## Paper Proposal: "Representing Disability and Emotion" Journal of Literary and Cultural Disabilities Studies Johanna Shapiro, Ph.D. March 16, 2009

Medical education does not typically pay attention to the emotions of its trainees. In fact, both the formal and informal curricula convey the message that the appropriate relational position vis-à-vis the patient is one of emotional distance and detachment. Yet it is well-documented that medical trainees have a range of intense emotional reactions to patients, not all of them positive. Students may feel anxiety, fear, frustration, impatience, and sadness, even disgust and revulsion.

The complicated emotions evoked in patient care are often particularly intense in clinical situations involving marginalized and stigmatized populations such as persons with HIV/AIDS, obesity, cultural difference, drug and alcohol abuse, and disabilities because of the heightened temptation to see these patients as threatening and alien others. As a case in point, disability can trigger feelings of loss, randomness and chaos, not only in the person with the disability, but also in the person observing the effects of disability. Unfortunately, medical school curriculum focusing on patients with disabilities is negligible, and what does exist rarely addresses the complexity of healthcare providers' emotional responses to their patients.

This paper will begin by using theoretical constructs of contamination, boundary maintenance, and othering to explore emotional attitudes of medical students toward persons with disabilities; where these responses emerge from intrapsychically; and what systemic pressures sustain them. I will argue that the performance of emotions that create distance between doctor and patient and the defining of the patient with disabilities as other are encouraged through the hidden curriculum. On an individual, psychological level, this performance creates a sense of safety and invulnerability that insulates the non-disabled medical student from the fragility and vulnerability that disability might otherwise engender. On a group level, otherness serves as a construct of exclusivity. By maintaining an emotional position of otherness toward persons with disabilities (as well as other minority and disadvantaged groups), the lowliest denizens of the world of medicine can foster a sense of homogeneity and conform to standards of belongingness. Unfortunately, othering and its emotional consequences do grave harm to both students and patients.

In this analysis, I contend that students initially often engage in reaction-formation, adopting the politically correct position that persons with disabilities are "just the same" as themselves. This position denies the capacity to confront and become comfortable with the idea of inalienable difference by requiring fundamental similarity among all people. It also enables students to avoid feelings of fear and dread that may be triggered in the presence of disability – the fallout from confrontation with fallibility, suffering, and alterity that inevitably threatens their sense of perfection and safety. Lack of pity was an important corrective to historically socially acceptable responses of seeing persons with disabilities as "less-than" and "feeling sorry for" their perceived lacunae, gaps, and deficiencies. However, the banner of "no pity" has created the perhaps unintended

consequence of "not noticing" disability, particularly in naïve learners. Students still struggle with what to do with difference; and it is emotionally easiest to ignore it by claiming that in all important ways "we're all the same." A more desirable critical stance might be "in and through," in which students authentically confront problematic emotions that arise in encounters with disability, discuss how these are encouraged and reinforced by the cultural norms operating within medicine, and open themselves to solidarity and connection with patients in a way that embraces (or at least does not turn away from) difference.

Although at first glance emotions may seem to be personal, idiosyncratic, and apolitical, in fact they are potent, albeit often unacknowledged, drivers of behavior in the professional domain, both in the dyadic interaction between doctor and patient, and in the larger institutional and societal structures where persons with disabilities intersect with the medical system. Emotions are contagious, in that we tend to mirror the expressed feelings of those around us, especially admired and powerful superiors. Thus, if attending physicians and residents are dismissive, judgmental, impatient, frustrated, or sarcastic regarding patients with disabilities, learners will swiftly incorporate these emotional performances into their own behavioral repertoire, to the detriment of patient care and the perpetuation of stereotypes that negatively label categories of people. For example, scholarship has documented that medical students learn to use derogatory humor to create distance between themselves and certain classes of stigmatized patients.

How emotional responses are valued, constructed, and performed within medical culture is not merely a private matter, but heavily influenced by normative group processes intimately tied to issues of membership, belonging, success, and advancement. Which emotions are allowed, and which suppressed – the regulation of permissible and "professional" emotions – stems less from individual predilections and values and more from the expectations and requirements of the profession. Tender emotions in learners, for instance, especially tears, are often seen as evidence of lack of professionalism. While judgmental negative emotions are disallowed by the formal curriculum, they are in fact pervasive in the "hidden" curriculum, the informal teaching conveyed through actual, as opposed to stated, behavior and attitudes. Yet little curricular time is spent teaching learners to first be aware of and identify their emotional reactions; then to realize that cultural norms in the profession variously encourage or stifle the expression of emotions; and finally to develop the skills to cultivate emotions that support professional attitudes of altruism, empathy, service, and connection. As a result, students often conclude that emotions are dangerous and best avoided. They try to deal with personal emotional responses through psychological defense mechanisms of denial, humor, minimization, rationalization, and sublimation.

After defining the problem of emotional nescience at both personal and systemic levels, I will then discuss how the humanities, including literature, readers' theater, art, and dance, can be integrated into medical education to help students use critical self-reflection first to excavate and examine their own emotions; then to recognize how such emotions are differentially reinforced or suppressed within the culture of medicine; and finally, to evoke alternative emotional responses, including witnessing, solidarity, and connection,

that offer different meaning possibilities in terms of student-patient relationships. As part of this discussion I will present a three step process that learners can experience through a critical engagement with literature and the arts: 1) Learning to accept rather than smooth out difference; and learning accept that understanding of the other is always incomplete 2) Learning to see self in others, both in terms of woundedness and wholeness 3) Learning to be open to mutuality in the physician-patient relationship, for example to see the disabled other as healer, as well as sufferer. Ultimately, I make the case that literary texts and works of art that give voice to the complexity of disability experiences present on opportunity for witnessing different ways of being in the world that, in the broadest sense, share with other ways of being unavoidable suffering and joy, yet also differ profoundly on certain significant dimensions. In turn, such witnessing can lead to solidarity with the disabled other as a consequence of the effort to see clearly, uncluttered by fear or threat or the desire to elide all difference. Applied to medical pedagogy, the result will be students who are better able to interrogate both their own problematic emotions and those supported by aspects of their training milieu; and who are better prepared to address emotions in the doctor-patient encounter in ways guided by awareness, integrity, humility, and solidarity.