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Forum: Pacific Rim Conference Strand - Disability Studies Envisioning Our Future

Guest Editors' Introduction

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University of Maine

We are particularly delighted to have been invited to guest edit this special issue of RDS. The issue represents an important milestone in the development of progressive, integrative thinking that is critical for disability studies to advance its value to higher education and to informing human rights in the complex global communities to which disability studies speaks.

Over the past 25 years, we have been passionate and committed to disability studies both as scholars and individuals with atypical bodies. Thus, watching this potent field shatter into fragments has been somewhat painful. In the early 1990s, we therefore set our own scholarly agenda to develop, test and teach theory, which had the potential of provoking meaningful and purposive dialog among thinkers and actors that at least on the surface seemed to contradict one another.

We began our theoretical journey by conceptualizing explanatory legitimacy theory, which was published in numerous articles and then in book format in 2004. Explanatory Legitimacy Theory remains useful in 2008 as it makes the distinctions among descriptive, explanatory, and the axiological or the legitimacy dimensions of the categorization of human diversity and identifies the relationships among these elements. Thus, using this lens, disability as a category is comprised of the three interactive elements: description, explanation, and legitimacy. And it is only at the point of legitimacy, where the judgment is made about who is disabled and what responses should be proffered for category members.

This theory allows for the presence of multiple explanations, thereby creating a fertile space in which diverse explanations for atypical human experience can mingle and serve many purposes.

When the planners of the 2008 PacRim conference made the commitment to a disability studies strand, this watershed event affirmed what we have been thinking over these past 25 years; that there is an important role for pluralistic views of disability and that these different views could only strengthen theory, research and practice to promote inclusive global communities and human rights. The articles in this issue illuminate the goal of the visionary PacRim planners, the importance of cross-fertilization and synthesis. Each of the articles takes on different aspects of disability and uses diverse theoretical lenses through which to do so.

Jarman's work discusses an approach to disability studies education through seminal ethical analytic models. Within this curriculum, students encounter and unpack the meaning of rights, personhood, respect, integration, dependence and interdependence. Moreover, Jarman embeds the study of disability within historical and current chronologies as she discusses how these contexts enrich student thinking.

Stevens' paper indicts policy and culture as influential in disability sexuality. She uses cultural policy thinking to analyze the diverse actions that have been undertaken by disabled individuals to express sexuality in the absence of this essential part of life in disability policy. She asserts that limited conversation about disability sexuality locates sexual practices in which disabled bodies engage in the realm of the deviant and challenges disability studies to be inclusive of sexuality.

Mitchell takes on disability and media. He discusses how undergraduate students use media to analyze and counter disability stereotype in multiple venues. In his article, he provides techniques and materials for this important area of teaching.

Finally, DePoy and Gilson conclude the special issue by examining the diverse traditions that had fractured the field, and provide an integrative explanatory model within explanatory legitimacy theory, juncture/disjuncture, through which disparate disciplines and purposes can increase the fit of environments and individuals. The article concludes with the call for locating disability within the larger discourses of diversity and social justice and illustrates their approach through systematic thinking and action techniques.

We anticipate that the model that the 2008 PacRim planners innovated will provide an example to other conference and scholarly venues to follow. Their model has the potential to become the genesis of new and productive collaboration among disparate disciplines and masters that will strengthen the field of disability studies and its effect on global inclusion.

***Editor's Note: The Call for Papers for PacRim 2009 is now posted online at www.pacrim.hawaii.edu.

Disability Studies Ethics: Theoretical Approaches for the Undergraduate Classroom

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Abstract: By challenging disability prejudice and advocating for people with disabilities in crucial bioethical debates, disability rights activists and scholars have been reformulating ethical discourse. This essay suggests pedagogical strategies for introducing undergraduates to an ethics of disability studies, and integrating disability perspectives into broader questions of social justice.

Key Words: ethics, disability studies, social justice

***Editor's Note: This article was anonymously peer reviewed.

Introduction

Disability studies scholars and rights activists, in their shared commitment to challenge stigmas around physical and cognitive impairments and advocate for full integration, self-determination, and maximum civic participation of disabled people, often find themselves engaged in reconfiguring ethical theory, debate, and action. At the heart of disability studies lies an ideal of social participation for all people, to the fullest extent possible, regardless of impairment diagnosis. This ideal positions disabled and nondisabled people as moral and legal equals, and does not formulate citizenship or personhood standards around rationality, independence, or self-sufficiency, as many ethical and social justice theories have done traditionally. In challenging physical and cognitive norms—as these have been defined and enforced—as well as historical exclusions of people with disabilities, an ethics of disability demands an expansion of long-standing conceptualizations of human embodiment and conscious engagement.

Discussing ethics from a disability perspective becomes all the more urgent and complex as we look at some of the most polarizing debates about human life, such as selective abortion, euthanasia, and the potential eugenic outcomes of prenatal testing and genetic technological advances. As many scholars in the field have pointed out, much of the medical and popular media representations of these debates have privileged cure and eradication of disability over attitudinal change and greater efforts to integrate and support the access needs of disabled people (Wendell, 1996; Parens & Asch, 2000; Glover, 2006).

At the University of Wyoming, as faculty members in the newly established undergraduate minor in disability studies¹ considered the layered ethical conversations that would inevitably arise within undergraduate courses, we decided to integrate ethical components across the core courses and popular electives of the curriculum.² This essay introduces some of the pedagogical and theoretical approaches we are implementing by looking closely at some of the disability ethics content in three distinct courses. The first, Introduction to Disability Studies, is a required survey course, where students are encouraged to extrapolate the driving ethical commitments of disability studies within a social justice context. The second elective course, Women with Disabilities, focuses on feminist approaches and multiple perspectives of disabled women. This course provides a unique location to explore care ethics and to introduce a few of the productive complications disability studies has introduced to feminist theories. The final required course, Supports and Services, provides students with opportunities to meet service professionals, disabled clients and activists, and policy ex-

perts who provide first-hand accounts of how local and national support systems operate. In addition, students are exposed to broader theories of human rights, social justice, and vulnerability, and are encouraged to use these critical lenses to analyze the ethical guidelines within their own fields or professions. The ultimate goal is to provide students in the minor with a comprehensive understanding of the principles animating disability studies, and with the tools for articulating and integrating these values into an active ethical practice in their professional lives—within and beyond academia.

Articulating an Ethics of Disability

As an interdisciplinary field of inquiry, disability studies draws upon many areas of scholarship to inform its ethical commitments. The introductory survey class reflects this diversity by encouraging students to identify and cull out from our course readings some of the foundational ethical principals informing disability studies. Drawing upon leading scholars and activists in the field, students investigate critiques of the medical and moral models, and explore the political salience of the British social model and the minority/civil rights model that has emerged in the United States. As the perspectives of disabled people are moved to the center, students come to realize how marginalized these voices are in mainstream public discourse, and how meanings of disability have been shaped by limiting cultural narratives built around individual tragedy, charity, and heroic overcoming.

From the outset, students are introduced to the ideals driving disability studies and disability rights, such as claims to full personhood and respect, maximum integration, and appreciation of dependencies and interdependencies. The importance of putting these ideals into practice are most salient as students are exposed to historical and contemporary exclusions of people with disabilities, the potentially oppressive power of medical authority, and the pervasive stereotypes that continue to cast disability as individual

medical tragedy, moral punishment, or villainous attribute.

As students begin to unpack the medical model, they are often struck by the power of the concept of *normal* to stigmatize and exclude people with disabilities. Linton (1998) has explained this process in the following way: “The medicalization of disability casts human variation as deviance from the norm, as pathological condition, as deficit, and significantly, as an individual burden and personal tragedy” (p. 11). Davis (1999) has elaborated further, pointing out that the very idea of normal, codified during the eugenics period, is relatively new. With the institutionalization of the bell curve in the early twentieth century, Davis has suggested, “The concept of normality...created an imperative to be normal” (p. 504) by drawing stark lines between so-called normal and abnormal bodies. Readings from such scholars push students to reevaluate their own assumptions about normalcy, and many uncover conceptual exclusions within their own thinking that become illuminating. The perspective shift from the medical to the social model, as well, is quite noticeable in the classroom. Wendell (1996) has captured the nature of this shift in *The Rejected Body*: “One of the most crucial factors in the deconstruction of disability is the change of perspective that causes us to look in the environment for both the source of the problem and the solutions” (p. 46). The invitation to look at specific environments allows students with and without disabilities to actively participate in locating barriers and suggesting ideas for more inclusive practices.

As we explore the nature of disability oppression and prejudice, students are also encouraged to approach the insights of disability studies as generative, and applicable to human experience more broadly. In this vein, we begin to focus on the ways that values produced by disability perspectives might enhance social theories, philosophical ideals, and cultural practices. In his classic essay on disability culture, Longmore

(1995) has delineated the provocative nature of disability values:

“[P]eople with disabilities have been affirming the validity of values drawn from their own experience. Those values are markedly different from, and even opposed to, nondisabled majority values. They declare that they prize not self-sufficiency but self-determination, not independence but interdependence, not functional separateness but personal connection, not physical autonomy but human community (p. 36).

In this formulation, Longmore has rightly drawn upon the experience of disabled people as an alternative “source of values and norms” (p. 36), and this provides an excellent starting point to discuss some of the major ethical traditions in philosophy, especially to investigate where the dominant assumptions critiqued above have originated, and how these theories continue to influence contemporary ideas and practices around disability.

While our foray into philosophy is admittedly superficial, students are introduced to key ethical theories and encouraged to think about concepts and exclusions that might affect people with disabilities. Initially, the class considers the differences between consequentialist (teleological) and nonconsequentialist (deontological) theories (Thiroux, 1998). Consequentialist theories such as egoism, and act and rule utilitarianism, share a focus upon consequences of actions, and determining rules or personal actions in order to bring about beneficial consequences. Nonconsequentialist theories, such as intuitionism, Kant’s duty ethics, and virtue ethics, differ in many ways but broadly share the assumption that human beings have an internal moral guide, or that they have the capability, through reason, to develop moral rules and abide by them. Such theories see ethics as a process of internal intuition or reflective learning. For the purposes of this paper, I’ll outline a few of the questions disability studies brings to the discussions of a

representational theory in each category: utilitarianism and Kant’s duty ethics.

Utilitarianism

Utilitarianism takes as its guiding principle that everyone should act according to the greatest good for all concerned. In other words, moral action is determined by evaluating potential ramifications, and moral agents are obligated to choose the optimal act, or the one determined to provide the best consequences (Thiroux, 1998; Kagan, 1998). In practice, however, it is extremely difficult to predict the outcomes an action will have upon everyone involved. More important to disability studies, the ideal of the greatest good for greatest number often devolves into cost-benefit debates where majority interests are pursued at minority groups’ expense. The legacies of utilitarianism are evident in resource allocation debates in modern industrialized societies, in which providing civic access, medical support, and other resources to people with disabilities center around cost-benefit analyses. Such models inevitably position those most in need of supports as least beneficial to the social fabric—assumptions built upon medical authority, which correlates increased impairment levels with decreased *quality of life*—a euphemism for lesser human worth. These arbitrary judgments portray people with disabilities as tragic sufferers who should be pitied, not as potential contributors to cultural life—or the bottom line. As Wendell (1996) has argued, this limiting mindset continues to make it very difficult to allocate disability resources, “because most people still think of disability as a personal or family responsibility, and...because public aid to people with disabilities has long been characterized as pure charity, rather than as a social investment in ability and productivity” (p. 51). In effect, utilitarian and medical model assumptions inhere within social thought and political structures and function invisibly as natural practices.

Kant

In contrast, Kant's duty ethics assumes that as people act from a sense of innate, rational duty, they will come to agree upon universal moral rules that will guide their actions—which, following such reasoning, will tend toward the good of everyone concerned. In this construct, moral decisions are determined through reason, and are assumed to be logically consistent (Furrow, 2006). In critique of Kant's enduring influence, Kittay (2002) has pointed out that his model connects human value and human dignity to pure rationality and moral duty:

“The capacity that elevates humans to the status of moral agents, [Kant] thought, is the rationality by which we judge if we can universalize maxims we choose for our own actions. Rational agency, he maintained, not our mere species membership, gives us the dignity of moral beings” (p. 262).

This privileging of rational agency, which implies an individual subjectivity based upon independence and autonomy, inevitably excludes people with a variety of intellectual or communicative impairments. As we explore more modern theories of humanitarian ethics and social justice, students are encouraged to ask how definitions of personhood, citizenship, and moral agency continue to reflect such ableist assumptions.

In order to trace the enduring nature of how the human is conceived through reason and competence, we consider the work of Rawls (1971), arguably one of the most influential modern social philosophers. Moving outside the boundaries of consequences and internal morality, Rawls (1971) focused upon developing a comprehensive theory of social justice by outlining the principles that should govern political structures. His goal was to determine what kind of social contract everyone could agree upon, taking into account the vast differences people hold about how to live. After looking at the basics of his theory of social justice, we consider

some of the problems his philosophical framework presents to disabled people. In his theory, Rawls (1971) defined the negotiating or acting parties as *competent adults*, thereby constructing a boundary that could be used to expel many people with cognitive, communicative, or other impairments. I borrow Nussbaum's (2002) critique of Rawls (1980), to extend the discussion of philosophical exclusions. The following quote from Rawls (as cited in Nussbaum, 2002) illustrates to students the rational methods still used to justify exclusions of people with disabilities from social discourse, and by extension, society:

“So let's add that all citizens are fully cooperating members of society over the course of a complete life. This means that everyone has sufficient intellectual powers to play a normal part in society, and no one suffers from unusual needs that are especially difficult to fulfill, for example, unusual and costly medical requirements. Of course, care for those with such requirements is a pressing practical question. But at this initial stage, the fundamental problem of social justice arises between those who are full and active and morally conscientious participants in society...Therefore, it is sensible to lay aside certain difficult complications. If we can work out a theory that covers the fundamental case, we can try to extend it to other cases later” (as cited in Nussbaum, 2002, p. 190).

As we consider this setting aside of so-called complications, we must ask how a theory of social justice can be built around the deliberate exclusion of people with dependencies. Also if such people are conceived of from the beginning as *difficult* and *complicated*, won't their integration back into the social fabric be fraught with problems as well? As students consider these questions in conjunction with disability studies values and ethical frameworks, they begin to see how the social structures we have inherited are very much a product of these philosophical constructs.

Dependency, Care, and Expanding Notions of the Human Subject

With common interests in embodiment, processes of othering, misuses of medical authority, the relationships between care and dependency, and the power asymmetries inherent in discourse of the public versus the private, feminist theorists and disability studies scholars share a good deal of analytical terrain. In our course, *Women with Disabilities*, we explore these intersections by first examining some of the important ways feminist traditions have informed disability studies critiques, especially through expanding the social model to consider discourses of embodiment, pain, and lived experiences of impairment. Borrowing from Thomson (2004), we explore the way disability enhances and broadens the conceptual framework of feminist theory, especially theories of justice. As Thomson has suggested, “understanding how disability operates as an identity category and cultural concept will enhance how we understand what it is to be human, our relationships with one another, and the experience of embodiment” (p. 76). In order to extend the conversation of disability ethics, this course investigates these intersections within the ethics of care tradition, and then looks closely at how feminist philosophers Kittay (2002) and Nussbaum (2002) have attempted to integrate disability into their own theoretical approaches to ethics and social justice.

As a starting point, students are introduced to the relatively new but sophisticated feminist literature devoted to an ethics of care. While this tradition reflects a wide epistemological scope, it is generally concerned with grounding moral knowledge, not in universal abstractions, but in relational knowledge and insight. Held (2006), who has written extensively on the subject, suggests that most ethics of care theories share several major features. Among these, the following three are most relevant to disability studies. First, care ethics challenges moral systems built upon independent, rational individu-

als by insisting that primary moral knowledge is gained through the relationships we build with those dependent upon us and upon whom we depend. An ethics of care demands that dependencies be considered central, not marginal, to conceptualizations of social justice.

Second, care ethics challenges rationalist frameworks by insisting that some emotions, such as sympathy, empathy, and even anger—especially against social oppression—are essential to developing moral knowledge. As Held (2006) has argued, “The ethics of care... typically appreciates the emotions and relational capabilities that enable morally concerned persons in actual interpersonal contexts to understand what would be best” (pp. 10-11). In other words, emotion and rationality allow people to make the most effective ethical decisions. Furthermore, the ability to understand and appreciate others’ emotions, especially in response to specific asymmetries in power or access to resources, enhances one’s ability to successfully evaluate specific ethical situations.

Third, drawing from feminist traditions more broadly, the ethics of care reconceptualizes long-standing notions of the private and public. Traditional moral theories have concentrated on the public, contractual domain, where abstracted equals enter into consensual agreements. This framework neglects the moral issues found within domestic, intimate, and familial locations. Care ethics insists that these so-called private arenas are part of the social fabric, and that social justice theories must also consider relations that are involuntary, asymmetrical, and non-contractual by nature.

The concepts listed above can be discussed in some depth as problematic binaries set up by traditional ethical theories, in which one element is always privileged over its contrastive other: independence over dependence; reason over emotion; and the public over the private. In addition, as the perspectives of women with disabilities are presented throughout the semester,

students witness how disability complicates and expands the scope of care ethics. As one example, while feminist theories of care have established a space for theorizing about the subjectivity and objectivity of caregivers and those dependent upon care, women with disabilities too often are positioned in the static role of *dependent*. Morris (2001) has critiqued feminist research focused upon “carers and their dependents,” because it has repeatedly “resulted in disabled and older women being excluded from the category of ‘women’ and classed as ‘dependents’ whose existence [is] a threat to non-disabled women’s economic opportunities” (pp. 6-7). As many women with disabilities have attested, this assignment of dependency subsumes all other identities, and locks them into objectified, passive positions that grossly misinterpret their complex relationships with care providers and the myriad other people in their lives.

As we consider disabled women’s experiences within an ethics of care, two feminist philosophers emerge as key to the discussion because both have taken the needs and demands of people with disabilities seriously in their theories of social justice. In the anthology entitled *The Subject of Care* (2002), the essays by Kittay and Nussbaum provide an interesting dialectic around an ethics of disability. The pioneering work of Kittay (1999; 2002) has challenged philosophy to take seriously the concerns of people like her daughter Sesha, who have significant cognitive and physical impairments. Following feminist traditions, both authors cogently critique liberalism’s failures to include people not classified as independent, rational, or self-sufficient, but whereas Kittay (2002) wonders if liberalism itself must be renounced, Nussbaum (2002) attempts to reconfigure a liberalist model to include the broad continuum of human capabilities. While it is beyond the scope of this paper to detail these arguments, I will sketch a few key ideas that students are encouraged to contemplate at greater depth.

In her essay, “When Caring is Just and Justice is Caring,” Kittay (2002) has suggested that people with significant intellectual impairments may actually pose a limit to liberalism’s ability to theorize human political interaction. She uses the example of her daughter Sesha, who cannot speak for herself, to demonstrate the descriptive limits of personhood within a liberal framework. In order for Sesha’s voice to be heard, she needs an advocate, someone relationally committed to understanding what she communicates. Kittay (2002) has posited that a model based on relationships, not rationality, would better account for the unique needs, joys, and profound contributions made by her daughter: “Seeing Sesha in her interactions with those who care for—and about—her reveals that being a person has little to do with rationality and everything to do with *relationships*—to our world and to those in it” (p. 266).

In accounting for dependencies, she thinks seriously about both the caregiver and the person needing care. She sees such relationships as complex, with profound interdependencies, but also as asymmetrical and not reciprocal in the ways that contractual liberalism demands. Acknowledging these intricacies, Kittay has put forward a theory of care that attempts to consider the interests of the cared for and the carer—while also being attentive to not putting these in absolute competition with one another. She has reformulated care as a multifaceted concept—“a labor, an attitude, and a virtue” (2002, p. 259). If all of these elements are not encouraged, if an attitudinal commitment is not made, or if the carer feels unappreciated or exploited, the quality of care and the relationships will inevitably suffer. In effect, she worries that neither the caregiver nor her (or his) charge is well represented under liberal theories. Quite the opposite, in fact, caregivers are often saddled with the stigma already attached to people with cognitive impairments. As Kittay (2002) has submitted quite pointedly:

“If we want to remove the prejudice and lack of understanding that blights the lives of people with mental retardation, we can begin by treating their caregivers as if their work mattered (because it does) and as if they mattered (because they do). To do this we need to provide caregivers with conditions that allow them to do their work” (p. 270).

Ultimately, she argues that any ethical thinking must integrate asymmetrical dependencies to push all of us toward acknowledging our very real dependencies on each other. She does not want to abandon working toward independence, liberty, and autonomy as goals, but sees an integration of dependencies as essential to reconfiguring our ideas and misconceptions about these terms as absolute ideals.

Nussbaum’s (2002) essay, “The Future of Feminist Liberalism,” takes the commitment to asymmetrical dependencies seriously, but argues that liberalism can be reconfigured to integrate the full range of human capacities. As discussed earlier, she develops important critiques of liberal philosophical traditions that assume active participation among independent actors. She discusses Rawls’ (1971) theory of social justice at some length, because although he acknowledges dependencies as part of the human condition, he still sets these aside as unusual and extreme. Like many feminist theorists (Kittay, 2002; Held, 2006; Morris, 2001), Nussbaum (2002) disagrees with this exception, and argues that dependencies, which are elemental to human life, must be integrated into any viable theory of justice.

In order to do this, Nussbaum (2002) has suggested expanding the political conception of the person and the idea of human dignity to include “the dignity of mentally disabled children and adults, the dignity of the senile demented elderly, and the dignity of babies at the breast” (p. 193). By including these and all other human subjects in the foundational framework of social organization, we are more inclined to

develop just and caring communities and institutions. She argues that by developing a theory of justice based upon human capabilities, in all their range and diversity, and the social obligations to support those capabilities, we would of necessity develop a different matrix for designing social systems.

As these two philosophers are put into conversation with one another, several questions emerge. We might ask, for example, if there is an implicit danger in Nussbaum’s (2002) language of capabilities. Does it return us to ideals of ability and rationality? Does her framework draw lines of exclusion or stigmatize differences, even as it attempts to address these concerns? Students might also discuss whether Nussbaum’s critique—that Kittay’s (2002) rejection of liberalism would result in the state becoming a “universal mother” (2002, p. 195) has merit. On the other hand, we ask if Kittay (2002) helps us imagine a more nurturing state, one whose responsibilities extend to the private domain of dependencies, interdependencies, and relationships. In such discussions, as students explore the strengths and potential pitfalls of a feminist ethics of care along with Kittay’s (2002) and Nussbaum’s (2002) elaborations of these theories, they become engaged in some of the exciting ways disability has begun to transform how scholars are thinking about justice, care, and social structures.

Centering Disability in Human Rights Discourse

Students in the undergraduate minor are required to complete an upper division course entitled Supports and Services prior to doing their practicum, where they will work directly with people with disabilities in locations such as non-profit providers, schools, state agencies, or advocacy groups. This final on-campus course provides students with practical information about how social service systems, direct support, and disability policies have been structured, and how some of these have changed in response to

disability rights and advocacy over the last few decades. In order to give students a wide range of perspectives, professionals, policy experts, and people with disabilities from a variety of fields present topics to the class. Throughout the semester, we draw upon ethical theories and debates introduced in previous courses to develop disability studies questions, critiques, and analyses of the professions and services we discuss. In one of the cornerstone assignments, students assess the ethical codes or guidelines of their own fields or professions, and suggest specific ways that disability perspectives might be more fully incorporated.

While the bulk of the curriculum focuses upon systems and policies in the U.S. and U.K., students are also exposed to selected international activist efforts and service models, so they can begin to compare different frameworks, and discuss what might be learned from alternative approaches. Within this more global context, we connect the conversation around ethics and social justice to an international discourse of rights and vulnerabilities. Turner (2006) has taken up the complex intersections between disability and universal rights in *Vulnerability and Human Rights*, so this text provides a framework for the class to consider how the demands for equality, accessibility and integration made by disabled people parallel those of other groups. Turner (2006) argues that as we witness global injustices, state sanctioned human rights abuses, and widespread human suffering, scholars need to pay attention to the issues that connect people across cultures, rather than to avoid the most difficult international conflicts in the name of cultural relativism. From this perspective, he builds a philosophical framework of ethics around embodiment, shared vulnerabilities and precariousness, which relates in key ways to care ethics, but moves the discussion from personhood, autonomy, and care relationships to one of universal rights.

By focusing more on commonalities than differences, Turner (2006) has suggested a mod-

el that attempts to unite people across cultures through shared ethical commitments to challenge injustices:

“While humans may not share a common culture, they are bound together by the risks and perturbations that arise from their vulnerability... This need for ontological security provides a strong moral argument against cultural relativism and offers an endorsement of rights claims for protections from suffering and indignity” (p. 9).

He stresses that most social formations, from family networks, community organizations, and educational systems, to health institutions, businesses and governments, have emerged in response to shared vulnerabilities and the precariousness of environments. These structures provide evidence of the natural bonds of human connectedness, shared dependencies, and social solidarity—not autonomy, self-sufficiency, or mythic independence.

In his conceptualization of individual and social development, Turner (2006) has delineated three essential processes that integrate disability experience into the broad continuum of the natural human experience: “embodiment,” “enselfment,” and “emplacement” (p. 27). In this construct, enselfment is the self-reflective process by which we understand how our bodies and our place in the world intersect. That is to say, whatever is enacted upon the body, be it pleasure, pain, or suffering, is also experienced and given meaning through one’s thoughts, cultural location, economic reality and so forth. This process of enselfment—of reflecting upon how one’s embodiment, cognitive capacity, economic status, ethnicity, gender, sexual preference, or personal aesthetic has influenced one’s social standing, is a key element in identifying human rights abuses, and recognizing or advocating for essential supports.

Well versed in the social model of disability and the failures of modern welfare states to adequately serve the needs of disabled citizens,

Turner (2006) frames his human rights model around vulnerability and embodiment specifically to address these exclusions from the outset. He has argued that because citizenship has been so fraught with inequities, unfair entitlements, and exclusions, “the language of human rights is ultimately the only plausible language for expressing the needs of people with impairment and disability” (2006, p. 90). He also suggests that vulnerability provides a language for embodiment that the strong social model has rendered invisible. In other words, a discourse around shared vulnerabilities will both include disabled people and provide a language for the phenomenology of impairment. By speaking of shared rights and vulnerabilities, the concerns of disabled people are integral to an understanding of justice and injustice—rather than being deferred indefinitely as a complication.

In outlining Turner’s (2006) human rights model at some length, I have intended to highlight one interesting theoretical approach to global issues that takes the critiques of disability studies scholarship seriously. Turner (2006) also enters into the ethical terrain developed in previous classes from a different direction, which provides ample material for discussion. After students have considered many theories foregrounding dependency and care, we can ask whether shared vulnerabilities really offers more traction than shared dependencies. Students are also encouraged to think about the limits of civil rights claims, and whether global rights discourse actually promises greater integration of disability. On the other side, even if it does offer a better framework for inclusion, how would this help people with disabilities who need to address issues at a local or national level? After considering these and many other questions, and looking at the ethics of disability from a variety of perspectives, students are better equipped to consider the ethical questions that may emerge in their own fields and professions with greater critical depth and skill.

Conclusion

As the meanings around disability continue to be haunted by exclusionary notions of human dignity, citizenship, and capacity, the field of disability studies will be engaged in rigorous ethical debates, many of which center around urgent liberties such as rights to life, reproductive freedom, and bodily integrity. Acknowledging the crucial nature of such public discourse, we have attempted to scaffold specific ethical components across our undergraduate minor in disability studies, in order to allow students to deepen their knowledge of ethical traditions, and understand how disability perspectives challenge and transform them. In considering the ethics of disability explicitly, students are encouraged to examine their own values, principles, and intellectual commitments, practices that will help guide the development of their own research questions, and provide them with skills to approach the complex moral and ethical issues they will inevitably encounter in the years to come.

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Endnotes

¹ The Disability Studies Minor was established at the University of Wyoming in 2006 by the Wyoming Institute for Disabilities (WIND), a University Center of Excellence for Developmental Disabilities (UCEDD), located in the College of Health Sciences.

² These efforts have been supported by a university wide initiative, called the Kaiser Ethics Project, which promotes the teaching of ethics across disciplines, and provides forums for faculty members to collaborate and share ideas.

Managing Unruly Bodies: Public Policy and Disability Sexuality

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FORUM

Abstract: Public policy that regulates and shapes the sexual and social lives of people with disabilities is focused on limiting freedom and agency. While analyzing the ideological underpinnings of such policy, the author also elucidates policy recommendations and ways that the field of disability studies can ameliorate the sexual status of people with disabilities.

Key Words: disability, sexuality, public policy

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Introduction

People with disabilities in the United States have historically been subjected to egregious forms of segregation and social devaluing. According to the disability section of the American Civil Liberties Union website:

“People with disabilities are still, far too often, treated as second class citizens, shunned and segregated by physical barriers and social stereotypes. They are discriminated against in employment, schools, and housing, robbed of their personal autonomy, sometimes even hidden away and forgotten by the larger society. Many people with disabilities continue to be excluded from the American dream” (2008).

Public policy regulating and shaping the lives of Americans often reflect the social status of people with disabilities through framing us as individuals who lack agency and therefore, need nondisabled people to step into our lives and control various aspects of it. This article seeks to not only criticize this dominant view of disability and query exactly how public policy does

and could shape the sexual lives of people with disabilities, but also serves as a potential guide to shape the subject matter of a disability studies public policy course focused on sexual issues.

Analyzing public policy through a disability studies lens reveals that its focus historically has been a product of the dominant medical model of disability because it enforces the notion that people with disabilities are non-agentic and need protection. Further, public policy regulates the sexual lives of people with disabilities to advance the eugenic agenda of preventing the propagation of our unruly bodies. While disability studies attempts to promulgate the notion that disability should be celebrated rather than shunned, public policy regulating the sexual lives of people with disabilities continues to depend on the notion of disability as a deviation from normalcy thus, necessitating intervention. People with disabilities do often deviate from normative bodily movement and ability thereby often provoking hostility and fear within many nondisabled people. Historically, many types of bodies that provoke anxiety, such as those that are of color or queer, tend to be intensely regulated in the public policy realm with the guise of protection at work (Shildrick, 2007). A disability studies public policy course focused on sexual issues would thus begin by positing the foundation of policy regulating our sexual lives within a sociopolitical context, as well as examine the historical underpinnings of that context.

The Perceived Policy Solutions to Manage Disability

Although rarely spoken of in the United States, there was once a pervasive eugenics movement attempting to make the population

of United States somehow more pure – and certainly more able. The United States had compulsorily sterilization initiatives to manage the reproductive rights of certain classes of people – namely individuals with intellectual and/or physical disabilities – nearly a decade before the Nazis started 4 Tiergartenstra_e (Black, 2003). Sterilization legislation gained widespread popular support in the 1920s. In 1933, Germany promulgated eugenics legislation based on legislation written in America. It is striking the extent to which Americans condemn Germany for its Nazi era methods of racial purification, yet rarely, if ever, discuss the fact that the United States was first to utilize the method of eugenics. Although, it is important to note that the Nazis annihilated millions of individuals, whereas the United States sterilized rather than killed individuals.

Until the mid-1970s in the United States, people who were mentally or physically disabled or ill, deaf, blind, epileptic, or physically deformed were targeted by compulsory sterilization legislation in thirty-three states (Lombardo, 1982). That legislation targeted many people with disabilities with the intent of eliminating defectives from the gene pool, in order to facilitate a better - more able - populace. In the Supreme Court case, *Buck v. Bell*, a student of eugenics Justice Oliver Wendell Holmes, Jr. (1927) wrote:

“It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind. The principle that sustains compulsory vaccination is broad enough to cover cutting the Fallopian tubes. Three generations of imbeciles are enough” (p. 207).

The only aspect of the holding in *Buck v. Bell* (1927) that has been deemed unconstitutional is that concerning the punitive sterilization of criminal individuals, whereas the sterilization

of people with disabilities continues to be held constitutional (Lombardo, 1985).

While one might hope that this sort of archaic understanding of the sexuality of people with disabilities has subsided around the world, unfortunately this is not the case. There are current examples of compulsory sterilization around the world. But it is beyond the purpose and scope of this paper to include an exhaustive list of those countries that deploy this method to manage the sexuality of people with disabilities. The national government of Australia recently adopted the *Children with Intellectual Disabilities (Regulation of Sterilization)* Bill 2006 authorizing forced sterilization (Frohman, 2007). In November of 2006, American Drs. Daniel F. Gunther and Douglas S. Diekema wrote in the *Archives of Pediatrics and Adolescent Medicine* about a controversial and legal procedure in which a severely intellectually and physically disabled six year old girl was given high levels of estrogen, underwent a hysterectomy and an appendectomy, and had her breast buds removed in order to stunt her growth and reproductive ability (MSNBC, 2006). The treatment also rendered the child unable to menstruate as she aged, effectively to keep her from entering puberty. The rationale behind the treatment:

“Achieving permanent growth attenuation while the child is still young and of manageable size [the procedure] would remove one of the major obstacles to family care and might extend the time that parents with the ability, resources, and inclination to care for their child at home might be able to do so” (MSNBC, 2006).

The authors of the article assert that the treatment is “both ethical and feasible and should be an option available to parents.” This case reflects the perceived lack of ethical issues related to the suppression of the sexuality of people with disabilities. Compulsory sterilization is an example of how public policy and general social perception permits if not encourages the treatment

of people with disabilities as if we lack agency, both socially and sexually, thus coinciding with the medical view of disability. A disability studies public policy course focused on sexual issues would query how stripping someone of one of the fundamental aspects of personhood, sexuality, could ever be deemed reasonable if society did not view people with disabilities as non-agentic and asexual?

A pervasive solution to the “disability problem,” although not a final solution, is the use of nursing homes to house unruly disabled bodies. Today, there are over two million disabled people warehoused in nursing homes; where disabled bodies are actually worth more to the Gross Domestic Product than at home (Russell, 1998). According to Russell (1998), the average person housed in an institution or nursing home is worth around \$40,000 each year to the service providers in control of the nursing home industry; a figure that does not include add-on billings such as medication, or inflationary increases in resident fees. This proposed disability studies course would challenge the commodification and segregation of people with disabilities, as well as critique an industry that not only turns a profit on our bodies, but also keep us hidden away from the socionormative populace. Thus, alleviating any potential discomfort with our deviant bodies (Susman, 1994).

Nursing homes serve as a powerful force in the social and sexual suppression of people with disabilities. In nursing homes, all aspects of a persons’ agency are completely removed from their power and they are effectively rendered objects to be stored and profited upon. A particularly offensive component of this aspect of oppression for many people with disabilities is that while institutionalized people with disabilities are in some cases permitted to marry, they are not permitted to engage in consensual sexual acts (Finger, 1992). Further, in the few situations where heterosexual sexual relations are deemed permissible, homosexual activity is often prohibited (Finger, 1992). And to move

beyond coupled sexual acts, there are countless instances of physical and psychological abuse exacted on people with disabilities if they engage in masturbation (Silverberg, 2006).

Another example of the felt need to suppress the sexuality of people with disabilities was noted in the recently ratified *United Nations Convention on the Rights of Persons with Disabilities*. In the arduous process of debating each word of the international human rights instrument, twenty-six countries, including the United States, refused the inclusion of an article explicitly dealing with various aspects of reproductive and sexual rights of people with disabilities (Adams-Spink, 2006). As a result of the labored debate, sexuality is only mentioned in Article 25(a) briefly under the purview of access to healthcare. The more extensive article concerning sexuality could have been socially ameliorative to people with disabilities globally through recognition of the numerous facets of our sexual lives.

The argument to catalyze the noninclusion of the sexuality article in the convention was based on the tactic of conflating disability into one category (Shildrick, 2007). Disabilities, like queer sexualities, come in a multitude of manifestations – with disability comprising impairments ranging from physical to sensory impairments. Many people who advocate for the rights of people with disabilities continue not to know how to deal with the sexual lives of individuals with cognitive impairments. The main impediment in resolving the question of the sexual rights of people with cognitive impairments is the understanding of individuals with reduced mental capacity as lacking capacity to consent. The focus on issues of informed consent of people with cognitive disabilities obscure the situations of people with different forms of disabilities, thus conflating the spectrum of disabilities into one category of people who lack the capacity to consent to any sexual act. Therefore, on an international level, people who possess an impairment that does not affect mental

capacity still lack the capacity to consent to any sexual act.

In many ways, the creation of this document is a progressive step for international law concerning people with disabilities, as it is recognition of the lack of access to fundamental human rights for the majority of people with disabilities around the world. Former United Nations Secretary General Kofi Annan stated that the convention offers a promise of “a way forward to ensure that those with disabilities enjoy the same human rights as everyone else -- in education, employment, access to buildings and other facilities, and access to justice” (Annan, 2006). But along with the promise of much needed progress, this convention is also an implicit codification of oppression because of its lack of an article dealing exclusively with sexual and reproductive rights. Instead of providing a path of sexual amelioration for people with disabilities, this convention silently supports the perception that many people with disabilities lack sexual agency and should be treated accordingly.

The Façade of Benevolence in Public Policy

These examples could be seen in the manner to which many individuals in applied fields studying disability frame them – as a manifestation of benevolence because people with disabilities need protection. According to this line of thinking, we need protection from ourselves and from nondisabled people who desire to prey upon our vulnerable nature. This statement is not intended to deny that many people with disabilities face physical and sexual abuse. People with disabilities comprise the highest risk community of people to face abuse globally (Light, 2003). Many groups of people, such as women and children, need government intervention to prevent their abuse, but the framing of policy as a benevolent act directly contradicts the values of disability studies because it politically disempowers people with disabilities by continuing to posit us as people who need someone to serve as

our advocates, representatives or keepers (Cocca, 2002; Bevacqua & Baker, 2004). Further, the belief that this sort of action is benevolent assuages people’s guilt when they treat people with disabilities as though we lack fundamental human needs and desires or social and political agency. I refuse to see these examples of policy as acts of benevolence and, rather, see them as forms of “erotophobia” (Wilkerson, 2002, p. 40).

Erotophobia manifests through the imposition of social taboos and constructs on certain classes of people in order to limit their sexual agency. This form of segregation is imbued with the medical ideology from which disability studies seeks to distance itself. This view is not only apparent in the social understanding of people with disabilities, but can also be seen as a force guiding policy and public perception of other devalued citizens, such as queer people. As Rubin (1999) assert, sex is a vector of oppression that “cuts across other modes of social inequality, sorting out individuals and groups according to its own intrinsic dynamics” (p. 160). Marginalizing people based on their sexuality is a powerful tool of social oppression and historically has been used to constrain the political and social agency of various groups of social dissidents and those regarded as “others,” such as queer, Black, and female individuals. Sexual stereotyping and other sexual harms, like imposing sexual shame on people through social oppression, are significant forces in perpetuating inequality of any oppressed group (Wilkerson, 2002). While one can argue that these social structures, such as that disseminating sexual shame associated with any particular identity, should not be viewed as a form of public policy, I contend that public policy is informed by and reinforces these public perceptions.

The Media’s Promotion of Oppressive Disability Narratives and Policies

A disability studies public policy course focused on sexual issues would need to examine

the role of the media as a form of public policy. By analyzing its power to construct, define, and perpetuate the value of people with disabilities. The media shapes our sexual subjectivities as much as public policy itself has the capacity to regulate (Brown, 2002). For the most part, disability is ignored by the media. But when people with disabilities are represented in large, commercial media, it is typically in a stereotypical manner, thus enforcing the medical model of disability. The dominant narratives of disability, including the “pathetic cripp” and the “supercrip,” are pervasive in media representation and thereby, transmit into widely accepted supercultural notions (Susman, 1994). These narratives of disability are imbued with the history of eugenics and freak shows. The eugenic view of people with disabilities as *useless eaters* (Nazi terminology) and breeders can be noted in representations of disability that entail a person being posited as childlike, helpless, weak, and essentially worthless (Shildrick, 2007). One example is the Jerry Lewis Telethon, devoted to raising money for the pathetic crips with Muscular Dystrophy. It is fascinating that what the pathetic crip really needs to be ameliorated is money.

The super-crip narrative is what one might think of when examining media representation of disability, as it is fairly commonplace within news stories, as well as sensationalized fictional depictions of disability. This entails a person with a disability who overachieves and is capable of just about everything without a drop of sweat and a perpetual smile. This narrative is imbued with the history of freak shows because it constructs physical and psychological distance between the nondisabled and the disabled person by exalting people with disabilities for engaging in simple acts. For example, both a person on a freak show stage and a person in a typical human interest story have been appreciated for playing the piano while being disabled (Larsen & Haller, 2002).

The media has a history of “representation and treatment of certain sexual practices and de-

sires as disabilities and illnesses [through which disability is denied positive access to media representation] loudly, repeatedly and not silently” (Kafer, 2003, p. 85). The social reality of living with a disability can prove to be challenging, often offensive, and remarkably disempowering and exclusionary from many cultural contexts, such as public policy. This is why there are disability scholars and activists to raise awareness of how so many people with disabilities are denied access to the fundamental rights, privileges, and responsibilities of human life and citizenship. The profoundly sad glimpse into the reality of the lives of people with disabilities, I present here makes me wonder, “What is to be done?” I counsel that disability studies needs to engage with sexual radicalism and catalyze dissemination of disability culture into the mainstream as social solutions to subvert the dominant medical discourse of disability.

Paths to Ameliorate the Sociosexual Status of Disability

I concur with Rubin’s (1999) assertion that there is an urgent need for a radical theory of sex to overturn the problems with sexuality, including the hierarchies of sexual value and ability. Her conception of a radical theory of sexuality must “identify, describe, and denounce erotic injustice and sexual oppression” (p. 148). For people with disabilities, a radical theory of sexuality in action would entail denouncing the popular images and policy codifications that define our lives. We need to subvert the negative images of disabilities and replace them with images that claim our beauty, difference, humanity, and sexuality in a way that is public and proud. The next step must be changing popular conceptions of disability, such that public policy can reflect this shift. Claiming disability culture and disseminating it into the mainstream is a powerful tool to challenge the dominant view of disability as socially devalued. Work by the unrelated Berkeley performance artists Frank Moore and Leroy Moore¹, as well as other artists

with disabilities, should be made more accessible to a larger scope of people. The images defining disability that pervade our culture must be countered with those that display our nuances and humanity. Through changing the cultural imagination about the status and meaning of disability, culture and thereby, public policy will shift to reflect this positive understanding.

The field of disability studies offers a valuable path to challenge the dominant images and social understandings of disability, thus ameliorating people with disabilities and temporarily nondisabled people as well. Statistics show that the majority of people will become disabled at some point in their lives – about eighty percent of people in the United States alone (Russell, 1998, p. Index). According to the United Nations fact sheet on disability, if a person lives to be seventy years old, they will experience disability for at least eight years or eleven and half percent of their lives (United Nations, 2006). That statistic does not take into account all the individuals who acquire disability through accident or illness earlier in life. Disability issues are not just the issues for people who are similarly situated to my (disabled) embodiment, rather they are everyone's issues. As the subject of an Academy Award winning film, O'Brien, stated, "Everyone eventually becomes disabled, unless they die first. How much more natural can you get?" (as cited in, Aquilera, 2001). The public policy focus on disability as an issue framed as one of limiting our sexual freedom does not just affect people who live in disabled bodies currently. Instead, it has the potential to affect everyone. That is what is so unique about disability, as it is an oppression status that anyone at anytime might acquire.

People with disabilities contend with an intersection of oppression concerning impairment and sexuality, as American society generally has anxiety around talking about sexuality in a healthy way, as well as apprehension in discussing disability. If adding other aspects of intersectionality that catalyze fear and thus silence,

such as queer sexualities and genders, racial and ethnic minorities, class and immigration status, the problem of sexuality becomes even more egregious for policy makers. But, this realization provides more support for more sexuality activists and scholars to be aware of disability and other intersectional issues related to sexuality. Finger (1992) said it best when she wrote:

"Sexuality is often the source of our deepest oppression; it is also often the source of our deepest pain. It's easier for us to talk about - and formulate strategies for changing - discrimination in employment, education, and housing than to talk about our exclusion from sexuality and reproduction."

Her quote is a call to action to initiate a revolution between our legs and our ears. This revolution can start to come to fruition is by analyzing how public policy might aid people with disabilities in accessing positive sexual lives. There are numerous actions currently in progress among of people with disabilities that work to enhance or help create our sexual lives, including facilitated sex, the use of sex surrogates, and the use of sex workers. This list is neither exhaustive, nor should creative policy makers stop with these suggestions alone. Additionally, disability scholars should take on the task of attempting to create solutions that address and ameliorate the sexual status of people with disabilities. A disability studies public policy course focused on sexual issues would need to start this process by engaging with these suggested methods of challenging the problems people with disabilities face in their sexual lives.

Facilitated sex involves the use of a personal care attendant providing a person with a disability sexual assistance, ranging from undressing a person prior to the sexual act to actually helping assist the individual in masturbation. This aspect of sexual access is quite controversial within both the disability community and the community of personal care attendants. Currently, this

issue has no real codification dealing with the legality of these services or whether they are compulsory for personal care attendants (Shildrick, 2007). Despite the controversy around this issue, many people do have access to this form of assistance and do not view it as a form of sex work. Instead, they believe that facilitated sex is a means of garnering aid for a basic life activity, similar to requiring aid to bathe for example (Earle, 2001).

An issue that few people consider as a sexual outlet for people with disabilities is the use of sex surrogates. Sex surrogates work to “enhance a set of foundation skills which help to develop a positive, healthy sexuality” (Poezl, 2001, p. 126) using means such as breathing, relaxation techniques, erotic touching exercises, and teaching effective communication skills. Interestingly, many people think of sex surrogates as analogous to prostitutes because they do, in some cases, engage in sexual acts with their clients. However, to date there is no case law regarding this subject and it remains perfectly legal (International Professional Surrogates Association, n.d.). While there has been no comprehensive empirical study concerning the effectiveness of sex surrogacy, anecdotal evidence suggests that this form of therapy is rather successful, especially for late-life virgins and those who have been excluded from accessing sexuality (Society for Human Sexuality, n.d.).

The use of sex workers has recently gained momentum in the media as a means of aiding people with disabilities in accessing sexual lives, especially on an international level (Rohrer, 2007). In Australia, sex workers are trained to deal with the sexual and physical abilities of people with disabilities and many sex workers work in accessible brothels (Life Site News, 2005). Denmark and the Netherlands are taking similar steps in providing people with disabilities access to sex workers, and in some cases, actually providing a government subsidy to pay for the services (Shildrick, 2007). Both the use of sex surrogates and sex workers can be viewed as

problematic. First, these services generally, if not exclusively, are used to serve men only (Rohrer, 2007). Second, providing sexual services on a paid basis reifies the notion that people with disabilities cannot procure sexual acts through our own volition. I find these aspects troubling but some men with disabilities find sex work to be incredibly freeing. One such individual, Asta Philpot, stated that after procuring sex work he “feels more confident with girls. I’m totally for it. Not one regret. Disabled people are so sheltered and protected, in an institutionalized force field” (as cited in Rohrer, 2007).

It would be beneficial if the United States would follow the lead of these countries and allow individuals of all abilities to seek sex work in a healthy and safe manner, thus supporting the human rights of both the client and the sex worker. But until those changes come to fruition, it is important for disability scholars and those who draft policy concerning the sexual lives of citizens in the United States (and beyond) to consider the issues of people with disabilities as important issues of our society. A disability studies public course focused on sexual issues would be a great point of departure to begin analyzing these issues in a collective way, as well as disseminate these ideas to people who might otherwise not engage with them. The recommendations I have offered for aiding people with disabilities in achieving a positive sexual life answer the question of whether sexuality is a human right and who is human enough to access that right.

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Endnotes

- ¹ Leroy Moore is a writer, advocate and journalist on issues related to disabled people and individuals of color. For more information, please check out: <http://www.future-link.com/407LEROYFMOOREJR.HTML>. Frank Moore is a performance artist and television personality. For more information, please check out: <http://www.eroplay.com/>

Using the Media to Teach Disability Stereotypes

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FORUM

Abstract: Arguably the most powerful purveyor of culture for the past 50 years in the United States has been the mass media. In this article I will present ways to use the media to engage students to observe and learn about stereotypes of people with disabilities.

Key Words: disability, media, stereotypes

***Editor's Note: This article was anonymously peer reviewed.

Introduction

We are literally bombarded daily by multiple forms of media, with the effect of perpetuating established cultural norms and at the same time, creating new ones. It would be almost impossible to teach about culture that is driven by well-established stereotypes in disability studies courses without using the mass media. The impact of media has grown extensively during the electronic information explosion of the past 20 years. News and information on any subject the imagination can produce is available literally in seconds with a few key strokes. Obviously, that offers potential for learning and teaching. It also has great potential for presenting inaccurate information that passes as truth. Ironically, the Internet is the fastest source for checking facts and data presented in other media and it can be a source of misinformation through stereotypes.

Purpose of Stereotypes

The media is using a tool created by society, stereotypes. If stereotypes are harmful why would we have them? The short answer is because it simplifies life. Stereotypes are based on schemas. A schema is a set of characteristics that

describe a common event or group (Schneider, 2004). The Merriam-Webster Online Dictionary (2008) defines schema as, "A mental codification of experience that includes a particular organized way of perceiving cognitively and responding to a complex situation or set of stimuli". When presenting this concept to students, examples are helpful. A good one that most students can relate to is camping. When we hear the word camping what comes to our mind? Students usually say "camp fires," "s'mores," "tents," "sleeping bags," and a few others. Another common schema is what happens when we go to a restaurant. We know that we will be approached by a greeter who will ask us certain questions such as, "How many?", "Smoking or non-smoking?", and "Table or booth?" Then, you will be asked to follow her. We know the drill. We do not have to ask what she means because we have a working schema about that situation.

It is easy to see how practical schemas lead to stereotypes. We hear characteristics linked to groups of people from the time that we can speak and understand language with little to no questioning of those pairings (Schneider, 2004). Therefore, unconsciously we use the stereotypes that were based on common schemas about groups of people as if they are fact. They serve to allow us to go through life more easily by using them as shorthand for information about people in those groups.

Students will sometimes argue that there are some positive stereotypes. The one most cited is, "Asian males are good in math." I argue that the characteristic is positive, but the stereotype is still harmful, as are all stereotypes because they paint everyone in the group with the same brush. What happens to Asian males who are

not good in math? Would they have a difficult time dealing with the pressure and a sense of failure? Would they have a difficult time exploring other interests, such as art or literature? Stereotypes take away our individuality (Schneider, 2004).

Other examples can explain how stereotypes can lead to discrimination. If people who hold power over people's opportunities act on their stereotypes to exclude people, it is discrimination (Johnson, 2005). An example that I use is a woman who wants to be a plumber. She would probably need an apprenticeship with a union to learn the trade and get jobs. If the gatekeeper of the union acts on the stereotype that women cannot be plumbers, then she will be denied that opportunity. That's discrimination.

Stereotypes serve a purpose and will always be present, so how do we mitigate their harmful effects? Leading students through that discussion is very helpful in shaping their future beliefs and actions.

Reasons Media Use Stereotypes

There are at least two reasons that media use stereotypes. First, and perhaps the most powerful reason, is that they work for them. The media's job in the business world is to capture an audience to sell to advertisers (Busselle, 2001). Stereotypes help them do that. The Media Awareness Network (2008) states that:

“Media stereotypes are inevitable, especially in the advertising, entertainment and news industries, which need as wide an audience as possible to quickly understand information. Stereotypes act like codes that give audiences a quick, common understanding of a person or group of people—usually relating to their class, ethnicity or race, gender, sexual orientation, social role or occupation.”

In their attempt to “catch” an audience to sell to, advertisers use the most powerful “bait”

that they have, stereotypes. In an analogy of a person fishing to catch fish, she is not concerned with the bait being good for the fish. As a matter of fact, most bait is made of hard plastic with big three-prong hooks. Obviously this is not good for the fish, but effective in catching them.

Second, most media producers, writers, editors, directors, and critics operate from their own vast stereotypes (Busselle, 2001). They have no way to see the world differently. The stereotypes seem real to all of us because they perpetuate the familiar. Therefore, there is little hope that the media will challenge stereotypes. And why should they? Is that their job? Are they businesses protecting their bottom line, as do all businesses or do they have a greater responsibility to society due to their tremendous power and constant presence? These are great discussion and essay test questions for the class.

Teaching Stereotypes

First, one must define the term stereotype and show the students how using them affects people. One simple technique is to define stereotype, prejudice and discrimination, then show how these harmful attitudes and actions come from stereotypes. Everyone is familiar with stereotypes, therefore I have the students in disability studies courses list common stereotypes about women and then men. They quickly personalize the concepts by identifying those that they believe about those two groups.

Second, one exposes the students to stereotypes and deviant roles about people with disabilities identified by scholars in their research. I use three sources: (a) Douglas' five strategies that societies use to deal with anomalies well summarized in Rosemarie Garland Thomson's book *Extraordinary Bodies* (Douglas as cited in Thomson, 1997), (b) Norden's ten stereotypes in movies from his book, *The Cinema of Isolation* (Norden, 1994), and (c) Wolfensberger's seven deviant roles, as listed in Condeluci's (1991) book, *Interdependence*. Although two of the

three sources are not directly related to the media, they describe stereotypes that are pervasive in society. The media reflects society's attitudes and it is easy to see them through studying the media (Busselle, 2001).

Douglas' Strategies

As an anthropologist, Douglas (as cited in Thomson, 1997) identified strategies that cultures use to deal with anomalies or people in marginal groups. Social groups can reduce ambiguity by assigning the anomalous element to one absolute category or the other (e.g., African-Americans, people with disabilities, homosexuals). Stereotypes occur when people are lumped together into an absolute category because they lose their identity and individual rights.

Strategy 1

The social group will attempt to eliminate the anomalous group, e.g., the Nazis' euthanasia program, legalized sterilization, the eugenics movement of the 20th century, and currently, the euthanasia program pushed by the Princeton University bioethics philosophy professor Peter Singer (Demarco, 2008).

Strategy 2

The dominant group will attempt to avoid the anomalous group, e.g., institutionalization and the "ugly" laws in U.S. In the later part of the 19th century, institutions were established to educate people with disabilities. When the Eugenics movement took over, people were put in institutions to protect society.

Strategy 3

The social group may label the anomalous group as dangerous, e.g., Lenny in *Of Mice and Men* (Steinbeck, 1937), Captain Ahab in *Moby Dick* (Melville, 1851), and Captain Hook in *Peter Pan* (Barrie, 1987). These are images and stereotypes that are seared in almost everyone's mind in our society from assignments in school to popular entertainment. One stereotype of people with mental illness is that they are dan-

gerous. Characters such as these, and news reports about people pleading not guilty by reason of insanity and shooters in random crimes who have mental illness create and perpetuate this stereotype.

Strategy 4

Society may embrace the anomalous group and include them. This is the only positive strategy. Even Fortune 500 companies have embraced diversity in recent years because diversity improves business (Thomson, 1997).

Norden's Ten Stereotypes

Norden (1994) reviewed movies that have characters with disabilities from the earliest silent era through the mid-1990s and identified ten stereotypes that have been used by the movie industry.

Stereotype 1

The Civilian Superstar: a world class performer in such fields as sports, the arts, politics, and medicine who seldom allows his or her disability to interfere with career goals, e.g., the main characters in *Forrest Gump* (Finerman & Zemeckis, 1994) and *A Beautiful Mind* (Howard, Grazer, & Howard, 2001). Forrest Gump was unique in that he embodied several stereotypes at once. He was a civilian superstar because everything he did was successful, quite a feat for someone with an IQ of 72. He was also a sweet innocent and tragic victim. His character served as an effective hook to reel in the audience. The character, John Nash, in *A Beautiful Mind* was based on a real person by that name who is a Nobel Prize winning mathematician with schizophrenia. He was also a superstar because he was able to control his illness without medication. People watching the film might thus judge a person who needs medication more harshly.

Stereotype 2

The Comic Misadventurer: a person whose disability causes self-directed problems, other

directed problems, or both (e.g., *See No Evil, Hear No Evil* Worth & Hiller, 1987) and *Mr. Magoo* (Myron & Tong, 1997). These are particularly harmful because they have nondisabled actors playing characters who are blind or deaf, stumbling around for the audience's amusement. That is inaccurate and demeaning. Our society stopped dressing white actors in black face to play over thirty years ago. One could not imagine that being done today.

Stereotype 3

The Elderly Dupe: an aged character, mostly limited to silent-era films, who because of a disability, usually blindness, is easily fooled by younger able-bodied types, (e.g., Isaac in *The Bible* (Laurentiis & Huston, 1966), the boy who is blind that was sold a dead parakeet in *Dumb and Dumber* (Wessler & Farrelly, 1994)). Most people know the Isaac story from the Bible, even if they have not seen the movie version. Isaac was the son of Abraham, who is believed to be the father of three major religions, Judaism, Christianity, and Islam. Therefore, passing his birthright to his eldest son is very important. Isaac has twin boys, with Esau being the oldest. When Isaac was about to die, he was blind. Jacob, the younger twin, came to him disguised as his older brother Esau. The ruse worked and Jacob became the heir to his lineage. In *Dumb and Dumber*, the character played by Jim Carrey sold a dead parakeet to a boy who was blind. The scene serves to get laughs at the expense of real people who are blind.

Stereotype 4

The High-Tech Guru: a wheelchair-using male who proves unusually adept at manipulating computers, communication consoles, and related paraphernalia. For example, Sam Heselmann, who was a wheelchair-using character who was able to enhance a photo of the alleged spy in the Pentagon and was killed in *No Way Out* (Ziskin & Donaldson, 1987). Sometimes, the character is blind, as in the case of the movie *Sneakers* (Parkes & Robinson, 1992).

Stereotype 5

The Noble Warrior: a war veteran with a disability, who made numerous appearances in movies immediately after World War I, World War II, and Vietnam. For example, Ron Kovic in *Born on the Fourth of July* (Ho & Stone, 1989), Luke Martin in *Coming Home* (Hellman & Ashby, 1978). Both were returning veterans from active duty in Vietnam with spinal cord injuries. Both became antiwar activists after returning home.

Stereotype 6

The Obsessive Avenger: a character, most often a doomed male, who does not rest until he has had his revenge on the person(s) responsible for disabling him and/or violating his moral code in some other way. The classic example is Captain Ahab in the book and movies *Moby Dick* (Melville, 1851). This is a common character, often done as a stereotype in movies, books, and plays.

Stereotype 7

The Saintly Sage: another elderly character, especially prevalent in the movies of the 1930s and 1940s, who despite blindness, can “see” things sighted people cannot and who dispenses much wisdom to his or her younger colleagues who ignore it at their own peril. A good example is the blind seer in the movie *O’ Brother Where Art Thou?* (Coen & Coen, 2000). He is only in one short scene where he tells the main characters their fates. This exploits a myth about people who are blind having a “sixth sense” to replace their loss of sight. This is one more stereotype that people who are blind have to face that is reinforced by the media.

Stereotype 8

The Sweet Innocent: a child or young woman typically pure, godly, humble, asexual, and exceptionally pitiable, and who, often receives a “miracle cure.” In the movie, *An Affair to Remember* (Wald & McCarey, 1957), the female character is hit by a car and becomes a paraple-

gic. She hides and will not contact the man she was supposed to meet because she does not want to be a burden to him. To the average person, this asexualizes women wheelchair-users.

Stereotype 9

The Techno Marvel: a person whose prosthesis or other equipment, often a high-tech device, frequently performs better than the limb, vision, or hearing it replaced. Many movies and television shows have this character, Darth Vader in *Star Wars* (Kurtz & Lucas, 1977), officer Alex Murphy in *Robocop* (Schmidt & Verhoeven, 1987), Steve Austin in *The Six Million Dollar Man* (Irving, 1993), and Jaime Sommers in *The Bionic Woman* (Bennett, 1976) to name a few.

Stereotype 10

The Tragic Victim: frequently a poverty-stricken social outcast, who expires by the film's end, if not earlier. This is probably the oldest and most over used of them all going back to Tiny Tim in *A Christmas Carol* (Schmidt & Verhoeven, 1987) and reinforced over the years by telethons raising money for a cure (Norden, 1994).

Wolfensberger's Seven Deviant Roles

Wolfensberger, (as cited in Condeluci, 1991) as a sociologist, identified seven deviant roles that our society uses to marginalize people with disabilities.

Role 1

Menace: similar to above, but can include characters such as Lenny in *Of Mice and Men* (Steinbeck, 1937). He was not seeking revenge, but his character is even more harmful because he does not appear to be dangerous. In the 1980s when group homes were being established for people who were developmentally disabled, they were in residential neighborhoods, but some neighbors filed lawsuits. One reason for wanting to keep group homes out of neighborhoods was that, "Those people are dangerous. They will hurt our kids." Most people are

required to read *Of Mice and Men* (Steinbeck, 1937) in high school, so it is possible that the book reinforces this stereotype.

Role 2

Object of Pity: the same as the "tragic victim," above.

Role 3

Sickness: similar to the "sweet innocent." The sick role is placed on people with disabilities in our society, which keeps expectations for success low. Sick people are not expected to do anything except get well.

Role 4

Object of Charity: usually because people with disabilities are seen as "tragic victims." Objects of charity have no power. They must accept whatever is given to them and be thankful.

Role 5

Object of Ridicule: similar to the "comic misadventure," but comes in many varieties from sitcoms to reality television.

Role 6

Eternal Child: similar to the "elderly dupe," but not age specific. Adults with obvious disabilities are talked down to and sometimes, literally patted on the head. Good examples in movies are the Carla Tate character in *The Other Sister* (Rose & Marshall, 1999), who was developmentally disabled and trying to get out on her own and have a relationship.

Role 7

Holy Innocent: similar to the "sweet innocent" with a religious twist (Condeluci, 1991).

Even a quick perusal reveals easy applications in the classroom from these three scholars' research with different disciplines. That lends itself to great in-class discussions and essay test questions. It quickly becomes clear to the students that society stereotypes people with disabilities in these ways.

After exposing the students to the stereotypes, I require them to use a form that I created called a Media Analysis Form (Appendix 1). Using this form, forces students to recognize the stereotypes in media and to consider their effects on the audience, as well as real people with disabilities. The first job, and perhaps the most important one, is to help students “see” the stereotypes used in all forms of media. They have been socialized to think they are reality. Therefore, the stereotypes feel real to them and they do not “see” them. Students report that after using this form, they “see” the stereotypes long past the assignments for the class. That, of course, is the goal.

To start the students’ discussion using the form, I show a few carefully chosen full-length movies in class. This is the primary reason that I always schedule my class for a three-hour session once a week. Movies that I have used are *Forrest Gump* (Finerman & Zemeckis, 1994), *Scent of a Woman* (Brest & Brest, 1992), *Extreme Measures* (Hurley & Apted, 1996), *Freaks* (Browning & Browning, 1932), *The Elephant Man* (Sanger & Lynch, 1980), *Gattaca* (De Vito & Niccol, 1997), *Born on the Fourth of July* (Ho & Stone, 1989), *At First Sight* (Cowen & Winkler, 1999), and *Murder Ball* (Mandel & Rubin, 2005). Themes that I present are cure, suicide, and society’s treatment of people with disabilities. *Extreme Measures* and *At First Sight* are opposites concerning cure and *Murder Ball* address cure as well. I show *Gattaca* and *Murder Ball* every semester because they address the issues of cure and empowerment.

These assignments lead up to a group media project. The class is capped at 40 students and every section is always full. I arbitrarily divide them into four groups and assign each group a media type. They are: (a) literature, (b) news, (c) movies, and (d) TV entertainment. Each student is required to analyze at least two pieces of work in her category using the Media Analysis Form. The group must analyze two time periods, before 1980 and after 1980. The movie,

TV, and literature groups must analyze both children’s and adult material. The news group must analyze all forms of news, print and electronic. The groups then present their findings to the class. One of the goals and effects of that assignment is to show them how stereotypes appear in all forms of media. The long-term effect of the course is that students identify stereotypes in all types of media in the future.

There are other sources that one can use to teach about stereotypes as well. Smart (2001) has a good discussion of stereotypes in her book, *Disability, Society and the Individual*. Charlton (1998) discusses the causes of the attitudes that our society has toward people with disabilities in his book, *Nothing About Us Without Us*. Although I only use a small portion of Thomson’s (1997) book, *Extraordinary Bodies*, she goes into depth using classical literature to make her points.

Because media of all types are so invasive in our lives, and because it reflects, uses, and creates stereotypes that affect real people with disabilities in our society, it is an essential source for instruction.

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Appendix 1

Electronic and Print Medium
Media Analysis Form

!

!

Course Section _____

Name of work _____

Type of work _____

ID# _____ Date reviewed ____ / ____ / ____

1. Identify all characters that have disabilities and describe their disabilities.
2. If fiction, what purpose do the characters' disabilities serve? (For example, why did the writer make Forest Gump a slow learner?) If not fiction, for what purpose was the work made/written?
3. List and discuss all of the stereotypes that you identified in the work based on those discussed in The Cinema of Isolation and/or the deviant roles in Interdependence.
4. Does the portrayal of characters with disabilities and disability issues: 1) create stereotypes, 2) perpetuate stereotypes, or 3) confront or defy stereotypes? List the stereotypes and discuss your answer.
5. If the images of the characters with disabilities in this work were the ONLY ones the viewers/readers ever saw, would their perceptions of people with disabilities be more positive or negative? Discuss your answers.
6. If the images of the characters with disabilities in this work were the ONLY ones the viewers/readers ever saw, would their perceptions of people with disabilities be more positive or negative? Discuss your answer.
7. Are real people with disabilities in our society exploited by the portrayal of the characters with disabilities? Discuss your answer.

Disability Studies: Origins, Current Conflict, and Resolution

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FORUM

Abstract: In this article, we identify the roots of disability studies in interdisciplinary intellectual traditions as the basis for its current creativity, as well as its challenges in serving multiple academic masters. Looking to the future, we suggest rethinking and teaching disability through an integrative, interactive framework of juncture/disjuncture.

Key Words: disability theory, interdisciplinary, diversity theory

***Editor's Note: This article was anonymously peer reviewed.

Introduction

Over the past four decades, academic attention to disability has undergone significant change and thus, has provoked debate about how higher education should interrogate and teach about disability. Challenging embodied medical deficiency as the essential characteristic of disability, the relatively new interdisciplinary field of disability studies has synthesized interdisciplinary thinking from multiple academic and professional arenas, including humanities, arts, social science, and natural sciences to inform definition, analysis, and response to disability. Not unexpectedly, the emergence of disability studies has been a multi-edged sword, creating both advancements in intellectual treatment of disability along with disagreement, conflict, and fractious argument among diverse academic and professional disciplines. If disability studies is to enthrone and disambiguate progressive inquiry and responses to diverse bodies, we suggest that the field not only can, but also must serve multiple academic masters within current higher education environments and their diverse purposes. We therefore begin our discussion by clarifying

the context in which disability studies lives – the current climate, scope, and purposes of higher education. We then look to recent history to trace the intellectual and professional path of disability definitions and theory. Anchored on this brief historical foray, we then propose a conceptual integrative approach to disability that is relevant to the multiple purposes of higher education and serves the varied bodies and experiences that have permeated the categorical boundaries of disability.

Higher Education Clarified

Similar to other institutions, universities are not immune to their knowledge, geographic, economic, political, and social contexts. And thus, while the primary purposes of universities are ostensibly the generation and transmission of knowledge, the advanced capitalism of the 21st century along with the erosion of public support have been a major impetuses in reshaping universities as complex, market-based entities rather than fortresses of intellectual life (Allen, Bonous-Hammarth, & Teranishi, 2006). Responding to these economic trends for their survival and growth, universities have turned to academic capitalism, or the implementation of business practices to redefine core functions of education, research, and service as products to be marketed and sold. However while economically relevant, academic capitalism has been indicted by many as one of the major factors that has obfuscated the intellectual purposes of higher education and that has created significant challenges in its wake for established as well as fledgling fields (Slaughter & Rhoades, 2004).

We suggest that higher education can maintain its intellectual integrity and provide a sound academic, as well as professional, foundation for

Table 1: Multiple Stewards, Multiple Purposes

Stewards	Purposes
Professional Education	Professional training in medicine, special education, social work, rehabilitation, architecture, etc.
Workforce Development	Continuing education and training for providers
Social Sciences	Examination of social and political issues raised (e.g., Baby Jane Doe, human rights, physician assisted suicide, etc.)
Arts and Humanities	Disability as representational, as embodied, as fabricated, as narrative of the body, depicted in media, designed

disability studies within an advanced capitalist context. We agree with Sullivan and Rosin (2008), who have proposed a model of “practical reason” as a contemporary framework for higher education that meets these aims. Curiously, this academic model, while hailed as new, is reminiscent of progressive thinkers of the 20th century such as Dewey (1916) and Eisner (1985). In concert with these seminal philosophers, practical reason is bounded within a teleological framework, that of integrating intellectual development anchored in the liberal arts with informed career and civic preparation for students. This scaffold provides a buttress against which disability studies can be solidly anchored as a field that not only serves, but also unites both academic and professional purposes within an intellectual tradition. However, this ideal is not currently in operation in most universities and scholarly societies that are concerned with disability studies.

Disability: Multiple Theories and Stewards

Although disability has been the object of curiosity, observation, and formal study for centuries, the academic field of disability studies is nascent, having been born and named approximately two decades ago (Davis, 1997; DePoy & Gilson, 2004). Countering research

and teaching about disability as a medical deficit in need of repair or rehabilitation, disability studies scholars and activists in the late 1980s and early 1990s explained disability as a social phenomenon, in which the concept of normal was constructed, and those whose embodied appearance or experience did not fit within it, were subject to cultural discrimination and exclusion (Davis, 1997; DePoy & Gilson, 2004). The introduction of the social model of disability was an important impetus in conceptually moving disability away from medical deviance and hegemony into the discourse of human construction, diversity, and discrimination. However, an unintended consequence of this theoretical shift was the creation of opposing explanations and academic stewards that cleaved the study of disability into academic and professional camps as depicted in Table 1.

Scholars in social sciences, arts, and humanities eschewed medical-biological perspectives from the new field, asserting that these approaches were not only outdated, but diminutive and exploitive of the large number of people who meet the eligibility criteria for disability. Still, many faculty and researchers in professional and health care fields, because they were concerned with disability, adopted the term “disability studies” as descriptive of their purview, despite their frequently articulated perception

of nonacceptance in disability studies scholarly and activist organizations.

Along these same lines, while not the only groups to address disability studies, two major organizations in the U.S., each with different purposes and conceptual foundations emerged, the Society for Disability Studies (SDS) and the Association of University Centers on Disability (AUCD). As a leader in disability studies scholarship situated in liberal arts, SDS advanced the guidelines in Table 2 in an effort to codify the essential elements of disability studies, omitting natural and medical sciences as definitive with the exception of interrogating the link between medical views and stigma. The Association of University Centers on Disability (AUCD), on the other hand focused its activity on supporting a network of extramurally funded centers in universities devoted to research, training disability policy and professional practitioners, and linking universities to communities through informed service.

More recently, in response to the chasm that even today continues to polarize disability scholars, several theorists have advanced integrative and axiological frameworks through which to understand disability as a complex set of

Table 2 Guidelines for Disability Studies Programs posited by the Society for Disability Studies (2004)

- Content: A “humanities, sciences, and social sciences” field
- Purpose: Should interrogate the connections between medical practice and stigmatizing disability
- Who leads: Leadership positions held by disabled people
- Who teaches: Academic faculty

value-based and purposive explanations that are posited for the atypical and which can inhabit the same explanatory space as friends or foes (DePoy & Gilson, 2004, 2008; Gilson & DePoy, 2008; Slingerland, 2008). This thinking fits well within the current academic climate and is consistent with the model of practical reason advanced by Sullivan and Rosin (2008).

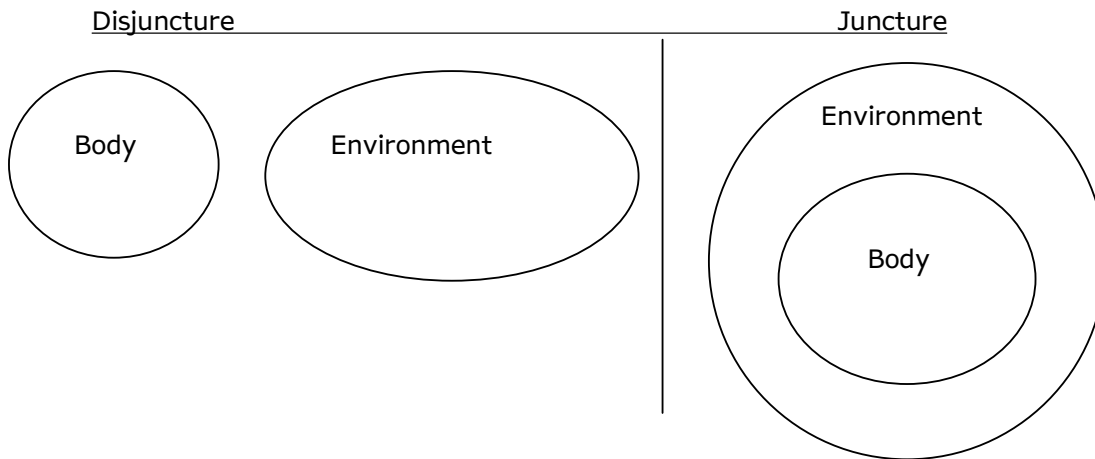
Integrative theories focus on challenging the dualism that separates the physical world from the world of ideas. While not directly addressing disability studies, Slingerland (2008) is a vocal critic of postmodernism and its conceptual distance, as well as distinction from natural science. Through his analysis of how cognitive science can inform culture and cultural studies, typically thought of as the domain of humanities and social sciences, Slingerland illuminates how sciences and humanities have much to contribute to one another. Similarly, fields such as literary Darwinism (Carroll, 2004) link humanities and sciences in a potent explanatory dialog.

Axiological frameworks, and here we focus on Explanatory Legitimacy, which explains diversity group membership and response as a function of how varied reasons for human phenomena are ascribed and judged (DePoy & Gilson, 2004), provide a discourse platform on which many explanations can be laid and then examined for their legitimacy. Making room for pluralism of purpose and thus explanation, eliminates the debate about which theory is correct, and through abductive logic, opens thinking and dialog for cooperation rather than competition among schools of thought (DePoy & Gilson, 2007).

As examples, expressive fields such as literary criticism have different aims than health professional fields in in-

terrogating disability, each guiding the valuation and selection of different explanatory theories of disability within their teleological boundaries. However, while purpose differentiates direction, its beauty lies in its acknowledgement of the truth-value of alternative explanations that although not primary in attaining specified aims, can inform and enrich analysis of disability.

Figure 1 Disjuncture/Juncture



Evidence of the positive influence that integrative and axiological theories have had on the relaxation of rigid lines within the stewardship of disability studies are the recent links to SDS added to the AUCD website and the increasing reference to disability through the aperture of arts and humanities in professional academic programs. These integrative trends not only create the opportunity for dialog and sharing of current thinking, but also are fertile for the generation of new seamless theory. Within the framework of explanatory legitimacy, we now discuss disjuncture theory (DePoy & Gilson, 2008) as explanatory of disability and demonstrate its potential to unite disparate thinking, academic stewards, learning aims and outcomes, and social action.

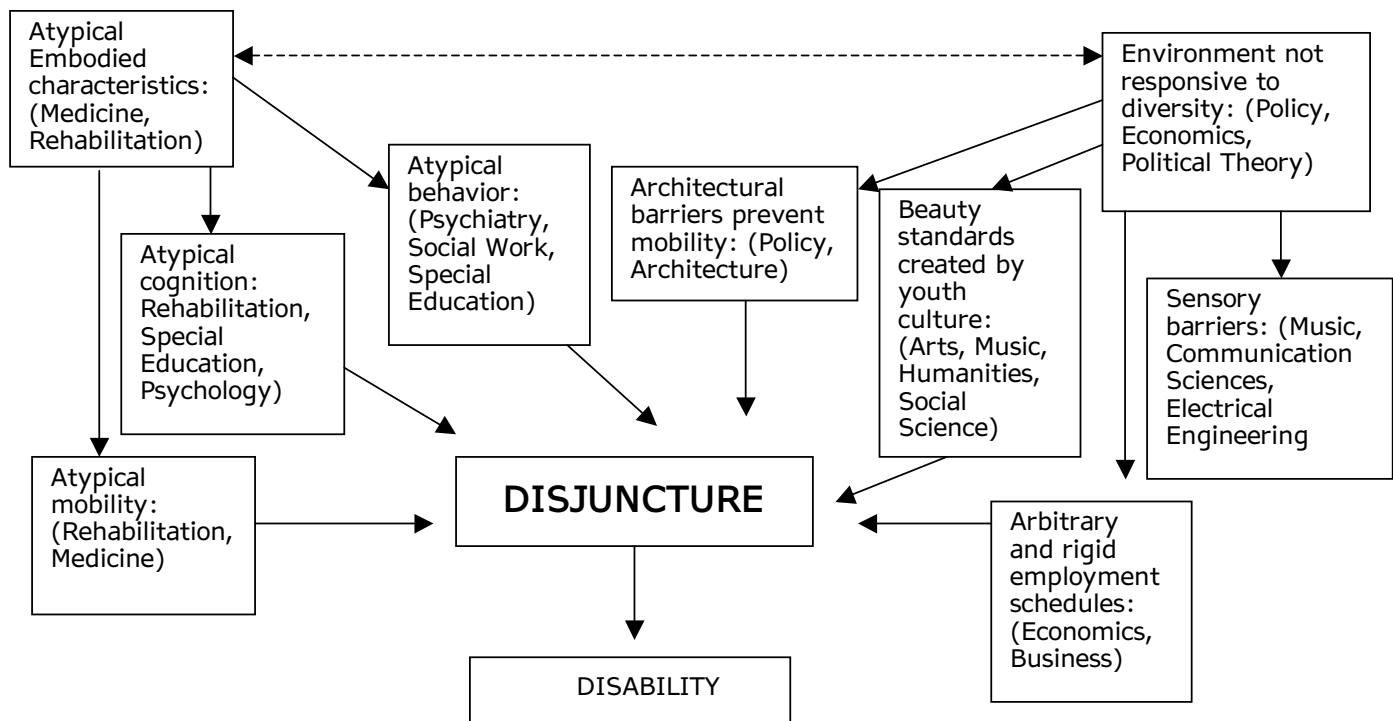
Disjuncture Theory

Figure 1 depicts disjuncture theory and its opposite, juncture. The word “disjuncture” is defined as a disconnected relationship between at least two entities. Conversely, juncture refers to a relationship of connection and goodness-of-fit. Applied to disability, disjuncture theory traverses disciplinary boundaries and indicts the ill-fit of humans and multiple environments as explanatory of disability. Thus, unlike the binary debate about the correctness of disability as either embodied or environmental, disjunc-

ture holds neither element as solely responsible but rather highlights the relationship between the two as the explanatory locus. This relational gaze not only halts the ongoing argument about the true nature of disability, but furthers the pluralistic opportunity for dialog and cooperative thinking and action among diverse fields. Considering disability as a function of both bodies and of environments therefore can bring multiple fields of knowledge to bear on healing disjuncture without dismissing the contribution of either the body or the environment to the explanatory repertoire. In addition, the term disjuncture does not demean the atypical body but rather looks to a less than satisfactory relationship between individuals and one or more types of environments as the target of change.

Figure 2 provides a graphic representation, using the problem mapping model (DePoy & Gilson, 2007) to depict the contribution and relationships of diverse academic and professional fields to disjuncture. The problem mapping process is a thinking method to expand a problem beyond its original conceptualization. One posits an initial statement (in this example disjuncture) and then maps upstream to theorize causes, and downstream to identify consequences. The value of this conceptual map is its movement beyond first impression to the creation of an integrated systemic approach to

Figure 2 Disjuncture



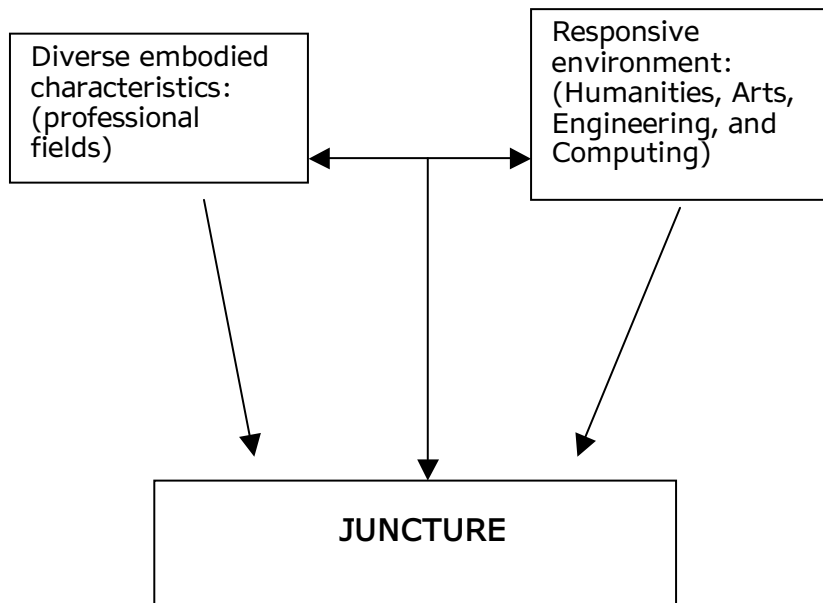
understanding problems as multidimensional, non-linear, and complex. Let us look in more detail at each element now.

The two text boxes on the top of Figure 2 represent the two prevailing and often conflicting causal models of disability, embodied and environmentally constructed. Note that they are connected with a broken arrow to depict their limited interaction. The term embodied broadly refers to the organic and experiential human corpus. Included are the sensory body, the cognitive body, the socialemotional body, the spiritual body, the economic body, the productive body, the body of ideas and meanings, and the body in multiple garb and spaces (Gilson & De-Poy, 2007). Within explanatory legitimacy, the atypical body catches attention, and depending on the explanation for what is atypical, may or may not be classified as disabled. Bodies that do not conform to prescriptive averages, are challenged to participate in environments in which they do not fit (See Figure 1). And as depicted in Figure 2, embodied elements of disability become, in large part, the province of professional attention, assessment and, if possible, repair. Within professional education in fields such

as medicine, health, special education, and so forth, studying and learning to heal disjuncture means remediating embodied deficits or making accommodations to permanently impaired bodies so that they can function in unchanged environments.

Environment refers to sets of conditions external to bodies, including but not limited to, physical, sensory, social, virtual, expressive, economic, policy, cultural, national, linguistic, global elements, and so forth. Figure 2, links these to the examination of environmental incapacity to meet diverse bodies. Because current built, virtual and abstract environments explicitly or implicitly conform to standards based on theoretical averages, a full range of diverse bodies, and particularly those that lie beyond typical appearance, behavior and experience often are met with discomfort at best in numerous environments. Even within the diversity rhetoric of the 21st century, it is curious to note that architectural, social, virtual, professional, policy and functional design standards operationalize theoretical, male-centric averages (Imre & Hall, 2001). As examples, our recent inquiry into the rationale for and derivation of architectural

Figure 3 Juncture



standards for door sizes, counter heights and the like, revealed the continued hegemony of Da-Vinci’s Vitruvian man as both the foundational ideal and basis for estimating average adult body sizes. This elongated misogynist adult image is the design bedrock for mass-produced and standardized building and product design practices (Gilson & DePoy, 2007). Similarly, assumptions about typical bodies, such as the ability to use both hands for manipulation, to think typically, to behave in an expected manner, to walk with a typical gait, to hear, to see, etc., provide the prevailing data on which design of varied environments is anchored. As depicted in Figure 2, environmental conditions and change are primarily the purview of liberal arts academic fields (e.g., sociology, music, art, communication theory, new media, among others) that

may consider bodies, but do not direct full attention to improving their functionality.

By accepting the explanation for disability as relational, that is to say, an ill-fit between embodied phenomena and the environments in which bodies act, the opportunities for multiple fields, in collaboration with one another, to posit the complexity of disability and thus, enlarge the range of legitimate responses becomes boundless. Figure 3 represents this theoretical state of juncture. Disjuncture theory creates a conceptual forum for creative and progressive

thinking, and action that expand analysis of disability beyond atypical embodied phenomena to the creation of juncture through the reciprocal relationship of diverse bodies and environments. Moreover, within this theoretical perimeter, juncture refers to equality, human rights, and justice that can be advanced through multiple response avenues.

Thus, in addition to transcending the binary medical-social model debate that is focused on impaired bodies and their treatment in environmental milieus, disjuncture theory guides purposive, legitimate human rights responses that have the potential to engage the interests, values, knowledge, and expertise of multiple fields in healing disjuncture for all populations. Disability, while possibly

Table 3 Juncture Collaborators

Political theory	Economics
Geography	Engineering
Medicine	Sociology
Business	Education
Law	Art
Technology	Literature
Disability studies	Folklore
Computer science	Architecture
Philosophy	Music
Communications	
Health, Education and Human Service Professions	

Table 4 Principles for Implementation

- Rethink disability studies as the fit of bodies and environments
- Promote informed action
- Marry disciplines in a purposive framework
- Broaden the disability studies discourse beyond bodies to purposive and informed thinking and action to advance equality of access and rights
- Locate thinking and action within the mission of universities- to educate students in scholarship and informed action.

being related to atypical bodies, may also indicate a broader state of ill-fit, locating disability squarely within theory, examination, teaching, learning, and social action aimed at social justice, rather than restricting it to remediation of an embodied condition through bodily treatment or environmental revision. Table 3 lists just some of the diverse fields that can collaborate in the academy to examine disjuncture as the basis for decreasing and forging directions to eliminating it.

In concert with contemporary rethinking of the academy and its purposes framed by the model of practical reason (Korner, 2001), the principles listed in Table 4 guide interdisciplinary inquiry and pedagogy, transcending the stale binary body-environment debate and positioning disability studies within a larger, collaborative, human rights academic agenda.

Resolution

To conclude, we discuss an example of the implementation of disjuncture theory. Over the past two years, we have engaged students in an ongoing project to promote equality of access to web-based health information. This project, framing and organizing several of our interdisciplinary disability studies courses, involves the design, development, testing, and dissemination of a website that translates existing health information into alternative literacy and accessible formats, regardless of the features on the original website. Currently, the project, is funded by the American Legacy Foundation ([www.](http://www.americanlegacy.org)

[americanlegacy.org](http://www.americanlegacy.org)), as it uses the web-portal to translate electronic smoking cessation information. Students and faculty from the fields of design, health and human service professions, education, art, computer science, English, and marketing are collaborating in diverse roles on this work.

Applying disjuncture theory to the project, barriers to information access are analyzed through problem mapping (DePoy & Gilson, 2007). These violations of human rights to information, and in this case health information, are serious, complex and cannot be resolved by monistic approaches, such as legislation or policy promulgation that are currently in place, but ineffectual in their stated aims. While the explicit access barriers are located at the intersection of bodies and the virtual, textual environment, problem map analysis of the disjuncture, as depicted in Figure 4, reveals the unpacked complexity of the initial problem statement. Figure 5, illustrates how disjuncture was approached and addressed in interdisciplinary study and response.

Note that in Figure 5, cognitive impairment and immigrant status are not changed but attention to these embodied phenomena as well as to the environment is a function of the intersection and collaboration of multiple fields. Moreover, consistent with the practical reason model, education using a disjuncture framework aided by problem mapping has multiple purposes and stewards.

Figure 4 Disjuncture Analysis

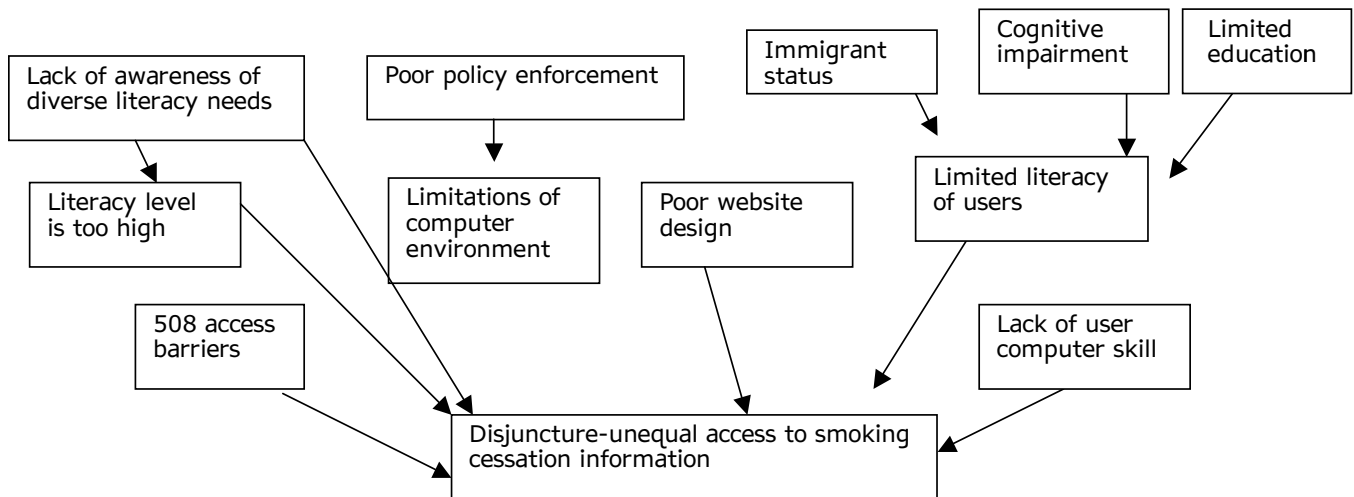
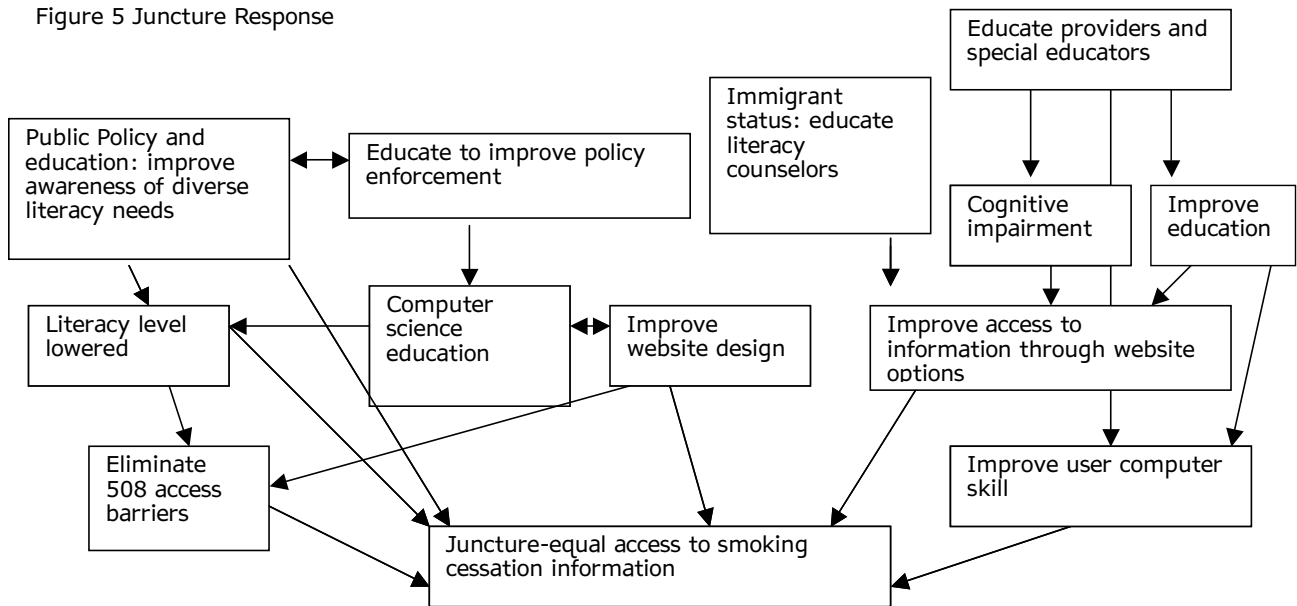


Figure 5 Juncture Response



As the 21st century proceeds, we envision the future of higher education as a context in which thinking and action transcend the rigid disciplinary boundaries that produce unfruitful debates about which theory is the truth. Within a purposive context, disability can be reconceptualized and met with socially just responses that require not a village of like-minded people, but an informed universe of varied perspectives and responses.

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Why People with MS are *Really* Leaving Work: From a Clayton's Choice to an Ugly Passage – A Phenomenological Study

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Research Article

Abstract: Where some studies have suggested that people with Multiple Sclerosis (MS) may leave a workplace as a result of disease progression, this qualitative study, situated in Australia, found that people with MS might really be leaving work as a result of ugly organizational processes. The influence of discrimination and a hostile work environment on the careers of people with MS seem to have been under-emphasized in previous studies. Two themes are reported that support this contention: that the decision to leave a workplace is effectively a “Clayton's Choice”-- the choice you have when you don't really have a choice -- and “An Ugly Passage.”

Key Words: Multiple Sclerosis; employment; discrimination

***Editor's Note: This article was anonymously peer reviewed.

Introduction

Multiple Sclerosis (MS) is one of the most prevalent neurological disorders in the world (Rumrill et al, 1998; Rumrill et al, 2000). In 2001, it was estimated that there were 2.5 million people in the world that have MS. It is also one of the most common chronic illnesses in the Western Hemisphere, affecting as many as 500,000 in the United States alone (Rumrill et al, 1998). In Australia, the National Health Survey of 2001 indicated that there were approximately 15,000 Australians with MS (MS Australia, 2003).

This paper is the first in a series of articles talking about “what is really going on” in the lives of people with MS. I am trying to shine a

light on the real story about the life and work of people with MS. As a person with MS myself, I have become increasingly frustrated with and concerned about the literature that is currently available about and for people with MS. It is my contention that the right questions are not being asked and, correspondingly, not being answered.

This paper focuses attention on why individuals with MS might really be leaving their place of work. At first glance, this might seem obvious: MS is a progressive disease; people with MS must leave work because the ravages of the disease force them too. However, I claim that this is not always the case and offer a different perspective.

Literature Review

MS: The Disease

Before understanding the social experiences of people living with MS, it is necessary to understand the physiological dimensions of this experience. MS is an often unpredictable, progressive, degenerative disease of the Central Nervous System (CNS) (Kraft, Freal, & Coryell, 1986; Rumrill, Tabor, Hennessey, & Minton, 1998), which is characterized by damage to the myelin sheath that insulates white matter tracts within the brain and along the spinal cord (Rumrill et al 2000: 109). Kraft (1981, cited in Rumrill, Tabor, Hennessey, & Minton, 2000, p. 109) compared the demyelination process in people with MS as the breakdown of rubberized coating that surrounds electrical wires, and that these breaks in the coating interfere with the transmission of electrical impulses. In people with MS, the slowed or impeded neurological impulses result

in uncoordinated or awkward physical responses to their environment (Kraft, 1981).

There are now reported five different disease course “types” of MS: benign; relapsing/remitting; primary progressive; secondary progressive; and progressive relapsing (Australian Multiple Sclerosis Longitudinal Study, 2003 p. 55). For the majority of people with MS – around 70 per cent – the course of the disease is characterized by seemingly random cycles of exacerbations (relapses) and remissions (Rumrill, Roessler, & Cook, 1998, p. 242). Not only is the person with MS unable to predict when (or for how long) an exacerbation will occur, they cannot anticipate with any certainty which symptoms to expect. The uncertainty caused by this cyclic ebb and flow of symptoms, rather than the symptoms themselves, has been argued to be a disruptive influence on virtually every life role (Rumrill, Roessler, & Cook, 1998).

The most common physiological symptom is fatigue (Kraft, Freal, & Coryell, 1986; Rumrill, Roessler, & Cook, 1998; Gregory, Disler, & Firth, 1993; Koch, Rumrill, Roessler, & Fitzgerald, 2001), followed by (in descending order) balance and coordination problems, diminished strength and stamina, motor dysfunction, bowel or bladder dysfunction, visual impairment, depression or anxiety, pain, cognitive difficulties, sexual dysfunction and speech impairment (Koch, Rumrill, Roessler, & Fitzgerald, 2001, p. 157; Rumrill, Roessler, & Cook, 1998). MS can cause problems in virtually every area of physical functioning.

Unseen symptoms, such as those just described, can create great confusion in the workplace, with those around the person with MS often not able to see that anything is wrong, making MS a disease that is almost always confusing and frustrating for everyone exposed to it, including employers (Vickers, 2001). Further, in 90% of cases, onset of the disease occurs between the ages of 15 and 50 years, striking the person during their peak years of education,

career development and family life (LaRocca, Kalb, Kendall, & Scheinberg, 1982; Jongbloed, 1998; Rumrill, Tabor, Hennessey, & Minton, 2000). These usually productive years can be disappointing for people with MS; specifically, career development slows and, in many cases, comes to a halt after diagnosis (Rumrill, Tabor, Hennessey, & Minton, 2000, p. 110).

MS and Employment

Disturbingly, the retention of employment for people with MS is even lower than figures for others with disabilities in general, and lower than would be expected even given the presence of a severe physical disability (Roessler & Rumrill, 1994). More than 90% of people with MS have employment histories, with most (60%) still working at the time of diagnosis (LaRocca & Hall, 1990; Roessler & Rumrill, 1994; LaRocca 1995; Rumrill, Tabor, Hennessey, & Minton, 2000, p. 210; LaRocca, 1995). Women are significantly less likely to be employed than are men. In the US, as many as 80 % of women with MS were unemployed compared to 66% of men (LaRocca, Kalb, Scheinberg, & Kendall, 1985; Rumrill, Tabor, Hennessey, & Minton, 2000). In Canada, the figures are similar: 70% of women and 58% of men with MS were reported to be unemployed (Edgley, Sullivan, & Dehoux, 1991; Rumrill, Tabor, Hennessey, Minton, 2000, p. 111). However, some studies have indicated that as few as 25 or 30% of people with MS are able to retain employment as their illness progresses (Jackson & Quaal, 1991; Roessler & Rumrill, 1994; Jongbloed, 1998: 194; Rumrill, Tabor, Hennessey, & Minton, 2000).

To date, most of the initiatives in response to this concerning phenomenon have placed emphasis on job retention (Sumner, 1995; Rumrill, Roessler, & Cook, 1998), that is, keeping people working who are currently working. However, this approach ignores the majority of people with MS who have successful work records but who are now unemployed, who may have left the workforce voluntarily, and who diminish their

chances of regaining employment with every passing day (Rumrill, 1996; Rumrill, Roessler, & Cook, 1998). Once a person disengages from work, several threats to their continuing career success become evident. First, there may be potential disincentives from social security support payments. Second, they may assume the “sick role” which does not encourage a return to independence or work. And third, they may socially detach from former co-workers (Rumrill, 1996; Rumrill, Roessler, & Cook, 1998). What is clear is that those individuals with MS who leave the work force are unlikely to return (Rumrill, Tabor, Hennessey, & Minton, 2000).

People with MS Leaving Work

We know that illness-related predictors of unemployment exist in many people with MS. These have been claimed to include severe physical disability, the presence of visual impairments, ambulatory problems, cognitive dysfunction and a steadily progressive disease process (Rumrill, Roessler, & Cook, 1998). A mixture of impairment and disability, as well as disease course, are predictive of not working (Ford, Gerry, Johnson, & Tennant, 2001, p. 520). Some have claimed that physical limitations and the physical inability to perform job tasks are the most commonly cited reason why people with MS are leaving the workforce (LaRocca, Kalb, Scheinberg, & Kendall, 1985; Rumrill, Tabor, Hennessey, & Minton 2000; Duggan, Fagan, & Yateman's, 1993). Ford and colleagues also assumed that people with MS are not working because of disease progression. For instance, they claimed that having a swallowing impairment – an indicator of disease progression -- increased the odds of not working by 8.7 times (Ford, Gerry, Johnson, & Tennant, 2001).

Along this vein, much of the Occupational Therapy (OT) literature concerns itself with promoting, maintaining or restoring occupational performance – retaining employment based on physical capacities (Jongbloed, 1998). Occupational difficulties tend to be considered from the perspective of individual's abilities and limita-

tions, and on any physical or other barriers on their immediate environment (Jongbloed, 1998). For example, it has been suggested the people with MS could improve their work performance with appropriate workplace enhancements such as job adjustments, environmental and assistive technology, social support and healthful self care practices (Gulick, 1992; Rumrill, Tabor, Hennessey, & Minton, 2000).

However, others have claimed that most of the variation in employment status seems to be due *not* to the severity of the disease or to educational, sex, or other demographic differences but, instead, to factors such as premorbid personality, coping style, characteristics of the workplace, and social support systems (LaRocca, Kalb, Kendall, & Scheinberg 1982, p. 256). Still others have argued that the capricious disease course – the cyclic ebb and flow of symptoms and disability – are what constitutes the most prominent impediment to adjustment following diagnosis and, thus, the biggest hurdle to continuing employment (Rumrill, Roessler, & Cook 1998).

Roessler and Rumrill (1994, p. 1) confirm that the severe and pervasive impact of multiple sclerosis is *just one* reason for the low rate of post-diagnosis employment. Other authors have pointed the fact that the levels of disability *do not equate directly* or comfortably with the levels of unemployment in people with MS, especially when compared, say, to people with other disabilities in the community (See, for example, Roessler & Rumrill, 1994; LaRocca & Hall, 1990). Physical disability has been confirmed as not being the only, or even the primary, cause of unemployment in people with MS (LaRocca, Kalb, Kendall, & Scheinberg 1982). People with MS often leave work for non MS-related reasons (Rumrill, Tabor, Hennessey, & Minton, 2000, p. 113).

So, while there has been some recognition that people with MS may be leaving work for a variety of reasons that may or may not be direct-

ly associated with the disease process and associated disability, what appears to have been largely ignored in the literature is the role of organizations and their processes, including the behavior of employers and managers, including the institutional, political, social or cultural aspects of organizational life. There have been a couple of exceptions: Ketelaer (1993) conducted a study in Belgium and found that employer attitudes and interactions with co-workers influenced employees' willingness to request MS-related accommodations at work. Sumner (1995) identified open communication and the willingness for the employer and employee to understand one another's concerns as key ingredients to successful job retention for people with MS (Sumner 1995; Rumrill, Tabot, Hennessey, & Minton, 2000).

However, there have been no studies that highlight the often brutal aspects of organizational life that may be significant contributors to people with MS leaving work. Prior work by this author in the broad area of living with invisible chronic illnesses has emphasized some of these themes, but specific studies on the working lives of people with MS have not previously been conducted (Vickers, 2001). I posit that, for some people with MS, giving up work is less about physical disability and more about the ugly side of organizational life. I argue that negative social and organizational phenomena, such as stereotyping, discrimination, and overzealous managerialism may be driving people with MS from their places of employment, either unnecessarily or prematurely.

Methodology

To date, no exploratory, purely qualitative studies of the experiences of people with MS, who have left the full time workforce, have been conducted. There have been studies conducted about people with MS and associated employment issues (Roessler & Rumrill, 1994; Salomone & O'Connell, 1998; Roessler, Fitzgerald, Rumrill, & Koch 2001; Koch, Rumrill, Roessler,

& Fitzgerald, 2001; Dyck & Jongbloed, 2000; Bishop, Tschopp, & Mulvihill, 2000; Edgley, Sullivan, & Dehoux, 1991; Gregory, Disler, & Firth, 1993; Gregory, Disler, & Firth, 1996; Hakim et al., 2000; Jongbloed, 1998; Rao, Leo, Ellington, Nauertz, Bernardin, & Unverzagt, 1991; LaRocca, Kalb, Kendall, & Scheinberg 1982; Roessler & Rumrill, 1995; Rumrill, Roessler, & Cook, 1998; Rumrill, Tabor, Hennessey, & Minton, 2000). However, none of these studies have been situated in Australia, none have been purely qualitative, and none have addressed the reasons why people with MS have left their place of work. Most studies simply assume that it is the disease process or some other physical, psychological or environmental impediment that is the problem – an assumption that I claim is not always accurate.

Heideggerian Phenomenology

I used Heideggerian phenomenology as the methodological vehicle for this study. The goal of Heideggerian phenomenology is to understand everyday practices (Benner, 1985, p. 5). The hermeneutic method outlined in Heidegger's *Being and Time* (1927/1962) proposed a method for the study of sacred texts and, indeed, a means of studying all human activities. It was developed in opposition to Husserl's transcendental phenomenology (Dreyfus, 1991), which requires the researcher to bracket their beliefs and experiences about the phenomenon under review.

Rather than bracketing my experiences, Heideggerian phenomenology accepted, even encouraged, my personal knowledge and experience of living and working with MS. According to Heidegger, the researcher's influence in phenomenological research cannot be underestimated. Indeed, it will determine what phenomena, facts and relations will enter their consciousness (Moss & Keen, 1981, p. 108). The researcher's sensitivity, orientation and perceptiveness will shape the interpretation (Osborne, 1990 p. 85). Heideggerian phenomenology allowed me to operate from an "inside" perspective, which was disclosed to respondents in all relevant docu-

mentation. I was aware that my inside status definitely brought with it a special privilege. I would have access, I believed, to special “inside” information:

“While it isn’t always true that the “inside” perspective on a person’s ... actions is necessarily more charitable, it does operate on different information than does the outside view. The inside information may be more negative than the outside perspective – but whatever the case, it will surely be different. The locus of your information, whether from the inside or outside, is the first central difference in how you attribute meaning to your own behavior compared to how you attribute it to the behavior of others” (Wilmot, 1975, p. 59).

At the time of the interviews, I had had MS for over twenty years, and had experienced varying levels of disability over that time. This brought a perspective and direction to the interviews that would have been lacking from one who had not lived and worked while having this disease. I knew what respondents were talking about for the most part having experienced it, feared it, lived it or, at the very least, read about what they were telling me and considered it as a possibility for my future. I was also able to ask questions that an outsider might shy away from and could encourage frank admissions by pointing to my own circumstances, if necessary. Others have noted that outsiders have difficulty gaining closely held information (Field & Morse, 1985, pp. 118-119). I did not seem to have that problem.

Participants

This qualitative study was not intended to be either representative or generalizable. It was intended to explore a phenomenon that is not well understood – why people with MS are really leaving work. Contact was made with potential respondents through the MS Society of New South Wales. I was invited to contact members

of support groups, which included attending meetings to explain the study and recruit potential respondents. I also placed an advertisement in my own neurologist’s office, advertising the study and inviting potential respondents to contact me directly.

I interviewed 20 respondents, with a total of 21 interviews being conducted as one respondent was interviewed twice. Interviews ranged from 1.5 hours to 3 hours in duration and were guided by focus areas that shifted as the interviews progressed. Sixteen women and four men participated in the interviews, a reasonable representation of the sex breakdown of the MS population worldwide, which is around 2:1. Ages of respondents ranged from 28 to 65 years, with a mean age of 47 years. In all, there were over 43 hours of interview data, including 35 tapes that were transcribed verbatim.¹ This resulted in 1,222 pages and 335,258 words of transcribed text available for thematic analysis. The study was approved by the University of Western Sydney Human Ethics Review Committee as well as having ethics approval from the Multiple Sclerosis Society of New South Wales. Pseudonyms have been used for all respondents, people and organizations mentioned during the interviews.

Finally, because quite a passage of time had elapsed since conducting the interviews and writing about them, I listened to all tapes again and corrected all of the final transcripts. This was a monumental additional task, but well worthwhile as it enabled me to recreate the details of the interviews in my mind, as if I had conducted them just yesterday.

Results

Why People with MS are *Really* Leaving Work

During this extensive series of interviews, no-one spoke of physical access issues at work hastening their departure, and no-one indicated that they had been unduly depressed or unable to function at work for psychological reasons, ei-

ther. However, many respondents did state that fundamental support for their disability was not present in their workplaces – even if the policies requiring such support were. Worse, several respondents reported being actively pushed out of their place of work against their will and before such time as their disability precluded their ability to do their job. Below I have reported two themes that emerged from the analysis: “A Clayton’s Choice” and “An Ugly Passage.”

A Clayton’s Choice

I have written elsewhere about the phenomenon of *Clayton’s Support*, which is the “support you get when you are not getting support” (Vickers, 2006b, p. 129). This concept borrows from the advertising campaign for a non-alcoholic beverage called Clayton’s, where consumers were encouraged to indulge in the drink they could have when not having an alcoholic drink. Here, I use the concept of Clayton’s once again, but this time in association with choice. I define a *Clayton’s Choice* as, “the choice you have when you don’t really have a choice.”

During the interviews, I heard many of the respondents describe to me just these kinds of choices. Some described having “chosen” to leave their place of work because the situation had become intolerable; that they were being forced out. Others had “chosen” to stay and were tolerating major difficulties and injustices at work because they felt they would be unlikely to get work elsewhere. They perceived widespread employer discrimination against people with disabilities in general and people with MS in particular.

One way in which the choice to leave an organization is really a Clayton’s Choice is when pressure is brought to bear on the person with MS to leave, by alienating them or downgrading their duties, by increasing what is expected of them, or by not being prepared to support that person’s physical needs in doing their job. Penny spoke of returning to work after she had been [incorrectly] diagnosed with a stroke after what

had actually been her first MS exacerbation. After a short period of convalescence, her doctor had said that she could return to her job as a Senior Library Manager at an Australian university. Unfortunately, upon her return, Penny was not allowed to return to her previous duties or to see her staff. She was intercepted on the morning of her arrival:

Penny: I had some problems at work ... Well, what happened when I got back to work [after the supposed stroke], because the neurologist said, “You can go back to work.” It was Friday, and he said, “You can go back to work on Monday.” So I rang up my employer, the person I was responsible to, and said, “I’m coming back to work on Monday.” And I turned up at work, and she actually *raced*, she must have seen me coming in and she raced downstairs to catch me in the toilet before I put my stuff away and went to my department. And I was not actually permitted [to go to her job]. She said, “Come back up with me.” ... She took me upstairs and talked to me, and they put me in a room by myself. [Penny is becoming very upset; weeping.]

MV: ... So, she put you in a room on your own?

Penny: Yes. I was given different duties. I was given a “special” job. But I was *devastated* [Starts weeping again].

MV: Yes, I’m sure. So you were the manager of this department at that time?

Penny: Yes, and very close to my staff. [Crying more loudly]. I was just looking forward to seeing them all. [Weeping again] ...

MV: And then she’s herded you into a room on your own, is that correct?

Penny: Yes, yes, yes. And I was given a job; it was to do with the procedures for the library, for the University Library. And I was responsible to the personnel-type manager to get this job done. So, they had a procedure manual that was very out-of-date, and they wanted someone to update it ...

MV: And you wouldn't have been in contact with anybody if you were stuck in the corner updating a policy manual?

Penny: No, it was pretty awful actually.

Penny was isolated from her colleagues, her work responsibilities were inappropriately downgraded from senior library manager to policy document editor, and these job responsibilities and location changes were made without appropriate discussion or consultation. Things didn't get much better. After finishing her "special project," Penny found herself a job in another section of the Library where some of the staff also became resentful. One woman actually complained about one of Penny's physical accommodations:

Penny: And things like, I needed a footstool under my desk, and she made a fuss about that.

Penny also needed to take a rest break during the day and would lie down in her lunch hour. She also needed to use the bathroom more frequently than most people. This meant that she had to ask for extra relief from certain demanding tasks, such as being rostered on to the information desk. This also apparently fuelled resentment against her, even though she was able to perform her duties:

Penny: ... I'd ask for rostering for the lunch break to allow me to have an hour for my lunch break. It would have to be rostered; I couldn't do more

than a certain time. Or even, say I'd come back from a tea break, and I'd be on the information desk, which is really pressured, but I'd need to go and urinate not long afterwards and that meant I would have to ask someone to come out. And you could tell by the expression that they didn't like it too much.

Unsurprisingly, over time, Penny became increasingly distressed at her workplace. When she visited her neurologist, he immediately recommended that she retire from work. What would be recorded about Penny's departure from her workplace would have been Penny's "choice" to take medical retirement, a choice supported by her doctor. I would argue this was a Clayton's Choice.

Mary, who, coincidentally, also worked in a University Library elsewhere, described her very severe onset of MS, where she was severely incapacitated for some time, and continued to have cognitive and speech problems subsequently. She initially returned to her job on a part time basis, working six hours a week, before increasing this to nine hours per week when she was able. Then she had another attack, and another, in quick succession, which landed her in hospital again for six weeks. At the same time, the management in the library where she worked changed:

Mary: It was fine until this [MS attack] happened again, suddenly. It's always sudden. And then the people, this was the management, they didn't think about me so much [laughing], because they are thinking about their dollars and cents [laughing]. And this new boss, she wanted to me to be retired ...

MV: When you came back after that, they wanted to you to go?

Mary: Well, they were very nice. They smiled a lot [both laughing]

and they didn't want me to go back to work. They came to me, to my place.

MV: Oh, they just didn't want you to come back at all?

Mary: No, that's exactly right ... They didn't want me because they had two people who had died recently with cancer and AIDS, so they didn't want that.

Of interest, Mary never actually returned to work after that episode. Her employers came and saw her at her home to discuss her future, even though Mary believed that she would have been able to return to work on reduced duties. According to Mary, the management where she worked *wanted* her to retire – it was hardly her choice. However, the official outcome would, once again, show the medical retirement of a person with MS -- another unfortunate example of a Clayton's Choice.

Irene reported similar insensitivity at the school where she worked. The new Principal at her school decided to move the staff room to another location giving Irene much further to walk. Irene was a woman in her fifties who had obvious difficulties walking and used a walking stick. It was clear to me that walking up and down steps, or any distance, would have been very difficult for her. However, the staff room was moved without appropriate consultation with Irene, or consideration of her physical disability:

Irene: The first Principal was very supportive ... and then, unfortunately, the Principal changed and ... the new Principal decided to have the staffroom moved across the playground into this building, which was very difficult for me [sounds upset].

MV: Did they talk to you or consult with you about doing, moving that?

Irene: Well, she said to me, "I found this wonderful staffroom but I don't know how *you're* going to manage Irene?" And I said, "Well, all I can do is give it a go," which I did. And at the end of one year I said, "Look this is not working for me." And she said, "Well, we can't take it back," [whispering] and I believed her ... and unfortunately the organizer for the Teacher's Federation, the Union, she said, "Irene, be very careful. If you make too much fuss, they may retire you." So I was really frightened. But after a year I just decided it was too much, and I just went and said to her, "Look, I cannot cope with this."

MV: How far across did you have to walk to get to the staffroom?

Irene: Well, it was down eleven steps. All up, eleven steps if you were coming back and across [Irene indicates a distance of about fifty meters]. So I mean it was a playground, not a huge playground, but a playground.

MV: Quite a distance for someone...

Irene: Absolutely, with a walking stick.

Even though the Principal had "asked" Irene about the decision to move the staff room, the decision had already been made – another Clayton's Choice. For Irene to have objected on the basis of her obvious physical disability would have required her to resist what all the other able bodied staff had already approved. I also point, with concern, to Irene's remarks about her future employment and the union representative's warning to her not to "make too much fuss." Irene found herself working in an intolerable situation, and fearful for her job. Her choice to say nothing for that twelve months was a Clayton's Choice.

An Ugly Passage

In addition to being presented with Clayton's Choices several respondents spoke of what I have described as their ugly passage away from their employment, post-diagnosis. Both Miranda and Jason were convinced that once their employers learned that they had MS, they tried to get rid of them. Jason reported being "counseled out" of his workplace and being given higher targets after disclosing his illness. However, it all started with Jason being reassured that there wouldn't be a problem. One of his colleagues rang him while he was off sick from work, just around the time he learned of his diagnosis:

Jason: ... A bloke from work phoned me up, *nominally*, to see how I was, and I was, "Oh, I've probably got MS." And it was, "Oh, gee. That is awful. We'll do everything we can to support you. Don't worry, it's not a problem." That lasted about a week ... He must have spoken to the owner of the company, and all the rest, and they'd probably worked out that this could cause them a problem, because they weren't a huge company, and so everybody had to do everything, and you certainly had to do, fulfill the expectations of the job. There weren't enough people at that level to carry me.

MV: At that point then, you were still having visual difficulties and a little bit of dexterity. Anything else?

Jason: No. At that time, I'm just thinking [pause]. No ... And, you know, I was, I was trying all the time to *not* create an opportunity for the constructive dismissal, but that was very much what was happening.

MV: ... What happened after you told them [about the diagnosis]?

Jason: Basically, they start to change my targets that I had to meet.

MV: What, higher?

Jason: Yes, and starting to require more. "We've decided we want to expand a little bit into other areas. We want you to take this on." So there was more to do. The sales targets that were set were being increased.

MV: Were they being increased for everyone, or do you think it was just for you?

Jason: They were *nominally* for everyone, but the way they were structured I felt they were, of course, paranoia -- but just because you're paranoid doesn't mean they're *not* out to get you -- and so I thought it was for me. Because other people, if they didn't make their targets, they just did what we'd all done previously: "Well, sorry, boss, I didn't make the targets." ... Because I also knew that they could *not* get rid of me because I'd got MS. But they can get rid of me if I don't do the job ... So, you know, knowing that added to the stress that I was experiencing.

MV: And what about their general demeanor and behavior towards you? Did it change?

Jason: Yes, in that it [pause]... they started to be more pedantic about things.

MV: Really scrutinizing?

Jason: Absolutely, yes.

MV: And you felt that the scrutiny wasn't the same for everybody?

Jason: That's right. And I knew that if I was being scrutinized, very closely, there were always going to be things that you could tick off. "Well, you're not doing this."

MV: They can *always* find something.

Jason: Anybody can.

What Jason describes would appear to be obvious discrimination. The rules might have been the same for all, but they were applied differently to him. He also reported having his work subjected to excessive scrutiny, a common bullying and victimization strategy. Jason ultimately resigned -- a Clayton's Choice -- even though he reported still being able to do his job. It was the deliberate changes of targets designed to make him fail that ultimately resulted in him being counseled out of his job.

Miranda had a similar experience. She made the mistake of sharing, in confidence, news of her illness to a fellow flight attendant where she worked. She then found that, suddenly, after over ten years as a flight attendant, there were reports being written about Miranda's poor work performance when for the past decade there had been none. As with Jason, the bullying and discrimination used to try and get Miranda to leave was being disguised as a legitimate organizational process (see other examples, Hutchinson, Vickers, Jackson, & Wilkes, 2005):

Miranda: ... Like the managers would say, "We are concerned for you as welfare, a duty of care." They would rip me out of the sky for any report that was written. This happened once, this happened twice, and this happens three times. I've got copies of all of them where this happened. The fourth time I saw the [employer's] doctor ... and he said to me, ... he was checking me and whatever, and I said, "Doctor Smith, I've got a limp and I'll show you. Here it is," because my left leg is weak. And I said, "The day I can't take my peers and passengers out of that air craft, I'll be telling you I'll be going". He said, "Miranda, I know," he said. "You are the talk of the town in the company now, because you've got MS and it's just, you

know how [employer] is, when they start the rumors." And he said, "Would you agree to an ergonomics testing? The company pays a lot of money to do it."

MV: Is this to test to see if you were still fit to fly, is that right?

Miranda: Yes. I agreed with that. It took about two months to get the results. I ended up going downhill, like that [she indicates with her hand a steep downward slope]. And pretty much the first trip back and I never flew after that.

MV: Do you think the stress affected that?

Miranda: Yes. Oh, *for sure*. But to prove that was so hard. Because you are talking about these people with *top* doctors, *top* lawyers, you know, and I did take it to the Union lawyer. I did take it to another lawyer and they looked at it and they said to me, "OK. It's 30, 40 thousand dollars. It will pay off a little bit off your mortgage. Is it worth it?" ... And I just looked at it and thought, "No."

Employers who wish to divest themselves of employees they don't want *can* be in the driver's seat in such situations, especially if the employee is emotionally, physically and financially vulnerable (Vickers, 2006a). Miranda and Jason were both financially vulnerable, their health was deteriorating, and neither could readily afford a lawyer to defend them, nor did they need to endure the additional stress that would result from the process that would most likely exacerbate their disability further. Miranda told of false reports being written about her, claiming she was unable to do her job. She felt that this was the beginning of a well orchestrated process to get rid of her, even though, at that time, she felt that she could fulfill her duties as required.

Miranda: I thought, "This is the way the Company wants me out. This is how they are going to find a way to discrimi-

nate against me, make me sign on a dotted line.” They’d probably prefer to see the back of me. I thought, “Yep. This is the way the Company’s going to do it... It’s going to look like if they are *not* discriminating and they’re doing the right thing.” And yes, *extremely stressed*, and knowing I had a mortgage to pay off ... And it was like, “Oh, my God, I’m going to lose my job!” And so panic, scared ... and I just had no idea what they were going to do ... I was yes, really scared. I thought, “I’m out of here now. This is the way the lovely Company’s going to get rid of me.”

Discussion

Some respondents reported working in intolerable conditions as a result of employers learning of their illness and making things difficult. Others found themselves leaving work when presented with a Clayton’s Choice. Others were simply unable to adequately defend the discriminatory and victimizing processes used to push them out.

The field of vocational rehabilitation has (so far) been unable to make an impact on understanding the troubling phenomenon whereby people with MS are prematurely leaving the workplace (Rumrill, Tabor, Hennessey, & Minton, 2000, p. 116). It is held that with continued emphasis on strategies such as job modifications, provision of new equipment, and job restructuring, people with disabilities can perform their usual work activities in a full time capacity for longer periods of time (Roessler & Rumrill, 1995). However, employer support of the accommodation process has been recognized to be critical to the job retention of people with disabilities (Roessler & Rumrill, 1995).

Unfortunately, what has been presented here is evidence that, sometimes, employer support is not forthcoming. Indeed, not only is the situation not positive, or even neutral, but

that darker organizational tactics such as bullying and discrimination are invoked deliberately to the detriment of the person with MS. There is evidence here that people with MS are being pushed out before they needed to be. I would also argue that legitimate organizational processes are being used to expedite such premature workplace separations. This requires further investigation.

It is imperative that researchers consider the results of this exploratory work. I claim that one unexplored reason why people with MS are leaving work prematurely is because of socially constructed assumptions that attach to disability in general, and to MS in particular. We have known for a long time that stigma attaches to illness and disease (Vickers, 2000; Vickers, 2001) with potentially deleterious outcomes for the subject of that stigma, both personally and professionally. In an environment of increasing managerialism and economic rationalism (Vickers, 1999) workers, especially managers, are often implicitly encouraged to be insensitive to the needs of people with disabilities, especially those who have a highly stigmatized illness, even though legislation exists that requires a contrary outcome (for example, Disability Discrimination Act, 1992). At the very least, there are mixed messages for managers who are legally required to make provision for people with disabilities.

While I acknowledge the existence of anti discrimination legislation around the world (for example: Americans with Disabilities Act [ADA], 1992; Disability Discrimination Act [DDA – Australia], 1992; Disability Discrimination Act [DDA – UK], 2005), perhaps it is a mistake to assume that because the laws are there employers will always adhere to them. Certainly, several respondents indicated their faith in these laws, as does much of the literature pertaining with employment difficulties for people with MS. The uncritical assumption appears to be that, because these laws are in place, discrimination against people with disabilities can no longer happen (see for example, Duggan,

Fagan, & Yateman, 1993; Roessler & Rumrill, 1995, p. 10; Roessler & Rumrill, 1994, p. 3; Rumrill et al, 1999; Rumrill, Tabor, Hennessey, & Minton, 2000; Huebner, 2000, p. 14). However, as already noted, people with disabilities are already likely to be more financially vulnerable than most. It is unlikely that they will take on the might of a large, well financed organizations with highly paid company lawyers experienced in litigating such cases in the interests of protecting the organization – and employers know this. As long as the burden of proof remains with victims of discrimination, the stress and expense of court cases is likely to provide a strong incentive for people with MS *not* to litigate, especially when the likely payouts are relatively so small (Vickers, 2006a).

In light of the qualitative evidence presented above, it is surely time to reconsider the plight of people with MS in an effort to keep them employed, or at least, employed for longer. Here is evidence that some people with MS leave work – apparently voluntarily -- because their employers have made it impossible for them to continue.

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Endnotes

¹There was just one tape that was not transcribed. For the first time in 13 years of conducting research interviews, I didn't believe that this respondent was telling the truth. She did not appear to understand many aspects of having MS, described some symptoms I thought to be highly unusual (unbelievable?), and didn't know anything about any of the medications that are being routinely prescribed. The interview just did not ring true. After consultation with the MS Society, I elected not to include this data in my study.



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Book Review

Title: *The History of My Shoes and The Evolution of Darwin's Theory*

Author: Kenny Fries

Publisher: Carroll and Graf Books, 2007

Paperback, ISBN: 0-78672-007-7, 206 pages

Cost: Amazon.com: \$10.17 USD

Reviewer: Nathan Say

If we called this title “a story”, it would be too simple; “narrative poetry” seems more appropriate. Every chapter or so, juxtaposes two different stories: that of the author’s specially fitted orthopedic shoes against Charles Darwin and Alfred Russell Wallace competing to develop and publish their theories of adaptations. Together, we see Kenny Fries experiencing his own adaptations throughout his entire life.

Fries currently teaches in the MFA-Poetry program at Goddard College in Vermont. This book, released in 2007 is his second autobiographical work (the first being *Body Remember: A Memoir*, 2003). Throughout the telling of his life in this book, his shoes play a constant role, whether its stories about coming of age, telling of his experiences with his partner Ian, or traveling throughout the world.

After reading the first couple of chapters, I thought this would be another disability memoir. However, I was wrong. It did not dawn on me until after I finished the book and was processing the experience, that Fries’ telling of the second “tale” regarding Charles Darwin and Alfred Russell Wallace was his way of coming full circle with his own disability experience.

While the author dislikes his shoes at the beginning of his work, towards the end when the two narratives come together, and Fries and his partner are at the place where Darwin and Wallace once were in the Galapagos (an archipelago of volcanic islands that are located 600

miles west of the country of Ecuador in South America where Darwin discovered his theories), that he becomes grateful for his shoes and the ability his shoes have to transport him all over the world.

I enjoyed the telling of his partner Ian’s struggle with Attention Deficit Hyperactivity Disorder (ADHD). I have ADHD, and reading about Ian behave and deal with his ADHD the same way that I deal and struggle with my own ADHD, was a relief because I realized other people struggle similarly and that the way I deal with it on a daily basis is just fine.

Fries’ traditional poetic lines, which can be seen in his previous books of poetry titled *Anesthesia: Poems* and *Desert Walking*, are as good, if not better than his narrative poetry. As a person who writes poetry, has multiple disabilities, and is also gay, it is valuable for me to use Kenny Fries’ experiences as a guide, because I realize I am not alone.

This was not an easy book for me to understand. I believe, however, this book, recognized as one winner of a 2007 Gustavus Myers Center Outstanding Book Award for Advancing Human Rights, will become an important piece of literature to our community and culture over the years because the author writes in a way that a general audience, who may not comprehend scientific writing, will be able to understand. Overall, I believe this is a book everyone will enjoy and gain new insights.

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- Fries, K. (1996) *Anesthesia: Poems*. Louisville, KY: Advocado Press.
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- Fries, K. (2000) *Desert walking*. Louisville, KY: Advocado Press.

Nathan Say is Project Coordinator for the "My Voice, My Choice" grant at the Center on Disability Studies at the University of Hawaii. He received a B.A. from Brigham Young University-Hawaii in 2007. His interests include Disability Studies/History/Activism, Women's Studies, and Human Sexuality Studies. He also enjoys writing poetry and blogging.

Book Review

Title: *Critical Disability Theory: Essays in Philosophy, Politics, Policy, and Law*

Authors: Dianne Pothier and Richard Devlin (Eds.)

Publisher: University of British Columbia Press, 2006

Cloth, ISBN: 9780774812030, 352 pages

Paperback, ISBN: 9780774812047, 352 pages

Cost: Cloth, \$85.00 USD; Paperback, \$32.95 USD

Reviewer: Carrie Griffin Basas

This volume of essays is joined by the thread that people with disabilities experience "dis-citizenship" in Canada, having been denied inclusion, equality, and power Canadians without disabilities enjoy (p. 2). The authors consistently reinforce the message "disability is not fundamentally a question of medicine or health, nor just is it just an issue of sensitivity and compassion" (p. 2). They use a sociocultural model of disability that goes beyond disability as a construct to look at ways disability status affects political rights, economic status, and community integration. Tools from various disciplines are useful as the authors create an approach they call critical disability theory. Critical disability theory goes beyond documenting the existence of oppression, and asks what purposes it serves and how it can be overturned? This quest is often in conflict with even liberalism's approach to

disability, which has depicted the experience as a monolithic, unfortunate aberration.

While largely academics, the authors do not offer their chapters as mere reflections on formal equality, but rather, they call for substantive equality – tangible changes in the everyday interactions of people with disabilities and their interfacing with cultural, economic, and political institutions, such as medicine, law, employment, nongovernmental organizations, and the state. They suggest these changes can be made from various approaches, including empowering individuals with disabilities at the community level, educating judges about critical disability theory, creating coalitions with other minority movements, and further documenting barriers people with disabilities face in Canadian society. Purposefully, they divide the book into four sections—"Setting the Context," "Conceptual Frameworks," "Policy Analyses," and "Legal Interrogations."

The book will appeal to readers interested in interdisciplinary approaches to understanding the marginalization of individuals with disabilities, and in particular, to American Studies scholars, comparative human rights researchers, policy analysts, higher education teachers, critical theorists, and civil rights lawyers. Canadian professionals in these fields may be more immediately drawn into the arguments and analysis, but the work has value globally. As Canada is often conjured as the image of social progress and liberalism to neighboring American scholars, this book removes some of that veneer and suggests opportunities for productive comparison and shared dilemmas.

The chief strength of this collection is its breadth. Authors touch upon such topics as Rawlsian justice, feminist theory, neo-liberalism, multiculturalism, hybrid identities, reproductive rights, gender stereotyping, and employment strategies. They bring together qualitative and quantitative research, textual deconstruction, legal analysis, personal narrative, and policy cri-

tique. In each chapter, the contributors demonstrate commitment and passion for their subject matter, adding layers of knowledge to the experience of disability in Canadian society.

As with many volumes of essays, the primary weakness with this book is one of organization. While the introduction provides an inspiring segue into the remainder, as the chapters build, the reader could use a short reintroduction to the separate sections and how they are intended to tie together. With just the addition of a few pages, the book could have better flow and the arguments advanced in each essay could be linked meaningfully and cohesively. A conclusion would serve the same purpose, but one is not included.

An appendix, detailing Canadian disability rights cases in the last twenty years, is provided. This section, however, comes as an abrupt ending. The background material it contains would be better placed in the introduction or a separate chapter. This volume, with its calls to action – both theoretically and politically – deserves a strong finish. As it stands now, the reader has difficulty understanding the chronology of the chapters and what linkages are intended. She returned to the introduction upon completion to cement what she had read in the essays.

With these minor suggestions for improvement in future iterations, *Critical Disability Theory* could be a catalyst for similar comparative projects, gathering scholars in the United States and abroad. The synergy these Canadian scholars model can be a positive force for social change because it increases awareness about work being done in other fields, while also establishing conduits for collaboration and goal-setting. That kind of effort takes scholars and people with disabilities beyond their established lenses to suggest alternatives and action.

Carrie Griffin Basas, J.D., is an Assistant Professor at the The University of Tulsa College of Law.

Book Review

Title: *Disability in Local and Global Worlds*

Authors: Benedicte Ingstad & Susan Reynolds Whyte (Eds.)

Publisher: University of California Press, 2007

Paperback, ISBN: 978-0-520-24617-1, 324 pages

Cost: Paperback, \$21.95 USD

Reviewer: Michael Stein

Disability in Local and Global Worlds is the first co edited volume of essays from Benedicte Ingstad and Susan Reynolds Whyte since *Disability and Culture* in 1995. Like its predecessor, the book contains leading ethnographic research on disability.

Although it can be challenging to read ethnographic analyses when researchers use field-specific terminology, anthropological studies of disability are valuable for lending insight and context to the social construction of disability. The essays comprising *Disability in Local and Global Worlds* also are interesting because they provide a window into the lives of people with disabilities internationally.

The book contains eleven studies, a pair of which are by the authors, and is divided into two parts grouped around the processes of understanding bodily identity in, respectively, local and global contexts (“Locating Embodied Identities” and “Localizing Policy and Technology”). This organizational metaphor seems a bit unclear despite the introduction that explains how the book is divided by these subjects. Ultimately the strength of the book is in the worlds it opens to readers through the stories, both positive and painful, that it presents of the lives of persons with disabilities in diverse cultures.

Disability in Local and Global Worlds, as the title suggests, covers a wide array of subjects. Among the more interesting contributions from

the first part, is a study of how perceptions of bodily “wholeness” by women subjected to female genital excision varies depending on whether they are in Somalia or London; and a chapter on the self-perception of being disabled by infertile people living in populous Egypt. Two of the more powerful contributions from the second part describe the state-generated definition of disability in modern day China and how that determination organizes and affects individuals within the category, as well as an examination of the central role that tricycles play for mobilizing and empowering individuals with physical disabilities in Uganda. Other chapters present examinations from other parts of the globe, including Botswana, Brazil, Israel, Italy, and Japan.

Disability in Local and Global Worlds contains a wealth of information that will be embraced by anyone interested in varying social and cultural constructions of disability. However, the book is targeted to an academic rather than a general audience. Graduate students from several disciplines including anthropology, disability studies, medicine, psychology, and sociology will clearly benefit from the book’s contents, as will others willing to work through occasionally inaccessible jargon. Additional studies from Professors Ingstad and Reynolds Whyte, both as editors of collections of disability-based anthropology research and as leading scholars in the field, are most welcome.

Michael Stein, J.D., is a professor at the William & Mary School of Law and Executive Director of the Harvard Project on Disability.

Reference

Ingstad, B. & Reynolds Whyte, S. (Eds.). (1995). *Disability and culture*. Berkeley, CA: University of California Press.

Audio Review

Title: *Rollover*

Authors: Andy Morgan and Johnny Crescendo

Publisher: Email adaptan@yahoo.com or write to Johnny at 3607 Windsor Dr, Bensalem PA, 19020. Make checks payable to Alan Holdsworth.

Format: CD

Cost: \$14 USD including postage. Contact by email for additional postage costs if you live outside US.

Reviewer: Steven E. Brown

*She'll hum these words forever until her dying day
They've taken my baby away*

I am a longtime Johnny Crescendo fan, so I was not surprised this CD, featuring longtime Crescendo collaborator Andy Morgan, spoke to me. In the growing assemblage of music by individuals with disabilities addressing the disability experience, Johnny’s music is generally the loudest, the most influenced by rock’n’roll. Still, his ballads most move me. His earlier song, *The Ballad of Josie Evans*, is one I have written about in numerous publications, including an earlier RDS review (Brown, 2007). The first song that grabbed my attention on *Rollover* was the “Ballad of Roy and Julie,” from which the lines at the beginning of this review are taken.

This long ballad, over eight minutes, is not upbeat. It is the true story of a couple with developmental disabilities who met, fell in love, and Julie (the names have been changed) became pregnant. As soon as Julie’s parents learned of this development (Roy was an orphan), they forbade the couple from ever seeing one another again. Shortly after the baby was born, Julie’s parents put the baby up for adoption. Roy, with the assistance of his social worker, succeeded in obtaining visiting rights to see his son. Julie, unhappily, was placed by her parents in a psychiatric institution. The song ends painting a

picture of Julie, alone in her room, sitting in a rocking chair, and endlessly repeating the words, “they’ve taken my baby away.”

One reason the “Ballad of Roy and Julie,” strikes a chord is these abominable situations still happen, despite our continued work and emphasis that people with all disabilities are just like all people – we have value. *Rollover’s* eight songs are dedicated to proving this point.

The CD begins with “Bad Day in a Bad Town,” the tale of a wheelchair user finding himself in an access and attitude unfriendly city. The hero of the story calls in his army of revolutionaries to change this town’s climate. At the end of the song, he moves on to the next bad town.

This song is followed by a disability rights, anti-institution version of an old Cole Porter song, “Don’t Lock Me In.” It is a rollicking folk song with a simple theme: let us live our own lives as we choose.

“Poppy,” an anti-war song, is based on Johnny’s conversations with his grandfather, a World War I veteran. “You Don’t Need Sympathy If

You’ve Got Soul,” was originally written for a deaf performer, and updated for this CD. Liberty, is a tribute to Liberty Resources, the Philadelphia Center for Independent Living, and others like it, and liberty, in general. “Inglis House,” condemns institutions everywhere, in an updated version of Johnny Cash’s “San Quentin.” The CD concludes with “Wheelchair Waltz,” an older song whose lyrics have undergone their third revision and may be the most lyrically upbeat song with the words, “I wanna dance with you, I wanna chance for you, I wanna romance with you, I wanna dance with you.”

This CD is my favorite one from Crescendo because it is the most sophisticated, to my amateur ears, musically and lyrically, and yet simple enough to be accessible to all. Like all of Johnny’s music, I highly recommend this for any disability rights, history, or culture library.

Reference

Brown, S. E. (2007). Review of *Tear down the walls*, by Johnny Crescendo. *Review of Disability Studies: An International Journal*, 2(4), 93-94.



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The Center on Disability Studies is the umbrella for some 25 funded projects. It originated as the Hawai'i University Affiliated Program (UAP) funded by the Administration on Developmental Disabilities of the U.S. Department of Health and Human Services. It was established in 1988 as part of a network of over 60 UAP's in the United States. It is now a University Center for Excellence in Disability Education, Research, and Service.

Although core funding for the Center is provided by the Administration on Developmental Disabilities, other federal and state funds are provided by the Maternal and Child Health Bureau of the U.S. Department of Education, various other programs in the U.S. Department of Education, the University of Hawai'i, and the State Planning Council on Developmental Disabilities.

The activities of the Center for Disability Studies extend throughout the state of Hawai'i, the mainland United States, and the Pacific region with funded projects in several initiative areas including intercultural relations and disability, mental health, special health needs, Pacific outreach, employment, and school and community inclusion.

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