIntosh identified two types of privilege. The first of these, “unearned advantages” (35), confer entitlements all people should have (such as physical safety and a feeling of belonging in society) to some groups and not to others.²² Examples related to social-disablement include those times when people living with

¹⁹ An excellent and very brief overview of what the author calls “theoretical movements” related to disability, with source citations for further reading, can be found on-line (Watermeyer). This paragraph is partially based in Watermeyer’s discussion. Strand Two of this paper examines employee experience at Evergreen through the lens of the social model.

²⁰ I borrowed the phrase “critical modality” from Lennard Davis, who uses it in reference to what he calls “the deafened moment” in literature (“Deafness” 882-883).

²¹ These practices also shape knowledge. For example, attributing denial solely to fear obscures questions about what cultural/political purposes such denial might serve. What do we fail to learn when we refuse to engage life experience and emotion – and specifically experiences and emotions of socially-disabled people and people living with impairments -- as sources of knowledge, for instance?

²² I agree with Wendell, who suggests that society’s responsibility to mitigate disability (that is, to provide accommodations and opportunity) should be focused specifically on participation in significant general aspects of daily life such as “work, social life, political life, religious life, cultural life, personal relationships, and recreation”–

impairments are kept from voting by inaccessible voting booths and buildings, or by lack of accessible transportation. They are denied opportunity to exercise one type of power vital to democracy, and others who can take part in the political process have an unearned advantage (National Organization on Disability). McIntosh labeled a second privilege type “conferred dominance,” defining this as the socially-granted privilege one group might have to control others (35, 36). The well-documented disparities between access to healthcare for people with chronic conditions (who are less likely to receive needed care) and those without; and the similarly well-attested tendency of US healthcare professionals to underserve people they perceive as belonging to socially-racialized groups other than white, are two cases in point (Association of Healthcare Journalists; Kaiser Family Foundation). Privilege enables certain groups of people to define what is “reasonable,” “correct” and “real” – in other words, to draft the agenda and to decide who or what gets taken seriously in almost all situations (Johnson 24-25, 33-34).

Privileges persist and become codified or institutionalized through social arrangements resulting in unequal access to power. I turn here to Carolyn Heilbrun’s definition of the latter term: “Power is the ability to take one’s place in whatever discourse is essential to action and the right to have one’s part matter” (18). The voting situation mentioned above is one obvious way some people living with impairments are kept from “discourse essential to action;” similarly, teachers who refuse to change classroom practices to meet specific learning needs deny those students whose learning is subsequently affected “the right to have one’s part matter.” There are many more ways, obvious and subtle, privilege denies power to people with impairments. Failures to educate about or to take seriously air quality (scented products) and smoking policies, and institutional processes of accommodation, and refusals to move meetings to accessible locations – thereby excluding specific people from classrooms, meetings and events – are common paths of oppression at Evergreen.

Privilege thrives on exclusion and denial. Its more direct dimension is discrimination. In his book *Privilege, Power and Difference*, Alan Johnson defines discrimination as “treating people unequally simply because they belong to a particular social category” (57). Throughout

and, of course, education. Lack of ability and opportunity to do something not essential to participation in these aspects of society -- Wendell uses the example of dancing – doesn’t necessarily disable a person in a wheelchair, but being kept from work meaningful to the individual because others are afraid or uncomfortable about working with her certainly does (*Rejected* 50).

my years as a teacher in several colleges, students impaired by hearing loss and a host of other conditions ranging from quadriplegia to diabetes have told me of classroom situations in which they were called names, spoken of in the third person as if they were not present, deliberately offered food the other person knew they were allergic to, told (sometimes by the teacher) that their conditions were “all in their head,” made the butt of practical jokes, left in a corner of the room to try to pick up what they could by reading rather than participating in small group activities or discussion, barred from field trips or special trainings because faculty and staff didn’t want to work with their needs, and so on. To keep this paper focused on its purpose, I will not go further here toward building the case that people living with impairments are actively discriminated against in U.S. society (and at Evergreen). Many sources address this nationally, particularly in the areas of employment, education, healthcare and participation in public activities. Locally, interviews with Evergreen students, staff and faculty living with impairments would provide a wealth of information.

In considering effective and just response to curricula and instructional design efforts that marginalize (and socially-disable) students in postsecondary writing classrooms, University of Minnesota faculty Patrick Bruch relies on a distinction made by Nancy Fraser in her book *Justice Interruptus*. Fraser describes two “broadly conceived, analytically distinct understandings of injustice” (Fraser 13). First is the socioeconomic, composed of “exploitation, . . . economic marginalization . . . and deprivation” (13); these are “distributive injustices requiring redistributive remedies” such as “increas[ing] the consumption share of economically disadvantaged groups” and, more radically, “transforming the political economy” (19, 20, 25). The second domain is the cultural or symbolic, where injustice is “rooted in social patterns of representation, interpretation and communication” (14); these are “injustices of misrecognition requiring remedies of recognition,” such as “accord[ing] positive recognition to a devalued group” – and “transforming the underlying cultural-valuation structure” (19, 20, 24). The action of remedy in both injustice domains presupposes acknowledgment of “the equal moral worth of persons” (25, 26).

While life itself is never this neat and Fraser’s analysis is much more complex than is represented here, the point of separating the two types of injustice conceptually is to acknowledge that efforts toward justice in one area might not affect or address the other. As Bruch points out, “economic enfranchisement may not, alone, remedy the unjust relations

attached to disability in current institutions. Persons labeled as disabled may still be culturally marginalized, misrecognized, and disrespected” (Bruch 4). Justice for Bruch in higher education has to do with acknowledging the necessity for more than one response or remedy (4), and with “interanimating redistributive and recognition-oriented remedies to educational injustice” (16), by redefining “what it means to participate in social practices like work and schooling so that part of the purpose of participating in such practices is to change the practice itself” (5) – with full participation by people living with impairments.

People Living with Impairments at Evergreen

Students

A form sent to new students admitted to Evergreen, before they register, asks students “with a diagnosed disability” to identify themselves. The reason given for the request is that “qualified individuals who have documented disabilities may be eligible for services from the Office of Access Services for Students with Disabilities” (Evergreen, Office of Access Services, “Access Evergreen”). In Fall 2004, 263 entering and continuing Evergreen students – 6 percent of the enrollment total of 4,046 – had formally identified themselves as “disabled,” through this process (Washington State Office of Financial Management).

This percentage is higher than that obtained in the National Postsecondary Aid Study (NPSAS) conducted in 1999-2000, which reported that 3.6 percent of undergraduates enrolled in U.S. postsecondary institutions answered “yes” when asked “Do you consider yourself to have a disability?” (Horn 17) – a question less restrictive than that on Evergreen’s form. However, Evergreen’s 6 percent is well below the 9.3 percent of undergraduates who identified themselves in the NPSAS study as living with at least one activity limitation or “vision, hearing or mobility impairment,” or with chronic physical, mental and emotional conditions *and* difficulties with one or more of five basic activities including learning (Horn 17). (An additional 2% of NPSAS respondents said they lived with an impairing condition, but did not have difficulties in school as a result (Horn 17)). Research on other populations confirms a similar disparity in numbers, between those who live with impairments and those who are willing to identify themselves with

the socially-stigmatizing label “disabled.”²³ Strong social and cultural forces may also limit an individual’s willingness to ask for what are often construed as “handouts” or “special rights.” Many people living with impairments do not need specialized services in learning situations. For all of these reasons, it would be misleading to use counts obtained by requesting declaration of “documented disability” during eligibility screening for services, as the only measure of numbers of Evergreen students living with impairing conditions.

The NPSAS respondents who self-identified most frequently cited orthopedic/mobility impairments (29.4 percent), followed by mental illness/depression (17 percent) and “health problems” (15.1 percent) (Horn 19). The study found that in general, when compared to their not-disabled peers, disabled students in the US tend to be (17):

- Earning an income that puts them in the lowest quartile among their student peers.
- Less likely to have parents who attained a four-year or graduate degree.
- Older.
- More likely to have children.
- More likely to be parenting alone.

In a 2003 synthesis of research, entitled *People with Disabilities and Postsecondary Education*, the National Council on Disability (an independent federal agency) found a number of concerns associated with the postsecondary preparedness of students living with impairments, and their success once they enroll. For example, “limited access to and availability of support” and “faculty members and other academic personnel . . . often unaware of disability needs and supports,” among a number of other factors, seriously impact participation and retention of students living with impairments and enrolled in higher education institutions. Students whose impairment experiences coincided with their K-12 education also may not have had access to adequate curriculum or guidance counseling or preparation for the transition from secondary to higher education, or to opportunities to learn two skills particularly vital to success at Evergreen: self-determination and self-advocacy (III).

Despite the barriers students living with impairments encounter and the additional factors that statistically place them “at risk,” however, they do persist in obtaining an education

²³ To my knowledge, only five of the 75 or so impaired students I worked with in four programs and courses focused on deafness, chronic illness and disability were actively working with Evergreen’s Office of Access Services. Several students I asked about this told me that they did not want disability “in their record,” and that experiences before coming to Evergreen – of bureaucracy, inadequate services and patronizing attitudes based in deficit models of disability – limited their willingness to seek out help labeled “for disabled.” In addition, several students had only a vague idea of what “documentation” might involve.

(although not at the same rate as no-impairment students). The U.S. Department of Education found that in 1994, 53 percent of postsecondary “students with disabilities” who had first registered in 1989-1990 were still enrolled or had attained a vocational certificate or degree, compared to 64 percent of “no disability” students (Horn and Berktold vi).

Impairing conditions affect people of color significantly more often than white populations in the U.S., as reported in a number of sources (Association of Healthcare Journalists; Kaiser Family Foundation). This stems from a number of factors, including differential access to health care when access is assessed by race, environmental racism, and the health effects of living in an oppressive society. I don’t know of research that considers the ways in which race, class, gender, etc., interact with disability in the classroom to complicate discriminatory environments for students living with impairments. But the increased prevalence of many illnesses and other disabling conditions among African Americans, Asians, American Indians/Alaska Natives, Native Hawaiians and other Pacific Islanders, and people of other and mixed races, when compared to whites; and among poorer US residents when compared to wealthier residents; renders the issue of higher education for students living with impairing conditions more complex and broader than it may first appear. The fact that a higher percentage of white undergraduates reported functional disabilities, when compared to most other racial groups consulted in the NPSAS study, may stem from additional factors limiting college admission and tenure of students of color, or other factors not assessed (Horn 130-131, 139).

Staff and Faculty

Washington State’s Department of Personnel states that 5.3 percent of the workforce in general government state agencies has formally disclosed an impairment, and that 1.3 percent (a figure that probably included additional individuals) (Standifer) qualify as disabled veterans. Proportions of impaired employees in the state’s postsecondary institutions are generally smaller. According to Evergreen’s Human Resources Office, in 2003 just 3.7 percent of employees had provided documentation of a disabling condition, and 1.1 percent were disabled veterans (Governor’s Affirmative Action Policy Committee 13-16). These figures are derived from data gathered through accommodation requests and by asking people to self-identify when applying for a job and immediately after hiring. According to Evergreen’s Human Resources Director Ken

Holstein, they underrepresent actual proportions of employees who live with impairments (Holstein 2/7/05 and 2/17/05).

On-the-job disclosure of disability is constrained by general and individual attitudes and values associated with social-disablement, and by employers' track records in this area. Approximately 20 percent of Washington State's civilian and not-institutionalized residents live with impairment resulting in at least one functional disability, a figure mirrored nationally according to the 2000 U.S. Census (Kinne 5, Waldrop 2). I have not found research that addresses the actual proportion of people living with impairments who are employed in higher education or generally, in Washington state or nationally. But again, prevalence among Evergreen employees cannot accurately be measured by numbers based solely in formal disclosure.

STRAND ONE: TEACHING STUDENTS/TEACHING CONTENT

Introduction to Strand One
Teaching Students Living with Impairments
 The Rhetoric of Formal Accommodation
 Full Inclusion
Methods of Engagement
 Program and Course Content: Disability Studies
 Universal Instructional Design

Introduction to Strand One

Because learning is enhanced when topics are examined from the perspectives of diverse groups and because such differences reflect the world around us, the college strives to create a rich mix in the composition of its student body, staff, and faculty, and to give serious consideration to issues of social class, age, race, ethnicity, (dis)ability, gender, religious preference, and sexual orientation.

The Evergreen State College “Evergreen’s Mission: Principles That Guide Evergreen's Educational Programs”

How can Evergreen as both institution and community give “serious consideration” to students living and learning with impairments and “(dis)ability”? This section addresses this question from the point of view of faculty teaching programs and courses. Two confluences of “teaching” and “disability” immediately come to mind: teaching students living with impairments, and – a different topic – program and course content about impairment, processes of social-disablement (including representations of impaired people, disability policy, etc.), and/or lives lived with impairments. I’ll address each separately below, after a brief introduction.

The undeniable classroom presence of students living with impairments surfaces a number of questions usually lying just underneath our daily decisions and actions as faculty. Is our job to teach students, or to teach content? If we don’t teach and assess every student in

exactly the same way, then what is fairness? Who (if anyone) should decide which students are capable of college-level academic work – and what standards and considerations should come into play? How far must faculty go in teaching individual students? If most students grasp a concept with one explanation, for example, must I repeat it two more times for those few whose learning difficulties or other differences from my assumed norm slow comprehension of new material, so that all can participate in a subsequent workshop? Whose responsibility is it to decide who, and what behaviors, are “suitable” or “appropriate” for a specific program? And how are the answers to these questions changed by the learning community context, structured as it is around, not individualized and privatized models of learning, but collaborative and social knowledge-making?

The most pressing overarching concerns I see for Evergreen faculty, related to teaching students with impairments, are three:

- the inadequate nature and amount of institutional attention paid to the issues of teaching and learning with impairment (including Evergreen’s over-reliance on formal accommodation as a single response), and the too-limited support provided to faculty and students as a result;
- absence of informed discussion and theorizing, and information about Disability Studies, that would help faculty consider how impairment and social-disablement both interrogate and enrich our current teaching and learning practices; and
- lack of relationship here between student support services staff and the faculty as a whole, including the lack of discussion and proactive, on-going technical assistance.

Each of these concerns grows, I think, from Evergreen’s present over-reliance on the medical model and formal processes of accommodation.

My purpose in Strand One will be to address these and other issues through the social and critical frameworks just developed. I draw on much that has been done elsewhere in U.S. postsecondary education relating to teaching students with impairments, while keeping in mind that Evergreen is unique in many ways.

I would prefer to discuss student experience at Evergreen from the student point of view, instead of that of one faculty. But so far as I’ve been able to discover, no one to date has undertaken the necessary research. I don’t know of any data, qualitative or quantitative, that

describes the experiences of Evergreen students living with impairments, in or out of classroom – or, for that matter, the experience of Evergreen faculty teaching students with impairments.

Teaching Students Living with Impairments

The Rhetoric of Formal Accommodation

It seems reasonable to assume the presence in *every* Evergreen program or course, of people living with various types of impairment, given the statistics in the previous section. Some impairments will directly affect learning – and hence teaching – and some will not.

Before turning to a short synopsis of laws and policies related to formal accommodation, I want to acknowledge, with Wilson and Lewiecki-Wilson, the fact that discussion of accommodation “brings into the academy a legal discourse that emphasizes equity, accommodation and reasonableness.” For faculty, this may raise ideas and issues with which we are unfamiliar or to which we already attach socially-charged emotions or meanings. I’d like to encourage us to resist what these authors characterize as a “retreat to business as usual. . . . in cases of conflict, the limits of the terms *reasonable* and *equitable* [and other rights-based concepts associated with teaching impaired students] are likely to return – like a compass needle to the north – to the dominant lines of power and the already inscribed attitudes” (302). My purpose in reflecting on these concepts here is to suggest that we move in a different direction.

Federal law “protect[s] students with disabilities from discrimination” and requires that “students with disabilities have *equal access* to information and to the avenues of communication” at U.S. colleges and universities (Grossman; emphasis added). This language is echoed at Evergreen, where “the mission of Access Services is to coordinate services that will ensure a student with a disability *equal access* to Evergreen program [sic] and activities” (Evergreen Office of Access Services “Access Evergreen”; emphasis added).

Laws do *not* require postsecondary institutions to “fundamentally alter” instruction in order to accommodate impaired students, or to prevent the exclusion of those whose impairments “manifest a ‘direct threat’ to the health and safety of themselves or others” (Grossman). Students living with impairments must “meet the ‘essential’ ‘academic’ and ‘technical’ standards of the college or university” and legal cases have established precedents to guide the interpretation of

these terms (Grossman).²⁴ Evergreen’s relevant policy, for example, states that it applies to “qualified students with disabilities,” and defines a qualified student as one

who, with or without reasonable accommodations, meets the academic and technical standards required for admission to, participation in, and/or fulfillment of the essential requirements of college programs or activities. (Policies and Procedures/Student Affairs/Students with Disabilities Policy IV)

Much has been written to establish the legal meaning of the term “reasonable accommodation.”²⁵ In general use, however, the word “accommodation” has come to denote legalized and problem-based retrofits undertaken in attempts to make already-planned or constructed activities and environments accessible to people who would otherwise be disabled by them. Very often, in a grudging gesture from the medical model toward the social, individualized accommodations to provide access – usually physical access – are understood to be the *only* obligation (moral or otherwise) of institutions and not-impaired people toward those living with impairments.

Evergreen relies exclusively on an individualized, disclosure-based accommodation procedure; one that, anecdotally, few students remember once they put aside the form they are mailed before they attend an Evergreen class. This single-path approach has historically created a number of problems for both faculty and students (and, I would guess – without any data whatsoever except anecdotes from other institutions – unnecessary expense). I will consider this type of system generally next, with examples from Evergreen’s system in particular.

In U.S. higher education practice, accommodation processes usually require student-initiated disclosure of impairment and requests for support, and involve people outside of specific courses or programs. There are sound legal reasons why faculty should not act as “gatekeepers” when students request accommodation, and why institutions should not expect them to do so. Asking students to go to an entity such as Evergreen’s Office of Access Services for formal documentation of impairment and determination of accommodation puts actions related to legal liability in the hands of appropriately-trained personnel.

²⁴ Legal requirements for K-12 and postsecondary education of students with impairments differ in many respects. A short and easily accessible discussion of these differences can be found in “Universal Design for Instruction: A New Paradigm for Adult Instruction in Postsecondary Education” (Scott, McGuire and Shaw 370-371).

²⁵ See Grossman for an accessible survey of relevant law, written for higher education faculty and administrators. The U.S. Department of Education has also published a six page brochure available online, entitled “Students with Disabilities Preparing for Postsecondary Education: Know Your Rights and Responsibilities.”

The resultant path of formal accommodation, however, may wend through request, confirmation of need, identification of and finally even experimentation with appropriate technology or procedures. For example, Evergreen's "Students with Disabilities" policy states "Many accommodations require time to arrange. Requests for accommodations should be received by the college six weeks prior to the beginning of the quarter . . ." (Policies and Procedures/Student Affairs/Students with Disabilities Policy VI). And Evergreen students may initiate additional negotiation for "modification to the program/course" with a request to Access Services, if

. . . even with academic adjustments and auxiliary aids/services provided by the college, he/she [student with impairing condition] is unable to complete the program/course requirements solely because of his/her disability. (Policies and Procedures/Student Affairs/Students with Disabilities Policy IX:A)

Bureaucracy aside, though, disclosure-based accommodation as the sole strategy for inclusion rests on a fatal error. Given prevailing social arrangements related to impairment, disclosure means risking unpleasant consequences, including exclusion. Why should a student label himself as "different" . . . especially formally? Why should he claim a contested status, particularly on those campuses where physical access to learning spaces is problematic (thus communicating lack of recognition of impairment), let alone cognitive and affectional access to learning activities and program community? Why expose himself, perhaps unnecessarily, to the frustrations and irritations of bureaucracy? And why should he pave the way for resentment and exclusion, when other students (and faculty) realize from obvious accommodations that he is different, even "abnormal"?²⁶

Past experience or an accurate reading of prevailing attitudes and behaviors may provide solid reasons why Evergreen students don't disclose impairing conditions – on the form sent to them soon after they become Evergreen students, on the form Access Services requests before an accommodation appointment, or in individual programs. Writing in the Fall 2003 *Washington Center News*, Marie Marquart explained her concerns as an Evergreen student working with a learning disability:

²⁶ Formal requests for accommodation also very often require students and others to place themselves in the position of claiming injury or victim status, or to reveal vulnerability to social discrimination, each something many people living with impairments are loathe to do. These concerns are discussed in more detail in Strand Two, from the point of view of Evergreen faculty/employees.

Once my problem, dyslexia, was defined, I became aware of one of the critical barriers associated with a learning disability: the time factor in learning a subject or task. Some instructors may view an individual's request for extra time [to complete assignments or assessments] as criticizing their teaching. In their classes, I am faced with the difficult and risky undertaking of inviting stigmatization and sharing [what others see as] personal inadequacy by disclosing my L[earning] D[isability]. (Marquart, Romero and Sandoz 25)

Looking at Marquart's dilemma through Fraser's schema of injustice, we can interpret it as having to do at one level with redistribution of a learning resource, that of time. But here Marquart is faced with asking for remedy in a situation in which there may not be accurate acknowledgement of her "equal moral worth" when compared to other learners, a prerequisite for addressing injustice (Fraser 25).

Lynette Romero, another Evergreen grad writing in the same *News* article, also noted difficulties with disclosure. A noticeable "disability" – in Romero's case, visual impairment signaled by a cane she used as a navigation aid – brought unwanted faculty acknowledgement. Romero recounted this story about her first evening in an Evergreen course:

. . . the instructor looked directly at my white cane and before asking my permission said, "I noticed you have a white cane, you must have special needs. Does anyone else in the class have special needs that need to be addressed?" By announcing my vision loss in this manner, the instructor literally took away my control, my power to present myself to my peers in the manner that I preferred. Full inclusion in this situation would have been letting me decide whether or not to disclose [talk about] my disability to the group as a whole. Unfortunately, the instructor's attitude reinforced the bias that people with disabilities are deviant from the normative part of society. (27)

Romero's story complicates that told by Marquart. As both authors suggest, genuine inclusion in education usually involves something more than simple material access to learning-related resources (here, presence in the classroom and more time on exams), and something more than bald acknowledgment. In fact, acknowledgment in Romero's case amounted to disrespect, one aspect of cultural injustice: The faculty immediately equated a mobility aid with "special" needs related to learning, and presented her own read of the situation to Romero's peers – an action based in and perpetuating misrecognition. For Romero, this action immediately raised issues of power, and questions about attitudes and assumptions. Fraser's redistributive remedies are not enough here to resolve the injustice, as we have moved into the cultural domain. Instead, positive recognition of blind (and by extension, impaired) students, and changing the "underlying cultural-valuational structure" must come into play (24).

Full Inclusion

Real access to education is a multi-dimensional enterprise. As noted by the National Council on Disability,

For most students, participation in postsecondary education is not limited to being physically present in a lecture hall. It is the possibility to ask questions, to discuss ideas with classmates, to have a critical conversation with professors about papers, to reflect upon readings, to explore the library, to have access to information in accessible formats at the same time as their non-disabled classmates, to work on a research project, to have coffee with friends, to participate at campus social and cultural events, and really take part in the college experience. A quality education is about coming away from each campus experience having gained knowledge about, and insight into, a wide variety of human experiences and disciplines. (2:B:1)

Formal and individualized accommodations will always be a necessary part of meaningful inclusion for people whose impairments dictate reliance on technology to read or write, and so on. But justice for Marquart, Romero and others in similar situations has something to do with opportunities for interactions based in awareness, and for enjoying the same meaningful educational experiences offered to not-impaired students. From the point of view of the student with impairment, there is an essential distinction to be made between inclusion (presence in the room, with little genuine awareness) and engagement (acknowledgement of the complexities of experience, and real opportunity to interact and learn meaningfully given one's physical, sensory, cognitive or affective terms).

In a second anecdote about her Evergreen experiences in a disabling society – disablement uninterrupted, I would add, in a campus environment stemming from reliance on formal accommodation as a single intervention strategy – Romero raises the shortcomings of what she terms “shallow inclusiveness required by law”:

. . . my first quarter back at college after a twenty five-year absence . . . In the rush of finding a good seat [on the first day of class] . . . another student plopped down beside me and asked, “Why do you get a note-taker, and the rest of us don't?” I realized at that point that the shallow inclusiveness required by law is often used to force normalization, creating the image that we are a ‘melting pot’ of identities. But unfortunately, as long as society continues to create separations between people who live with disabilities and those who don't, equality can never really be achieved just by granting accommodations. Individual attitudes must also change . . . When the student made that remark to me, I lost my feeling of belonging in that classroom. (Marquart, Romero and Sandoz 27)

Perfect safety and protection are illusory in inquiry-based learning; faculty can't script student interactions, and in my opinion we shouldn't try. But what, then, *can* we do to encourage responsible awareness, relationship and engagement with learning in our classroom communities? And how can we position students with impairment to belong? Before we consider several specific concepts related to program design and classroom practice, Marquart suggests as a first step the same broad working approach articulated in Evergreen's Mission, that of taking seriously students living with impairments – in this case, as knowers.

Most individuals with a learning disability have learned to appraise a situation or task with prudence, using a high degree of awareness, intuitiveness, and insight regarding the individuals and the environment of the situation . . . I had a positive experience while attending one of my first classes at The Evergreen State College. The instructor noticed I was having difficulty with my writing. Within our discussion, she expressed her concern and shared that even though she is a published author, she was still unsure of how to help. I specifically remember her words, which were, "I would like for us to teach each other, but I will wait for your lead." This was a turning point; the thought had never occurred to me, that I might have knowledge, experience, or a point of view that someone would want to learn. The other aspects of this conversation were her physical gestures and voice tones: they both expressed respect. (Marquart, Romero and Sandoz 25)

Accommodations and requests for disclosure, while intended to neutralize individualized "deficits" or to "normalize" differences in sensory capabilities or information processing, don't in themselves go beyond simple acknowledgement of impairment. Redefining impairment's relevance, value and even usefulness to the business at hand – changing the way we think about impairment in relation to learning – can accomplish this, though. And it has been my experience that taking that extra step to reconceptualize also enables useful reflection on practices of teaching and learning in general.

Methods of Engagement

Teachers model hope to their students.

Amy L. Faulstich, Evergreen student

For better or for worse, the people in our lives help constitute us as subjects – in practical ways such as duties taken on within teaching teams ("I'll do that if you'll do this."), and in more personal ways as well. A turning point for Marquart came when, after she had been dismissed from several postsecondary schools, an Evergreen faculty treated her as, not a problem labeled

“dyslexia,” but a knower worthy of respect. Teachers play an important role in students’ understandings of themselves as learners.

Classroom communities and teacher-student relationships frequently repeat a version of larger social arrangements of power and privilege unless conscious attempts are made to intervene, as Romero emphasizes above (Gutierrez; Wilson and Lewiecki-Wilson 306). In this section I will discuss two such interventions, one focused on program content (Fraser’s cultural domain) and the other on teaching practices related to distribution (material access to learning resources). Elizabeth Ellsworth’s excellent question has guided my thinking here: “Which interpretations and ‘sense making’ do . . . discourses [including, for our purposes here, “teaching practices”] facilitate, which do they silence and marginalize, and what interests do they appear to serve” (Ellsworth 298, n. 1)?

Program and Course Content: Disability Studies

The Modern Language Association’s anthology entitled *Disability Studies: Enabling the Humanities* opens with a short survey of the pervasiveness of impairment in imaging specific concepts: “lame ideas, blind justice, dumb luck, paralyzed wills, deaf ears, crippling traffic, and idiotic relatives.” Impairment and social disablement flourish in U.S. cultural representations, providing ample opportunities to address these two conditions as “subject[s] of critical inquiry and . . . category[ies] of critical analysis”. For the volume’s editors, in the essays they selected “disability serves as a master trope that challenges pervasive social fictions about the experiences of embodiment” (Snyder, Brueggemann and Thomson 1,3,4); and study of disability experience offers the opportunity to test “the seam where body joins culture” (Jeffreys 33). Interrogation of social constructivism plays a big part in the work of disability studies, but in tension with the undeniable and corporeal experience of impairment (Jeffreys, Wendell “Unhealthy”).

As a relatively new interdisciplinary field in academia, disability studies builds from feminist and postmodern insights, and relies on theory developed by post-colonial thinkers for its conviction that “subjects [must] speak for themselves rather than being spoken for” (Wilson 150). Scholars, teachers and students working in this area draw from a number of traditional academic fields in their work to examine and “redress the exclusion of disability and disabled

people from our critical discourses, our scholarly imaginations, and our classrooms” (Snyder, Brueggemann and Thomson 3).²⁷ And from our public and private lives.

A number of articles suggest ways to use disability studies components in classes in a wide variety of subjects. For example, writing in the *Technical Communication Quarterly*, James Wilson describes first interrogating the concept of “normal” through writings and videos by people living with impairments, in an upper level seminar for students interested in writing professionally, and then comparing texts on autism in order to explore “who has the right to speak for others” (157). The texts – from *Science* and the *New England Journal of Medicine*, and from Oliver Sacks’ case study of Temple Grandin and Grandin’s own writing – reveal very different representations of people living with autism. (Grandin is a Ph.D.-holder who teaches at Colorado State University). “The point here,” Wilson writes, “is to consider the dynamics – and implications – of medical science’s appropriation of subjectivity and rhetorical agency. . . . How do we, as medical and science writers, avoid such pitfalls” (Wilson 158-159).

Several U.S. universities offer formal programs in Disability Studies, including a Ph.D. at University of Illinois at Chicago. The field’s professional group is the Society for Disability Studies, founded in 1982. Appendix 2 contains a list of resources about Disability Studies, and about using related material in courses in a variety of fields.

Universal Instructional Design

Evergreen’s tradition of student-centered and learning community-based pedagogy – the “how” of our work as faculty – was crafted from deliberate experimentation and awareness of the importance of intervening in everyday power and privilege arrangements. In company with others in the constructed position of “teacher,” however, we are much more likely than students to establish initial and often on-going parameters for knowledge-making within a particular learning situation. Faculty have an influential say in “what is learned and who gets to learn particular forms of knowledge” (Gutierrez) – and how.

Choices related to methods of content transmission and learning activity play a big role in determining who can fully access learning.²⁸ The student who can hear and comprehend easily

²⁷ I made a list of the fields I read articles from, while designing a two-quarter disability studies program: science, medicine, anthropology, sociology, psychology, counseling, rehabilitation, history, political science, statistics, management, art, ethics, philosophy, music, literature, law, film studies, sport studies, culture studies, American studies and feminist, post-modern, post-colonial and queer theory.

words spoken in English may understand and retain more from a lecture than will a student for whom hearing or aural comprehension, or English, are difficult. Others for whom the kinesthetic is primary will engage more deeply and learn more quickly and thoroughly via movement or performance.

Formal accommodation processes, while sometimes necessary, can and often do involve last-minute changes to programs or courses and extra work (Scott, McGuire and Shaw 372) extending well into a quarter. The shoehorn-the student-into-the-classroom-and-course approach, especially when relied on too heavily, can also result in classroom practices that don't fit well with pedagogical choices or methods preferred by faculty. What can faculty do to optimize learning opportunities for all, while retaining the autonomy to manage teaching strategies and avoiding unnecessary work?

One answer is an integrative instructional approach adapted from building and product design, called Universal Instructional Design (UID).²⁹ To designers, "universal design" means creating "products and environments . . . usable by all people, to the greatest extent possible, without the need for adaptation" (Mace). Flexibility of use, and equitable use by people with a variety of abilities and preferences, are hallmarks; quite often, uses that designers had not foreseen become standard, as in the case of electronic door openers and curb cuts originally installed for wheelchair users.

Universal design in teaching is about proactively designing learning environments, materials and activities for equitable use (access) and meaningful participation by people from a wide range of diversity. In many cases, one or two proactive and low-effort strategies – such as providing handouts in both hard and electronic copies and arranging for several students to post their lecture notes online each week – can meet the needs of students with a wide spread of learning requirements ranging from oversized text (visual impairments), to voiced text (learning disabilities, visual impairments, a preference for learning aurally) and help with notetaking

²⁸ Instructional design shapes the specific knowledge, as well, even in collaborative learning environments. The lecture-only class is a different experience, and may result in a different knowing, than the program built around conceptual workshops a la Don Finkle.

²⁹ Also referred to as "universal design of instruction" (UDI) "universal design for learning" (UDL) and "universal design in education." Although UID is the only approach I address in this paper, there are others faculty can use to positively affect the educational experiences and inclusion of people of difference, including impairments. See for example the University of Washington's excellent faculty web resources on inclusive teaching, at <http://depts.washington.edu/cidrweb/inclusive/> >.

(paralysis, learning disabilities, slow or imperfect comprehension of spoken English, visual learning style, collaborative learners).

UID allows faculty to move “from a focus on compliance, accommodations and nondiscrimination to an emphasis on teaching and learning” (Scot, McGuire and Embry), and inserts learners – and teachers – living with impairments into a field of diversity, instead of the separate and often discriminated against category of “disabled” (“Summary of Universal Design”). From being singled out, impaired students move into becoming an integral part of the classroom community, for the simple reason that everyone has choices about how to participate and how to evidence their learning. If all students have unlimited time on essay exams, or the choice between an exam and a paper or presentation, no student is “special.”

Universal design is not a one-size-fits-all approach; the “universal” refers to “flexible design that is specifically created to be used in diverse ways” (Scott, McGuire and Embry). Common sites for applications of universal design in the classroom are the class “culture” (ideally, one of hospitality and awareness); and three aspects of information delivery that are often referred to as UID’s “essential qualities:” representation (delivery of content via several modalities), engagement (student choice of flexible routes of engagement with program/course material), and expression (an array of methods for assessment/demonstration of learning) (Izzo and Murray 32). The resources in Appendix 1 provide additional information about UID, including specific teaching strategies and case study articles by faculty teaching in a variety of disciplines.

I’ve been experimenting with UID in my Evergreen programs for three years, and have found it to communicate powerfully to all students that I take seriously learning-related differences (and by extension, all difference). I tell students what I am doing and why in my pre-program letter, and again during the first class session. All handouts and many program readings are made available electronically, workshop materials are posted on our program site on Blackboard for previewing before class sessions (except when faculty don’t get them done on time!), we read aloud the instructions for any in-class activities, program members help each other remember not to wear scented products and the locations of designated smoking areas. And so on. Most of our work in class is collaborative, in the individual student’s choice of “quiet” and “noisy” rooms. Students have several choices of ways to document their learning; for example, although all students write pre-seminar papers and complete a final project, there are structured

and unstructured options for these, and final presentations may or may not involve speaking. Although we rarely discuss UID as such during the quarter, students often mention it in one form or another in course evaluations and student evaluations of faculty. I've become a better and more creative teacher as I've begun to examine my practices from a student point of view. My workload has shifted (to somewhat more work before the program begins, and somewhat less during the quarter) but remains roughly equivalent overall. My own observations and student feedback have made it clear to me that UID can have positive effects on student motivation and learning in learning community situations.

UID's purpose is *not* to render impairments invisible by reducing the need for specialized accommodation (although that may be one result). Instead, UID provides for engagement on the part of people who are each different from socialized "norms," and different from each other, especially engagement that recognizes the social aspects of knowledge-making through awareness, openness and collaboration. As a practice, UID dovetails perfectly with the social model of impairment; as three University of Minnesota faculty point out in an article discussing their own classroom innovations, "Universal Instructional Design is an outgrowth of an interactional, social constructivist approach to disability issues . . . [UID] explores how individuals interact with the environment to construct knowledge" (Higbee, Chung and Hsu 14).

Real inclusion of people living with impairments in diverse communities of learning cannot be simply an appendage to business-as-usual. While I agree with Thomas Hehir that "universal design [of learning] is a matter of simple justice" (29), I don't think that techniques and opportunities are enough by themselves. The presence of students living and learning with impairments in our programs and courses, and the availability of UID and other inclusive teaching approaches, compel an answer to the questions: "Instead of normal/abnormal, why not just different" (Wilson 154)? And, "How does disability [and impairment] help us think critically about traditional beliefs in the academy about individual work, standardization of skills, and fairness (conceptualized as sameness)" (Wilson and Lewieki-Wilson 299)? Marquart, a member of the first Evergreen course in which I applied UID, puts yet another way the need for one of Fraser's cultural-valuational shifts as part of UID's implementation: "How can we genuinely implement universal design in the classroom without understanding and respecting the need for universal design? If we are to make a change [to full inclusion of people living with impairments] then all participants – faculty and students – need to engage in the small acts of

creating an environment of openness, understanding, and sharing . . .” (26). Small acts, that is, that recognize the presence of difference.³⁰

³⁰ There is more to be said about transforming classrooms, and about teaching for intersubjective understanding. Quite a few writers have addressed these topics, so I will not go farther here.

STRAND 2: STAFF AND FACULTY LIVING WITH IMPAIRMENTS

Introduction to Strand Two

Environmental Sensitivities/Multiple Chemical Sensitivities as “Impairment”

Socially-Disabling People Living with Environmental Sensitivities

Because learning is enhanced when topics are examined from the perspectives of diverse groups and because such differences reflect the world around us, the college strives to create a rich mix in the composition of its student body, staff, and faculty, and to give serious consideration to issues of social class, age, race, ethnicity, (dis)ability, gender, religious preference, and sexual orientation.

The Evergreen State College “Evergreen’s Mission: Principles That Guide Evergreen's Educational Programs”

Introduction

How can Evergreen as both institution and community give “serious consideration” to staff and faculty living and working with impairments and “(dis) ability”? How might we recognize them fully as colleagues possessed of moral worth? In what ways do we succeed at this now? In what ways do we fail? How might we change?

This strand has the flavor of a case study, based as it is in two conditions I know from my own experience, breathing disorders and environmental sensitivities. I make this choice without apology, since a number of staff and faculty live with these conditions, which in addition raise significant and “messy” questions about the relationship between impairment and social practices. The dearth of public information about the work experiences of Evergreen employees living with impairments also suggests beginning with the specific. But I’m aware of the possibility that focus on particular types of experience might inadvertently silence or make invisible other insights and lives. I invite people living with other impairments and hence different social-disablements to add their knowledge to this discussion.

In occasionally relating my own experiences in what follows, I intend to ask for comprehension of larger points, and the experiences of Evergreen community members who live with impairments as a group. Most especially, I do not want to position myself as a victim. Individualized response to my own situation and experiences is not what I am after here, as my

experiences at Evergreen have taught me that over the long run, these by themselves prove and improve nothing. My hope is that readers will keep in mind a larger picture.

The experiences of people living with environmental sensitivities/Multiple Chemical Sensitivity (ES/MCS) provide a particularly clear illustration of the ways in which social arrangements of privilege and power interact with impairment to construct disability. After a brief explanation of ES/MCS as impairment, the rest of Strand 2 will use both generic and specific experiences of people living with this condition to represent the lives and concerns of Evergreen employees whom environment/impairment interactions render “disabled.”

Environmental Sensitivities/Multiple Chemical Sensitivities as “Impairment”

Writing in the *Archives of Environmental Health*, Caress notes that ES/MCS is now “generally acknowledged as a condition in which individuals experience adverse reactions when exposed to low levels of chemicals found in everyday substances” (Caress, Steinemann and Waddick 429). Social Security and some workers’ compensation and disability programs (private and public) award payments on the basis of multiple chemical sensitivity, and the condition is covered by the Americans with Disabilities Act on a case-by-case basis.

Population-based studies in California and Georgia suggest that 12 to 16 percent of U.S. residents live with unusual sensitivity to common chemical compounds; in the widely-reported Georgia study, more than half of this group (52.2 percent) said their symptoms after an exposure were “severe” or “moderately severe” (Caress, Steinemann and Waddick 432; see also Caress and Steinemann “Review” and Caress and Steinemann “Prevalence”). Chemical hypersensitivity has been reported across gender, age, education, income and race/ethnicity groups (Caress, Steinemann and Waddick 435), and across marital status, employment, education, and geographic location (Kreutzer).

ES/MCS (also sometimes called environmental illness, or EI) seems to begin either with repeated low-level exposures, or one event involving massive contact (Gibson, Elms and Ruding 1499). People thus made sensitive react to subsequent exposures to this and similar chemicals (a process termed “triggering”). Sensitivities may be permanent, and symptom clusters in response to exposure tend to be stable in any one individual (Caress Steinemann and Waddick 432; Gibson 1), although they may vary in intensity. Different symptom clusters may appear in

different people exposed to the same trigger, and repeated exposures can increase the severity of reactions, or over time spread them across additional triggers. ES/MCS-related symptoms can appear in any organ system, from neurological to digestive.

Symptom triggers common to more than half of Georgia study respondents included perfume, cleaning products, pesticides, tobacco smoke, new carpet, salon/barber, public parks, and car exhaust. Fresh ink, chlorine, furniture and barbeque and wood smoke were mentioned by more than one-quarter of subjects (Caress, Steinemann and Waddick 432, 433).

Exposure-induced symptoms for all chemically sensitive respondents begin soon after exposure, and last a minimum of several hours, stretching to several weeks for a substantial minority (11.6 percent) (Caress, Steinemann and Waddick 432). Frequently-reported symptoms after exposure include headache, burning eyes, nausea, asthma or asthma-like symptoms (Caress, Steinemann and Waddick 433). Joffres and associates found the following additional general symptoms (that is, on-going symptoms not necessarily linked to specific episodes of exposure) in 90 percent of individuals who responded to their survey: difficulty concentrating, fatigue, tiredness not relieved by rest or sleep, sneezing and congestion, forgetfulness/poor memory, irritability (163).

In three studies of sensitive people's own evaluations of "health interventions" for ES/MCS, chemical avoidance was rated as the most effective. The 917 respondents in an additional investigation listed avoidance, creation of a chemical-free living space, air filters to prevent exposure, rotation diet, and oxygen to cope with exposures as among the most helpful "treatments" (Gibson, Elms and Ruding 1498, 1499).

Socially-Disabling People who Live with Environmental Sensitivities

Not-sensitive people often find it difficult to smell or taste concentrations of chemicals and other substances such as dust and molds that trigger symptoms in ES/MCS people. Many of those symptoms – headache, burning eyes, nausea, fatigue, difficulty thinking – do not lend themselves to tangible appraisal (Magill and Suruda). And in fact ES/MCS symptoms, in company with their underlying physiological state or condition, may be much less obvious even to medical technology than the reality that someone can't reach a door handle. Add the facts that

medical science hasn't yet settled on a cause for ES/MCS, and that popular wisdom says it is "all in their heads," and people living with ES/MCS become objects of others' suspicion.³¹

At the same time, dominant cultural ideas about epistemology, especially causation and evidence – general insistence on concrete substantiation of risk or hazard, practices of limiting proof to so-called objective measurement, and cultural requirements for traceable cause and effect as a basis for action – reinforce wide-spread doubt and denial of ES/MCS people's experiences. People whose physical tolerance falls within "normal" ranges usually have the privilege of ignoring air quality unless they develop immediate or persistent symptoms traceable to something tangible: headaches every time a colleague wears a certain perfume, for example. Their privileged degree of tolerance seems "natural" or "the way things are" to them. And because they aren't as sensitive to chemicals and other substances as ES/MCS people, and can't or don't perceive most common ES/MCS symptoms, "normates," to borrow Rosemary Garland Thomson's good term (Davis *Bending* 38), simply don't believe that there is a problem. (Socially-disabled people sometimes think of this dynamic as the "tyranny of the normal."³²)

On the other hand, people whose tolerances for trigger substances are not within "normal" or "expected" ranges are frequently socially-disabled in both of Fraser's injustice domains discussed above. In the material realm, we may be obliged by job expectations or other social imperatives to remain in indoor spaces and outdoor areas that harm us, because of concentrations present of what for us are toxins. Or the severity of our symptoms may force us to leave, so that we are in effect left without access. This dilemma, taking place as it does in an obdurate society (hence the anxiety and depression mentioned in n. 15 above) can and has resulted in people being forced by increasingly severe physical symptoms into finding a new apartment or house,

³¹ Ambiguity in medical science generally, as in the case of ES/MCS specifically, often results in competing theories about cause "which are usually centered on the question of whether the syndrome is primarily psychological or physical" (Cooper 109). Although the popular conception of ES/MCS is that it originates from psychogenic or hysterical starting points – that is, "all in their heads" – in the Georgia study, only 1.4 percent of people who reported sensitivity to common chemicals said they had experienced emotional problems before onset, while 37.7 percent experienced anxiety, depression or other emotional problems after. The researchers concluded that this data "tends to weaken the notion that MCS is psychogenic. These findings apparently indicate that physical problems emerge first and emotional problems [if any] follow" (Caress, Steinemann and Waddick 434, 435). Writing in the *American Family Physician*, Magill and Suruda comment that studies showing a causative link between what they term "psychiatric problems" and MCS are unsound methodologically (a conclusion echoed by Joffres 163-164). Roughly three-quarters (73.9 percent) of chemically sensitive people also report allergies to natural substances such as dust or pollen, and more than half (53.6 percent) say they live with other medical conditions in addition to chemical hypersensitivity (Caress, Steinemann and Waddick 432).

³² The earliest use of the phrase I know of came from Leslie Fiedler, in a 1984 article of the same name about attitudes toward congenital malformations.

changing or ceasing employment, moving to a different geographic location, and so on (Caress, Steinemann and Waddick 431, 434-435; Gibson, Elms and Ruding 1501, 1503).

Reasons for assessing this situation as one of injustice, rather than ES/MCS people's "bad luck" or even "just deserts," may become more clear when we recall that disability is caused by the interaction of impairment and (constructed) environments. In the same way that door handle design and location are the result of human choices, so are most problems with the general qualities – especially, in the case of ES/MCS, the air or water qualities – of a specific setting. (Outdoor air temperatures and dust are obvious exceptions, although agriculture, mining and other dirt-related practices can contribute to the latter.) Developers can dispose of organic material they've cleared from a building site in several ecologically-friendly ways that don't pollute; it's just cheaper to burn it. People don't *need* to wear scented products to sustain life; they've simply been taught to believe perfume and scented aftershave and deodorant and fabric softener are a necessary prerequisite to being accepted by others. Tobacco smokers choose when and where they light up; gardeners and farmers (including agricultural conglomerates) make decisions to use dangerous pesticides rather than safer methods; corporations and printers buy huge lots of paper fabricated by the usual and highly polluting method instead of insisting on chlorine-free processes. And so on. Human choices mean that perfume, cigarette smoke, engine emissions, scented fabric softener and industrial chemicals pervade U.S. social and geographic spaces, even the most mundane; one in three people living with MCS find it difficult, for example, to shop in stores (Caress, Steinemann and Waddick 431).

People socially-disabled by the narrow ranges of air quality³³ considered "acceptable" and "healthy" – people with medical histories and past experiences that tell them even minimal exposure to diesel exhaust or to cigarette or wood smoke will bring on an asthma attack or hives – don't have the luxury of inattention to their surroundings (or of waiting for quantitative evidence of a problem).³⁴ If our reactions are severe and we are to participate in community life, in other words, we must proactively minimize our exposure to these substances. And we must

³³ People living with ES/MCS also react to chemicals in and on water, food, clothing, paper, plastic surfaces, personal products, etc. Air, water and food are the most common sites of communal tension. For example, Lacey recently decided to add chlorine to city water, an action that may force a number of people to move.

³⁴ For example, my body reacts to repeated or prolonged exposures to tobacco and wood smoke with swelling and pain in my ears, swollen lymph glands, nosebleeds, sinus infections, wheezing, skin rashes, and impaired memory, balance and capacity to think. I also become more susceptible than usual to other types of infection.

often do so despite the fact that not-sensitive people don't perceive – or believe – there is a problem.

This necessity makes our lives public – because often we must ask others to change what are for them personal and habitual practices – and renders us vulnerable. Customary denial of the actuality of our experiences usually places us in a one-down position as we ask for change; our attempts to “take one's place in whatever discourse is essential to action” and our claims to “the right to have one's part matter” (Heilbrun 18) – that is, to moral agency and “standing” – are frequently refused, by others who do not recognize our experiences as either authentic or having anything to do with them. It is here we encounter Fraser's second type of injustice, that of “cultural domination . . . nonrecognition . . . and disrespect” (Fraser 14, qtd. in Bruch 4), and its attendant values, attitudes and emotions.

People who do not perceive themselves as experiencing symptoms related to specific substances habitually make assumptions about those who do, particularly if the person does not “look sick.” Pamela Gibson, who has conducted over a decade of research with people living with ES/MCS, writes that

Our [U.S.] cultural response to MCS has been almost entirely negative. People with this primarily invisible disability have been ignored, de-legitimized, dropped as friends, discriminated against in the workplace, fired from their jobs, and excluded from housing and medical care. (Gibson 9)

As a person living with chemical sensitivities, the labels given me by not-ES/MCS people at Evergreen and elsewhere include “troublemaker,” “neurotic,” “crazy,” “hysterical,” “paranoid” and “sick” – with all of the attendant negative social connotations.

Because so much of modern air pollution is human-made, and the result of choices made for expediency or comfort rather than true necessity, it is quite difficult for chemically sensitive people simply to absent themselves – usually repeatedly, often permanently – from desired activities and locations.³⁵ In fact, to many people experiencing reactions from unnecessary

³⁵ Realistically, when confronted with an environment containing symptom triggers, people living with ES/MCS have four choices: 1) stay in the space and endure the resulting physical reactions, 2) try to negotiate moving to a different location, 3) work over time to have the amount of the troublesome substance reduced in local air or water, meanwhile simply enduring, or 4) simply absent ourselves from the space and whatever activities occur there. We do not have the option to do nothing (choice 1), unless we want to live with the results – and in general, every physical reaction to a trigger renders our reactions the next time more severe. Yet choices 2 and 3 both require the cooperation of others, which may or may not be forthcoming. Choice 4 means acquiescing to exclusion made “necessary” by other people's choices, with the attendant emotional experience of vulnerability and exclusion.

exposures, it becomes nearly impossible to think of these situations as anything other than deliberate exclusion. An exile, that is, so often made “necessary” not by our reactions to chemical substances – *which our bodies don’t manifest unless the triggers are present* – but by other people’s generally unreflective and often casual choices to release these substances into the air without consideration of effects on others. In cases of substances not legally regulated such as perfume, for example, people with ES/MCS must “depend upon the compassion and flexibility of others” to keep environments free from triggers (Gibson 46) – others who, as is the case with many smokers at Evergreen, simply may refuse (without consequence) to demonstrate either characteristic.³⁶ Yet their choices to “misrecognize” – disbelieve, disregard and deny needs of ES/MCS people (cultural injustice) – leads to the forced exclusion of us from physical and social environments, including those connected with our work (material injustice).

In the absence of effective ways to respond to either type of injustice, a fair number of U.S. residents with very severe multiple chemical sensitivities become virtual recluses, often living (usually in poverty) in remote locations, sometimes in cars or metal trailers as they try to manage serious physical complications (Gibson, Elms and Ruding 1503). Although I have had to camp in a tent from time to time to recover enough from strong exposures so that my body will again tolerate the unavoidable low-level exposures in my apartment or house, my body is not usually that sensitive. I don’t want it to become that way through prolonged or repeated exposures; the anger and fear of even occasional periods of exile have taught me that would be like.

When I seem completely symptom free, and choose not to enter a specific building or to attend a meeting with people whose clothes smell strongly of fabric softener, I am firstly minimizing whatever symptoms I have that day (caused by earlier unavoidable exposures) in order to accrue the benefits of appearing to be “normal” (social interaction, retaining my job), and secondly, protecting my health. And when I ask others to stop making choices that harm or exclude me (the unavoidably public aspect of living with environmental sensitivities) – that is, when I request that a meeting be moved, that people stop wearing scented products, that smokers light up in designated campus locations well away from air intakes and normal foot traffic – I am asking that people make inclusive (and just), rather than exclusive (and unjust), choices. My

³⁶ Injustice in the cultural domain is also a large part of the lives of people living with many impairments other than ES/MCS.

alternative would be to live the deterioration and damage of my body until I'm not able to work or be with other people.³⁷ The frustration I feel in simply writing these words reminds me that feminist theorist Marilyn Frye identifies the double bind – “no win” situations in which choices are few and all have negative consequences – as characteristic of the experience of oppression (2).

That's a suggestion of the internal experience, the phenomenology, of the experience of injustices connected to living with environmental sensitivities and trying to manage air quality in one's immediate surroundings.³⁸ I wrote it in order to ask a question. As noted above, there is only so much people living with ES/MCS can do to remain functional in communal settings; other people's choices result in air and water quality that excludes just as effectively as a door that cannot be opened. But if it is social practices, not physical necessities – and often the practices of not-impaired people acting without sufficient understanding of or care for others – that result in disability, then whose responsibility *is* disability and its amelioration?

The common sense, business-as-usual answer to this question is “the disabled people, of course.” But that's privilege and the medical model talking. Here's a socially-disabled person's take on one of the many complex ways that not-disabled privilege plays out: When I as a chemically-sensitive person am part of a work group, and my accessibility needs are not asked about or otherwise considered in selecting meeting locations (as they often are not at Evergreen, despite the fact that I have been chemically sensitive the entire ten years I've taught here and have requested accommodation from day one), then I may be excluded initially by someone else's decision – and without reference to anything I have done or failed to do, or to my capability of contributing to the group's work.

The next step, if I decide it is worth the energy and risks of frustration, anger and knowledge of conscious exclusion, is disclosure. Reminding people I live with impairment is claiming a specific and stigmatized public identity, and is tantamount to emphasizing vulnerability to victimization (the one-down position just visited on all prospective attendees, by failure to consult proactively about environmental needs) to people already revealed as at best forgetful, probably unaware, possibly uncaring and at worst potentially hostile. (I have experienced each of

³⁷ The Evergreen library carries an excellent and accurate film about the lives of people living with moderate to moderately-severe environmental sensitivities, entitled *Funny You Don't Look Sick* (Susan Abod).

³⁸ Gibson's work as a whole makes public a number of stories from the lives of chemically sensitive people. In a handbook for people working with MCS people through the Independent Living Movement, she includes a chapter entitled “Identity, Self, and Psychology in MCS” (Chpt. 6).

these at Evergreen, though thankfully the first three have been the most common.) If I do ask that the meeting be moved and am told that it would be “too much trouble” or that I will simply have to miss it, then I am twice expelled – this second time as a result of deliberate and often face-to-face choices to exclude me from participation, and hence from the social reciprocity that interactions between equals foster.

There’s more. Because participation and power are linked especially closely at Evergreen, an institution that runs primarily not on structure but on personal relationship and collaboration, where people are kept from participating they are kept from power (Freeman; Wendell “Unhealthy” 25-26); that is, from taking part in Heilbrun’s “discourse essential to action” (18). Their words go unheard, and after a time, unspoken. They become nonentities; over time, nonmembers. When failure to include them – and every person with specific needs – becomes habitual, then it becomes one of many routines in a wider and inequitable system of privilege and power, a system that oppresses people solely because they live with impairments.³⁹ And at that point, beyond reminding people that we do exist, and offering to educate, *there isn’t anything we as people disabled by others’ choices can do.*

In exploring this impasse with colleagues and students, I’ve found the concept of accommodation as it is usually thought of to be a useful solution only in specific and fairly rare instances; in my experience, most Evergreen employees living with impairments either do not need or do not request accommodations, for fear of one of several types of reprisal.⁴⁰ And yet formal accommodation based in disclosure of need and documentation of impairment – which usually addresses access only, not full acknowledgement or inclusion – is in effect Evergreen’s sole avenue of communal response to employee experience of impairment and social-disablement.

As commonly understood in relation to employment, and as codified in the Americans with Disabilities Act (ADA), individual “accommodation” is a process for meeting specific and individual needs – “needs” as determined against a socially-constructed definition of “normal” –

³⁹ This is perhaps most obvious in the case of inaccessible meeting locations, but it also happens to people whose impairments do not leave them with enough energy to participate in a community life that often seems fueled by presence and passion. I have worked in other situations in which awareness of this issue has resulted in creative methods of inclusion.

⁴⁰ This impression was confirmed by Human Resources Director Ken Holstein in a recent email message, when in response to my question about counts of staff and faculty who self-identify as “disabled,” he wrote, “We do know that there are [Evergreen] employees who will not self-identify [as living with impairments] because they do not want the stigma of being considered disabled . . .” (Holstein 2/7/05).

if medical professionals (not solely the impaired individuals) attest to the needs, and the accommodations requested are “reasonable.” The statute itself and subsequent case law have defined “disability” and “reasonable”; legal mandates for change in cases of individual request, and accompanying formal social responsibility, are limited accordingly. The potential for disempowerment and social disabling of people living with impairments in such a system is obvious. We may or may not be allowed to participate in “discourse essential to action,” and what we say or do may or may not “matter”(Heilbrun 18). This formal approach to individual accommodation, while based in function (social model) also applies the medical model – requiring as it does a medical confirmation of diagnosis with an identifiable cause, residing in a specific and single body.

Too, when it is the only approach to inclusion, case-by-case accommodation can create as many problems as it solves.⁴¹ First, the required disclosure and documentation of impairment can expose impaired people to discrimination, including harassment, in a potentially-hostile environment – an odd way to work toward genuine inclusion. Formal on-the-job accommodation processes also focus attention on requests for adjustment to the work environment as requests to normalize differences, differences too often interpreted as “problems” that might entail expensive “solutions.” Given these connotations, the employee living with impairment is frequently seen as representing a deficit, a person who can’t do her or his work without “help.” Feminist philosopher Iris Marion Young suggests that some of this negative response may grow out of a “politics of resentment” on the part of colleagues, who would like their own frustrations with job stresses and circumstances to be heard, and who subsequently express anger toward legally-sanctioned requests under the ADA (Young 171).

The prospect of altering environments to include people working with impairments also probes previously unexamined suppositions, with the frequent result that what is actually about communal response to difference becomes formulated as an issue of competing individual rights. When supervisors and administrators are reluctant to support or grant accommodation, or simply uninformed, requests for accommodation can become contrived dramas of “rights” v. “reasonable,” or “injury” v. “responsibility.” Requestors are forced by attitudes and by the legalized nature of the proceedings to position themselves as victims seeking help and redress –

⁴¹ Strand One examines Evergreen’s over-reliance on formal accommodation and accompanying service provision as the only institutional response to student impairment in the classroom, and problems associated with this single-approach strategy.

rather than what they are: work colleagues who need a setting altered in order to participate fully in communal endeavors, including their jobs.⁴²

Formal accommodation generally addresses only Fraser's material injustices of access, not necessarily the cultural injustices of "domination . . . nonrecognition . . . and disrespect" (14). Accommodation based in particular individuals' situations will always be necessary in specific cases, as when a blind employee reads via software that voices printed materials and electronic communications. But, as the ADA (and other laws and policies) also makes clear, individualized accommodation by request is not the *sole* useful response to the realities of impairment. ADA requirements include specified proactive steps related to a generalized accessibility to public transit, public accommodations and State and local government buildings, for example (U.S. Department of Justice).

Unless and until we can characterize accommodation requests as opportunities to broaden our collective (legal, political, institutional, cultural discourse) standards of "normal" and "acceptable" or do away with them altogether – and until we choose to make this characterization operational, thereby increasing the number of people who can be present and participating – accommodation processes will continue to position employees living with impairments as deficits best addressed through the medical model. There response becomes too much like pity – condescension on the part of the "haves," the "normal" people, toward the "have-nots," those poor damaged ones who have no choices except the ones "we" make for them. Or too much like competition for resources falsely made scarce. As we have seen, exclusion based in perceptions about impairment is very often a matter of temporarily-not-impaired people's attitudes and choices based in comfortable (for them) institutional and cultural arrangements – not of impaired people's actual limitations or incapacities. I have tried to show that it is this process of social-disablement, not people living with impairments, which should change.

In the next section, I make some suggestions toward several responses that I hope we as the Evergreen community will join with formal accommodation to develop a multi-faceted – and

⁴² Of course, socially-disabled people are both – subjects of discrimination, and colleagues. Too often, however, not-impaired people think of those living with impairments as victims of fate or their own choices, and deny all responsibility for disablement in communal environments such as work. My thinking about the ways in which formal accommodation focuses on normalization, and associated requests become articulated via injury rhetoric, has been shaped by Carl Gutierrez-Jones' work on race and racism, as presented in his article entitled "Injury by Design."

better – way to address the complexities inherent in taking both impairment and social disablement seriously.

TOWARD EVERGREEN AS KNOWLEDGEABLE BODY: HEALTH IS MEMBERSHIP

“Community . . . is the Smallest Unit of Health”

Recommendations

Conclusion

“My understanding of truly inclusive education is that all students in a school, regardless of their strengths or weaknesses in any area, become part of the school community.”

Lynette Romero, B.A., Evergreen

(qtd. in Marquart, Romero and Sandoz 26)

May 5, 1900.

Dear Sir:

As an aid to me in determining my plans for study the coming year, I apply to you for information as to the possibility of my taking the regular courses in Radcliffe College. . . . The conditions under which I work require the presence of Miss Sullivan, who has been my teacher and companion for thirteen years, as an interpreter of oral speech and as a reader of examination papers. In college she, or possibly in some subjects some one else, would of necessity be with me in the lecture-room and at recitations. I should do all my written work on a typewriter, and if a Professor could not understand my speech, I could write out my answers to his questions and hand them to him after the recitation. Is it possible for the College to accommodate itself to these unprecedented conditions . . . ?

Helen Keller, B.A. Radcliffe College, 1904⁴³

(Keller Pt. II)

“Is it possible for the College to accommodate itself to these unprecedented conditions . . . ?”⁴⁴ Genuine relationship – full inclusion – involves mutual engagement, as Keller recognizes by explaining the steps she will take to meet academic requirements while also asking for institutional and faculty flexibility in matters of communication and assessment. It seems to me that Keller’s question to her college summarizes my question to mine. Can Evergreen as institution and community take students, staff and faculty living with impairments seriously enough to enter with us into authentically reciprocal relationship? A relationship that

⁴³ Keller was the first DeafBlind person to earn a B.A. She did so despite widespread skepticism that this was possible, as deaf people had historically been assumed to be unintelligent – i.e., “dumb.”

⁴⁴ Keller asked this question 70 years before Edmund Gleazer pointed out that “We are not building a college with the student. The question we ought to ask is whether the college is . . . student material. . . . It is the student we are building, and it is the function of the college to facilitate that process. We have him [sic] as he is rather than as we wish he were . . .” (qtd. in Malnarich vii).

acknowledges current injustices affecting both meaningful access to resources *and* full recognition of people living with impairments, while at the same time working toward effective response to social disablement? How might Evergreen’s students, staff and faculty draw on the contributions that experiences of impairment can make – in this and in other communal endeavors?

“Community . . . is the Smallest Unit of Health”

Wendell Barry’s provocative observation that “community . . . is the smallest unit of health” (90) suggests a new paradigm for thinking about inclusion, a paradigm that moves well beyond legalistic requests.⁴⁵ In his essay “Health as Membership,” Barry points to the impossibility of considering the living human body in isolation.

The body alone is not, properly speaking, a body. Divided from its sources of air, food, drink, clothing, shelter, and companionship, a body is, properly speaking, a cadaver . . . (94).

The body in relationship, however, is an “organic” (91) (that is, not mechanical) entity enmeshed in “wholeness” (89) and “belonging” (87). Humans live not alone, but in “an interinvolvement with other bodies and other creatures, living and unliving, that is too complex to diagram or describe.” (95). There it is: We’re all connected.

In this interinvolvement, “health is membership” (86) – in community.⁴⁶ Although Barry doesn’t touch on this point, the relationship here goes both ways. Research has long revealed that people are healthier when they are involved in social relations (House 76). And communities themselves are more robust when human connections are actively valued, and felt obligations

⁴⁵ Few paradigms are entirely new; federal and state laws such as the ADA hint at this one in requiring changes in the built environment to include groups of people, thereby enabling them to participate in a wider range of social settings.

⁴⁶ In invoking health in an essay on impairment, I want to avoid opposing the two. It is possible to be d/Deaf and “healthy” in the sense of “not ill,” for example, and (arguably) to be psychologically (or physically) “healthy” while living with physical (or psychological) impairment. I am also skirting a tension in the disability rights movement, between those who are “disabled” in the common use of the term (one-armed, paralyzed, developmentally disabled) and who resist the label “sick” with its negative social connotations, and those who are ill and resist the label “disabled” for the same reasons (Wendell “Unhealthy” 17-22). Like “disability,” “health” is a socially-constructed concept. It is worth noting that sociologists and public health professionals often link social factors and health. See, for example, the Washington State Department of Health’s background on the topic, “Social Determinants of Health,” at <http://www.doh.wa.gov/HWS/doc/RPF/RPF_Soc.doc>. I am using “health” here to mean something along the lines of “meaningful and full inclusion” in both of Fraser’s injustice domains, and in the way that Barry recognizes concepts of “wholeness,” “belonging” and “interinvolvement.”

and opportunities for mutual goodwill mesh into active reciprocity, as both Robert Putnam (in *Bowling Alone*) and Lewis Hyde (in *The Gift*) have shown.⁴⁷

How might community, health and membership play out at Evergreen in relation to impairments? First, community members (including those in institutional positions of authority) could recognize social-disablement affecting teaching, learning, and employment as something other than one individual's specific impairment, and as a multi-faceted human situation requiring responses broader and more complex than narrow adherence to law. I made an attempt at articulating this, using chemical sensitivities as a focus, in an editorial essay published last year in the *Cooper Point Journal* (Sandoz):

Here's the inescapable deal: We share the air. It isn't yours, it isn't mine; it doesn't belong to smokers or non-smokers, or even to the Wellness Committee. At bottom, this isn't about who has the "right" to breathe, or who is "allowed" to act in ways that expose other people to trigger substances (many of which, including tobacco, wood and candle smoke, are toxic to everybody).

After redefining the issues, perhaps we could examine our practices. Here's an analogy for such a communal process: A typical Evergreen potluck might offer several varieties of chips, two or three main dishes made with tahini or peanut sauce and a number of chocolate-based desserts. The person allergic or sensitive to corn, chocolate, sesame seeds and peanuts (allergies accompanying a variety of chronic illnesses) can be present in the room if the peanut allergy is not severe, but will have to go hungry if she did not bring her own food (a form of exclusion). Unless, that is, program members discuss allergies ahead of time, and arrange enough alternatives so that everyone could enjoy a complete meal while also participating in the same reciprocal relationship . . . everyone, that is, except the woman who did not feel able to talk about newly-identified allergies without emotions she did not want to reveal, and the quadriplegic man who doesn't want people to see the mess he makes when he uses silverware to eat.

An aware faculty or student potluck organizer might announce a request that everyone bring an ingredient card (or save the package) to put by their dish, and also have a discrete

⁴⁷ Although I can't address it here, I do want to raise the question of what would happen if we viewed health not as a commodity (think of the huge section of our economy devoted to healthcare), but as a gift to be received and given. The work of both of these authors pertains, in their different but related emphases on reciprocity.

conversation with the student who uses a wheelchair, to figure out if there are foods he can comfortably eat in public (pizza? A sandwich wrap?) or other ways to make things work. Aware community members would make sure this all gets done. The point, after all, is celebration of togetherness through the mutual gifting of food. Not a sorting out based on who can eat what or how.

Recommendations

In considering ways an aware community might be seeded through work done specifically at the institutional level, I put together a list of five suggestions. Each is based on what I hope by now is obvious: if socially-disabled/impaired people are to be bona fide members of teaching and learning community, not-socially-disabled/impaired people must recognize and deconstruct their own privilege. This means, in part, taking seriously our experiences by refusing to use fears – about expense, about personal vulnerability, about change, about difference itself – as excuses to exclude us in real ways, especially in discourse essential to action. It means accepting the fact that socially-disabled people – and all people living with impairments – are experienced, feeling human beings. It means relating to us fully, as colleagues and people.⁴⁸

Here are some ideas about places to start:

I. Acknowledge the historical, social and institutional natures of exclusion and discrimination on Evergreen's campuses, and the undeniable presence of people living with impairments. Training all staff and faculty in their legal responsibilities toward people living with impairments, in the inadequacy of legal requirements as the sole gesture toward community, and in practical ways to include proactively and then to respond to specific requests for inclusion might be one effective way to begin this. Make training and on-going technical assistance in Universal Instructional Design (discussed in Strand One) available to all faculty.⁴⁹ These steps

⁴⁸ As philosopher Susan Wendell points out, "One has to be aware of the subjectivity of a person to imagine her/his experience of events and how s/he might be affected by one's actions" (*Rejected* 65).

⁴⁹ Many colleges educate faculty and staff in multiple ways: mandatory training sessions, faculty and staff development opportunities, the on-going provision of technical assistance; speakers and films; brochures, articles and handouts available in hard copy and online. Standards from the Association on Higher Education And Disability (AHEAD), which according to the organization "present a consensus among experts in the field regarding minimum essential services," direct colleges to "Promote universal design in instruction" (2.2), and to "Provide disability awareness training for campus constituencies such as faculty, staff, and administrators" (3.3), among other performance measures.

would help solve some of the issues connected to the present over-reliance on, and misunderstanding of, formal processes of accommodation as adequate strategies for responsible intersubjectivity and inclusion.

II. As a matter of official policy, identify and act on ways to make all Evergreen settings (physical, cognitive, affective, sensory) more inclusive. One cost-free action: Include on all materials for any event or meeting sponsored by Evergreen (or held on campus) information about requesting specific accommodations. Remind potential participants to refrain from using scented products and to smoke only in designated areas, as part of this notice.⁵⁰

III. Make widely available on all Evergreen campuses information about how and where students, staff and faculty can formally request accommodation, and how and where staff and faculty can refer students who may need assessment or support services. And then provide the needed (legally-mandated) services to all who qualify, in a timely manner, with recognition of the legitimacy of the need and the vulnerability inherent in asking, and without additional emotional repercussions to the requestor. Sanction staff and faculty who refuse to take accommodation requests seriously, and who treat others uncivilly or fail to respond competently.⁵¹

IV. Employ proven health promotion techniques to educate the campus community on TESC smoking and scented product policies, and enforce policies restricting driving on campus. Require all people doing facilities work (cleaning, painting, remodeling, etc.) to post advance notice on the outer doors of buildings, and in the areas themselves. Attach real consequences to failure to demonstrate proactive awareness of others' needs.

⁵⁰ Not only are smoking areas and refraining from scented products official Evergreen policy, but many campuses, businesses and government institutions (including many in Washington State, such as North Seattle Community College (Furutani, North Seattle Community College) and WSU-Pierce County Cooperative Extension, now have the policies and routinely publish notices. Wording can be found by following the URLs and organization names at the Fragranced Products Information Network's website, <http://www.fpinva.org/Access%20Issues/policies_wordage.htm> (Shannon).

⁵¹ Unfortunately, I have repeatedly experienced each of these – threats, attempts to shame or make me feel guilty, and refusal to accommodate – at Evergreen. Others here have told me of similar experiences.

V. Establish a DTF or President's advisory group⁵² charged to actively examine the following questions, make recommendations, and oversee their implementation: Who can be a fully participating member of our larger Evergreen community and of specific program learning communities, and when, where, and why? Who cannot be, and when, where and why? How can we, together, initiate and sustain qualities of awareness and full inclusion (the affording of moral agency and standing) in every Evergreen program and course and at every Evergreen event and location, qualities that nurture teaching, learning and living?

Mary Fuller and others at the University of Gloucestershire adapted other scholars' work to outline stages or phases that might be involved in transformation toward "inclusive teaching, learning and assessment practice" for students learning with impairments (whom they refer to as "disabled students"), as listed below.

1. No notice taken of the lack of disabled students.
2. Absence of disabled students noted.
3. Exploring why there is a lack.
4. Analysis of disabled students' experiences of teaching, learning and assessment.
5. Challenging the paradigm—changing the curriculum and learning environment.
6. A transformed inclusive system.

I have attempted to notice the cultural (and too often, physical) absence of Evergreen community members with impairments from Evergreen contexts, to explore some reasons why such absence might be the case, and to challenge relevant Evergreen paradigms and practices. What can we do now to pay real attention to impaired people's experiences, and to work toward transforming our system?

Conclusion

Throughout this paper, I've spoken from my competencies in several areas: as teacher and scholar, as a long-time employee of Evergreen and of Washington State government, as a person who has worked in both healthcare and public health, as a person living with chronic illness, and as a person qualified by personal experience to speak about both causing and opposing social disablement. I've suggested that my entrée into the Evergreen community, and

⁵² Official committees advising administrators are active on a number of higher ed campuses in the U.S. A quick Google search found these names as a start: UCLA, UC-San Francisco, Michigan State University, Columbia University, and the University of Wisconsin system.

that of others, should be based solely in our actual qualifications and capabilities as employees and students (and our adherence to laws and the Social Contract). Given that, there are no excuses for social disablement in a community that prides itself on collaboration and learning across significant difference – that is, in Evergreen environments of learning, working and teaching.

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Wilson, James C. "Making Disability Visible: How Disability Studies Might Transform the Medical and Science Writing Classroom." *Technical Communication Quarterly* 9:2 (Spring 2000): 149-161.

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APPENDIX 1: WEB RESOURCES ON UNIVERSAL INSTRUCTIONAL DESIGN

Universal Instructional Design in Postsecondary Environments: Conceptual Information

Higbee, Jeanne L. ed. *Curriculum Transformation and Disability (CTAD): Implementing Universal Design in Higher Education*. Minneapolis, MN: Center for Research on Developmental Education and Urban Literacy, General College, University of Minnesota. 2003. February 26, 2005. <<http://www.gen.umn.edu/research/crdeul/books.htm>>.

Very readable collection of articles by faculty and other professionals at the University of Minnesota. Includes information about UID in teaching, housing, counseling centers, learning centers, and multicultural education.

Izzo, M. & Murray, A. "Applying Universal Design for Learning Principles to Enhance Achievement of College Students." 2003. Ohio State University. October 31, 2004.

<http://telr-research.osu.edu/learning_objects/documents/Izzo-Murray.pdf>.

Good summary article, including discussion of seven implementation guidelines.

The Ohio State University Partnership Grant. "Fast Facts for Faculty." February 5, 2005.

<<http://telr.osu.edu/dpg/fastfact/index.html>>.

Good quick overview of universal design, with additional relevant guides and links.

Scott, Sally S., Joan M. McGuire and Stan F. Shaw. "Universal Design for Instruction: A New Paradigm for Adult Instruction in Postsecondary Education" *Remedial and Special Education*, 24:6, (Nov/Dec 2003): 369-379. (EBSCOHOST)

Very good overview complete with discussion of differences in mandated education between K-12 and postsecondary education, and nine principles of universal design with classroom ideas.

Teaching Ideas and Resources

Burgstahler, Sheryl. "Universal Design." January 12, 2005. University of Washington DO-IT. February 5, 2005. <<http://www.washington.edu/doi/Brochures/Programs/ud.html>>.

Guides and a link list for the application of Universal Design in a number of higher education contexts, including instruction, conference presentations, and student services activities.

Higbee, Jeanne L. ed. *Curriculum Transformation and Disability (CTAD): Implementing Universal Design in Higher Education*. Minneapolis, MN: Center for Research on Developmental Education and Urban Literacy, General College, University of Minnesota. 2003. February 26, 2005. <<http://www.gen.umn.edu/research/crdeul/books.htm>>.

Very usable collection, with chapters on implementing UID in writing, math, psychology, history and legal studies courses, and working with students with severe impairments.

Higbee, Jeanne L., Carl J. Chung, and Leon Hsu, "Enhancing the Inclusiveness of First-Year Courses Through Universal Instructional Design." *Best Practices for Access and Retention in Higher Education*. Minneapolis, MN: Center for Research on Developmental Education and Urban Literacy, General College, University of Minnesota. 2004. February 27, 2005.

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Some UID theory, and comments from faculty who redesigned physical science, symbolic logic and psychology courses.

The Ohio State University Partnership Grant. "Fast Facts for Faculty." February 5, 2005.

<<http://telr.osu.edu/dpg/fastfact/mswfiles/UniversalDesign.doc>>.

Practical "fast fact" brochures for faculty on working with students learning with impairments. (including creating accessible Web content).

"Universal Instructional Design." N.d. Teacher Support Services, University of Guelph (Canada). October 31, 2004. <<http://www.tss.uoguelph.ca/uid/index.html>>.

Includes an instructional workbook for faculty, based in Guelph's seven principles of UID, and a second workbook of UID checklists for faculty planning a course.

Websites of Ideas and Resources: Field Work and Students with Impairments

"Field Work." University of Washington DO-IT.

<<http://www.washington.edu/doi/Faculty/Strategies/Academic/Fieldwork/>>.

Suggestions and resources.

General Resources (K – 12)

"Teaching Every Student." March 2004. Center for Applied Special Technology (CAST). October 31, 2004. <<http://www.cast.org/teachingeverystudent/>>.

Detailed information about UID (here termed "Universal Design for Learning", or UDL), with principles based in brain research. Not specific to postsecondary education. The Center for Applied Special Technology has been a leader in UDL.

APPENDIX 2: DISABILITY STUDIES TEACHING RESOURCES

Syllabi and Lesson Collections Online

Brueggemann, Brenda. "Brenda Brueggemann." April 1, 2003. The Ohio State University. <<http://people.cohums.ohio-state.edu/brueggemann1/default.htm>>.

Links to Disability Studies course websites in drama, English, film, and composition.

"Disability Studies for Teachers." 2004. Center on Human Policy, School of Education, Syracuse University. March 6, 2005. <<http://www.disabilitystudiesforteachers.org/>>.

From the website: "... a web-based resource for teachers who want to introduce students in social studies, history, literature, and related subjects in grades 6-12 to disability studies and disability history. Resources on this site also can be adapted for use in postsecondary education." Includes 5 content units.

"Disability Studies in the Humanities." August 2000. Crossroads Project of the American Studies Association. March 6, 2005. <<http://www.georgetown.edu/crossroads/interests/ds-hum/>>.

Links to syllabi and web resources.

"Medical Humanities Syllabi." August 2003. New York University School of Medicine. March 6, 2005. <<http://mchip00.med.nyu.edu/lit-med/Syllabi.html>>.

Syllabi on 25 topics related to the medical humanities, including disability, mental illness and social issues in medicine.

"History of Medicine." September 28, 2004. United States National Library of Medicine. March 6, 2005. <<http://www.nlm.nih.gov/hmd/collections/digital/syllabi/institutions.html>>.

Syllabi with titles ranging from "A Social History of American Public Health" to "Women and Medicine."

Disability Studies: Introductory Articles

Articles about teaching disability studies content in classes based in traditional academic fields can be found in a variety of scholarly and teaching publications. The articles below provide an overview of Disability Studies as a field.

Davis, Lennard J. "Crips Strike Back: The Rise of Disability Studies." *Bending Over Backwards: Disability, Dismodernism, and Other Difficult Positions*. New York: New York University Press, 2002. 33-46.

Linton, Simi, Susan Mello, and John O'Neill. "Disability Studies: Expanding the Parameters of Diversity." *Radical Teacher*. 47:4. Oct. 31, 1995. (PROQUEST DIRECT)

Taylor, Steven J. "Why Teach Disability Studies? An Essay for Teachers." 2004. Center on Human Policy, School of Education, Syracuse University. March 6, 2005. <http://www.disabilitystudiesforteachers.org/files/WHY_TEACH_DISABILITY_STUDIES.pdf>.

Disability Studies Theory

These are books I've found useful or that are often recommended by other faculty. There are many more!

- Charlton, James I. *Nothing About Us Without Us: Disability Oppression and Empowerment*. Berkeley: University of California Press, 1998.
- Davis, Lennard J., ed. *The Disability Studies Reader*. New York: Routledge, 1997.
- Frank, Arthur W. *The Wounded Storyteller: Body, Illness, and Ethics*. Chicago: University of Chicago Press, 1995.
- Kleinman, Arthur. *The Illness Narratives: Suffering, Healing, and the Human Condition*. New York: Basic Books, 1988.
- Linton, Simi. *Claiming Disability: Knowledge and Identity*. New York University Press, 1998.
- Mitchell, David T. and Sharon L. Snyder, eds. *The Body and Physical Difference: Discourses of Disability*. Ann Arbor: University of Michigan Press, 1997.
- Thomson, Rosemarie Garland. *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*. New York: Columbia University Press, 1997.
- Wendell, Susan. *The Rejected Body: Feminist Philosophical Reflections on Disability*. New York: Routledge, 1996.
- Wilson, James C. and Cynthia Lewiecki-Wilson. *Embodied Rhetorics: Disability in Language and Culture*. Carbondale: Southern Illinois University Press, 2001.
- Wrigley, Owen. *Politics of Deafness*. Washington, D.C.: Gallaudet University Press, 1996.

Society for Disability Studies

<http://www.uic.edu/orgs/sds/>

Website of a 2003-2004 Evergreen program, *Chronic Illness, Disability and Deafness*

<http://academic.evergreen.edu/curricular/disabilityandillness/>

Lots of resources useful in student research and assignments.

Arts and Medicine Project at the New York University School of Medicine

<http://endeavor.med.nyu.edu/lit-med/lit-med-db/topview.html>

Annotated index of relevant fiction, poetry and film from the Arts and Medicine Project at the New York University School of Medicine. Can be searched by word or phrase, keyword, title, name of author, gender of author, physician authors, authors of selected ethnicity, genre, era and annotator.