

Limits and Improvisation: Liberating Aspects of Disability

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Personal narrative is a valuable resource for identifying research questions and understanding the complexities of being a disabled person. The process of writing the following vignettes has been one of discovery; both of my own identity formation as a disabled person and of areas to be researched in disability identity, the arts and learning.

Martha just told me that her son has been diagnosed with muscular dystrophy-she doesn't yet know what type. I don't have MD, don't know the first thing about it, but because I am disabled, friends and colleagues often informally consult me about these issues. I don't really mind. I just don't always know what to say, especially when it isn't the person directly affected doing the asking. Usually I try to listen more than offer advice. In this case, I am struck by Martha's sense of loss and her pain. Her son will not be the person she imagined him to be, that is most certainly true. I can empathize with the sudden sense of chaos, the loss of control, that has come over her.

When I first began having seizures and other symptoms of what would eventually be diagnosed as lupus, suddenly nothing in the world made sense anymore, nothing was predictable, everything was dissonant. It was about that time that I first read Joan Didion's *The White Album* (1979). In it she says, "We tell ourselves stories in order to live" (p. 11). That is, we impose narratives on disparate events and images in our lives in order to make sense of the world. The trick is that these narratives are never really fixed.

Take some of the narratives I had twelve years ago, before lupus hit my central nervous system. I expected continued success as a graduate student in art history and I was certain the internships I held would lead to a career in museum education. On a more basic level, I never questioned my ability to articulate my thoughts. When I needed to speak, I could express myself; when I wanted to write, my hand could form the letters. I also assumed that I would go through each day without losing consciousness. Then the narrative shifted; these certainties were lost. As life became an unpredictable series of good days and bad days, it seemed that my body was spinning out of control.

But then again, I never had complete control over my body or my abilities. I only had expectations based on past experience and what the world - through schooling, film, books, and the media - had taught me was "normal." I just happened to fit in with society's notion of physical normalcy for the first 27 years of my life. I did have a variety of illnesses during those years, some of them relatively serious. But those illnesses were finite and didn't permanently affect my physical state. They didn't affect the essence of who I was, or at least they didn't affect how other people perceived me and related to me. This was different. I was assigned new labels - new limits - in discussions with everyone from doctors to friends to the folks in the Department of Motor Vehicles. I was an "epileptic", or in the new terminology, "a person with a seizure disorder." I was disabled but only in the sense that I was on disability leave; disability was linked to the ability to work. Actually, I was becoming a disabled person; one with an unpredictable, chronic illness that has its ebbs and flows. Over the years some symptoms have progressed while others rarely see the light of day.

One of Didion's narratives dissolved when she was diagnosed with multiple sclerosis in 1968. Her comparison of the nonsensical nature of her symptoms and physical future with the social and political upheaval that year is, to me, a particularly eloquent way of stating that disability is far closer to reality than most "normalcy" (Didion, 1979). Unfortunately, I don't think this insight which speaks so directly to my experience will bring Martha much comfort right now.

So what do I say? My heart goes out to her but, being on the other side so to speak, my primary concern is how her son will respond to her view of what he has become. After all, he is only becoming who he is. So I struggle to support Martha while trying to somehow express that Eric still has a very real life to be lived, albeit dramatically different than she had ever expected. I offer to ask

friends about resources she and Eric might access and to see if someone with MD might talk with both of them along the way.

But that still doesn't get at what I really want to tell her, what I want her to know and to believe. Although her son and I currently have little in common, I try to relate how I am coming to experience disability and its ever changing meaning for me. Ultimately that is all I really can do. As I mull it over, I begin to wonder: When did I begin embracing what disability has added to my life, even as others seem to only comprehend the loss?

John Hockenberry (1995) talks about the "harrowing twinge" he gets when thinking that he might have missed the moment of the accident: "I might have missed what my life has become" (p. 69). Having a chronic illness, I can't pinpoint a set moment in its onset that would be parallel to Hockenberry's, the critical moment I might have missed. There are, however, moments and encounters that forever altered my perceptions of disability, that changed the narratives I impose on disability experience. To have missed these moments - now that's a harrowing thought.

It's the end of a long first day of the summer institute on multicultural education. A group of local performers are on stage. The final actor is going through the rigors of applying for disability insurance. The success of her efforts will be in her proving how little she can do. I'm in the back of the room, stunned, sinking into the wall, looking around at the teachers in the workshop wondering if they can see that this is me on stage, that it took me over a year to fill out the damn application forms because I was so ashamed, that I'm crying and laughing and thankful to be heard, even if it is in someone else's voice.

I'm in a large university cafeteria waiting for the disability arts center planning meeting to begin. I listen to the varied speech patterns and the hum of electric wheelchairs as the group of artists, arts administrators, professors and disability advocates gets settled in. I eat my sandwich and feel oddly out of place.

When Carol Gill and I met a couple of months ago to discuss my research interests in disability and art, she invited me to this planning meeting. But now that I'm here, I wonder, do I really belong? Will I be accepted? Do I want to be accepted? My disabilities aren't always visible so I feel like I should wear a sticker saying, "I qualify." I try not to worry about this and hope my association with Carol will be enough to establish some legitimacy.

The meeting is finally getting underway. The topic of the day is "disability culture." A facilitator (who makes it clear that she doesn't have a disability and needs us to educate her) begins taking us through a brainstorming exercise on characteristics of disability culture. Words come out slowly at first but then the momentum builds . . .

talent
humor
risk-taking
resourceful
joyful
creative
frustrating
opportunity
active
possibility
awareness of other perspectives
alive
painful
proud

ambiguity
celebration
community

The words lead to a discussion of who should be exhibited and served by this art and culture center. Should people with and without disabilities be represented? I quietly implode, my inner voice wondering what we would then call it, the "culture center that disabled folks can get into?" But if we don't compromise, will we offend the nondisabled supporters in the group? Would we, god forbid, appear to be excluding nondisabled people?

The facilitator tries to bridge the gap: "Aren't we all disabled in some way? There are many things that I can't do. We all have different abilities."

That does it. We all feel compelled to speak at once.

"But it doesn't limit your rights!"

"You aren't considered 'abnormal.'"

"You aren't discriminated against because of it!"

"No one is suggesting that you would be better off dead!"

The voices go on. Carol talks about the medical model of disability in which physical variation is viewed as defect, as deviance from the norm. She compares the disability rights movement with the women's movement citing the credo, "biology is not destiny," and she notes that an important part of the women's movement early on was simply the act of coming together to share stories and experience. The conversation is boisterous and rich. One of the voices is mine.

And I realize that I have never been with so many disabled people outside of a hospital; that is, I've never been with an entire group of disabled people as people. I've been with groups of disabled patients. I see how isolated I have been and I don't want to leave. I am both exhilarated and outraged; most of all I am stunned at the utter certainty of my own feelings. As I tell Carol later, I am realizing that I have "strong opinions that run deep."

I feel so naive, not quite knowing how to explore this new territory and wondering why I hadn't found some of these folks earlier. Suddenly I am very invested in this art center. I want it to be a center "of" disability art rather than simply "for" people with disabilities. I want a place to congregate and create that is led by disabled people. I can't help but wonder, what might have been said or learned about disability culture at this meeting if only disabled people had been present and, as important, facilitated the conversation? When I get home, I call my friend, Gail, and tell her, "Now I understand why the African American students in college wanted their own floor in the dorm!"

"It isn't my responsibility to educate you!"

I've just exploded, in my own quiet way, in a disability studies seminar. I'm not even officially a part of the class; the professor generously offered to include me as I try to learn more about the future doctoral program.

Somehow what I am beginning to call the "full disclosure" law has become a topic of conversation. It was noted that the more open a disabled person is to explaining their condition, the more educated, comfortable and, accommodating others are able to be. It all sounds so simple, so clear-so impossible. In practice, this usually means that if nondisabled people ask about the whys and whats of a disabled persons' condition, disabled people must dispense information. I find myself trying to explain that this can quickly become an invasion of privacy, that "full disclosure" usually comes back to haunt you in lowered expectations in the workplace and in school, and that for me, it is incredibly tiring to constantly interrupt work or play to revisit seizures or lupus and why the sun and certain artificial lighting aggravates both. Add to this the fact that most disabilities vary in some way from day to day and simple explanations only create more confusion.

I had expected to be challenged by this seminar but I didn't expect how central my identity as a disabled person would become as I read the material, participated in discussions and formulated research questions. On the one hand this is incredibly invigorating and exciting. My training in art

history is resurfacing as I become intrigued by representations and themes of disability in the arts and the media. I wonder how artists with disabilities represent physical, psychological and sensory variation in their work. What meanings are assigned to disability by disabled people? How does this compare with the traditional iconography? If there is a disability culture, how is it reflected in the art and media produced by disabled people?

The joy of this inquiry, however, is balanced by the intensity of my reactions to some of the course material. The writers I take exception to seem to analyze with little direct consultation with the subjects; that is, the voices of disabled people often seem to be missing or are easily dismissed in favor of the "objective" interpretation of the researcher. At times my words seem to carry the weight of the entire disabled community (at least it feels that way). But how can my experiences speak for such a diverse range of people?

I wonder about the reactions to my comments and analyses of the course material. If I become angry, are disabled people overly sensitive? If I relate readings or support my opinions with my own experience, do disabled people take things too personally? Are we too close to the situation to do credible research? If I reveal specifics about my disabilities, will I appear to be less promising as a doctoral student? Or worse, will I become the object being studied? And I have to wonder: Do nondisabled people spend as much time considering how their subjective experience impacts their research in disability studies as I do mine? After all, I know my assumptions about disability have changed dramatically since I became disabled. It strikes me how different this experience might be if more people who identify as disabled were a part of the class, how important it is to have a sense of connected knowing in situations like these, simply to be understood and to avoid being relegated to the margins.

What really bothers me is that I am grateful to have experiences of disabled people included and valued (why don't I simply expect this?). It actually goes far beyond that in this case. The professor has welcomed my input, my feedback; the time we have spent hashing out my research question has been invaluable. Ultimately, I suppose I am learning how naive I have been, assuming that by entering a world where "disability studies" is central that I would be entering a world where disability is never pathology.

Developing a tolerance for ambiguity and "not knowing" is fundamental to learning, to problem solving, to any form of meaningful creation whether you're disabled or not. I know I'm more inclined to experiment and take risks in all aspects of my life since I became disabled; it's a benefit of realizing that control is an illusion. Part of what disability has done for me (when it hasn't been cast as defect), is to resurrect improvisational skills I used in theater and in play when I was younger. "Not knowing" is now as much about possibilities to explore and outcomes to eagerly anticipate as it is about anxiety or fear of the unknown. Perhaps that's why I find the relationship between disability and the arts so intriguing; the arts hone these same improvisational skills, albeit in a disciplined way. It's an odd paradox. Although disability is usually viewed in terms of limits, in many ways it also liberates.

Chuck Close - an artist with both physical and learning disabilities - made two comments in a June 1998 lecture at the Museum of Contemporary Art in Chicago which spoke directly to these connections between disability and the arts. In discussing his artistic process, Close stated that "ease is the enemy of the artist." He consistently limits his tools, methods and materials to those with which he is unfamiliar in order to make use of "how liberating limitations are."

These limitations are, in effect, aspects of disability experience Close recreates in order to enhance his artistic capabilities. He has learned that "limits" necessitate improvisation, resourcefulness, and skill development; he sets limits in order to learn and thereby create. Although Close chooses not to identify himself as an "artist with disabilities," I would argue that aspects of disability experience play an integral role in his artistic process and identity.

I began writing this essay just before I went to a colloquium on disability studies and the humanities at Ohio State in April 1998. As always seems to be the case when coming together with other disabled people, I found common language, common experience and a level of comfort that I don't seem to find elsewhere. It's as if a part of me relaxes that I don't even realize is tense. Mark Willis (1998), a writer and storyteller, gave a talk at the colloquium in which he shared stories of his family whose genetic heritage has led to multiple disabilities. Four generations of experience in living with disabilities led him to consider his family members' lives in terms of improvisation: "We improvise our lives out of what we have, composing the score as we go" (p. 1) On my best days, that is the beauty of disability-rigid expectations set aside for the art of improvisation.

I'm sometimes asked why I often use the term "disabled person" rather than "person with a disability." As Simi Linton (1998) outlines in *Claiming Disability: Knowledge and Identity*, disability and my experiences arising from it are an integral part of my identity that can't be (nor would I want them to be) separated from my "person." In many respects I think I would remain "disabled" whether I still had disabilities or not. The limitations might be lifted, but my view of the world and myself would remain forever changed.

I don't really know why or when this shift in identity occurred. When I consider the moments highlighted in these brief vignettes, a recurring element seems to be simply being with other disabled people outside of medical settings. Reading and discussing literature and research by disabled authors; gathering to begin a new organization; attending conferences on disability studies; and developing new friendships have all enabled my current understanding of disability to be based on who disabled people really are - what we really do - and how we represent ourselves. To return to Hockenberry, I experience a "harrowing twinge" at the thought of not having had these experiences, of remaining isolated in an "able" world, and missing the beauty and possibility of improvisation.

References

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- Some material found in this article is found in: Morrissey, M. 1998. "Changing Expectations: Shifting Narratives on Disability" in Nelson, C. L. and Kim A. Wilson, Eds. *Seeding the process of multicultural education*, 17-28. Minneapolis: Minnesota Inclusiveness Program.