

Personal Reflections on Disability Culture

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Abstract: Ten years ago, few of us knew what the phrase disability culture meant. Since then, there's been a proliferation of articles, books and discussions about this concept. The author reflects on changes of the past decade.

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The Blossoming Culture of Disability

Writing in the mid-1990s about disability culture, I described the emerging concept of disability culture:

“The existence of a disability culture is a relatively new and contested idea. Not surprising, perhaps, for a group that has long been described with terms like "in-valid," "impaired," "limited," "crippled," and so forth.”¹

I also perceived change in the air, as reflected in the following paragraph:

“Scholars would be hard-pressed to discover terms of hope, endearment, or ability associated with people with disabilities. But as rights and social standing have become more available to disabled individuals so too has the need and belief in the integrity of group, community, and cultural identity.”²

I then quoted my friend, the late scholar Kirk MacGugan, who wrote in an unpublished manuscript:

"To date, no one has written the history, of the Disability Rights movement or told the stories of the persons with disabilities who lived the movement that forever changed the lives of persons with disabilities in America." ³

I concluded that introductory section, called, “A Blossoming Culture of Disability,” with the following summation from two survey respondents:

“Another respondent offered two definitions of disability culture. ‘First it is the filter through which we people with disabilities experience

the world (shared experiences, & thoughtfully developed concepts). 2nd our expression of ourselves in writing, words, art, etc. as well as organizations, etc.’ Those two sentences concisely summarize the status of disability culture as it exists today.”⁴

Ten years later, I’ve been contemplating ways that the idea of disability culture has—and hasn’t—changed during the previous decade.

A Decade of Change

Perhaps the single most dramatic change during the past decade is the proliferation of discussions about disability culture. There are some obvious ways to quantify this explosion. A Yahoo search conducted December 24, 2003, entering the phrase, “Disability Culture,” turned up 5,740 entries. The same search on Google revealed 8,520 entries.

Looking at some of the sites returned by Google demonstrates how common the idea of disability culture has become during the last ten years. There are sites that specifically tout disability culture as the highlight of their product, for example, “The artwork of artists with disabilities is explored within the context of disability culture in the exhibit, 'Art, Disability & Expression'...”⁵ Or, “The culture and media these artist/activists are producing has come to be collectively called **Disability Culture...**”⁶ An Amazon.com customer named Carolyn, who calls herself “an enlightened PWD [person with a disability] has a Listmania! feature called, “An Introduction to Disability Culture.”⁷ C. Marfisi, a student of the Temple University Disability Studies program, presented a paper entitled, “Disability Culture-What’s the Purpose?” at the inaugural meeting of the Cultural Studies Association in Oakland, California, in June 2003.⁸

Each of the examples in the preceding paragraph came from the December 24, 2003, Google search. The now seemingly endless procession of sites about disability culture hardly ends there.

A webzine calling itself *Delirium: An Interdisciplinary Webzine of Culture and Criticism* (<http://www.deliriumjournal.org>) seeks submissions “in any genre or form, and from any disciplinary perspective, on any issue related to disability culture.”⁹ Another, newer journal, *Breath & Shadow*, intends to be a monthly journal of disability culture and literature. It is described as a journal that “will feature poetry, fiction, essays, interviews, drama, and other writing that examines the human experience of living with disability.”¹⁰

Times have changed since Kirk MacGugan despaired, in the early 1990s, that no one had written about the history of the disability rights movement. While Kirk did not live to see the implementation of disability studies programs, described in another article elsewhere in this issue, she was one of the people who provided the impetus for those who have survived to research and write about our movement.

And write we have. When I published *Investigating a Culture of Disability*, I wrote a section called, “Deviants, Invalids and Freedom Fighters: Historical Perceptions of People with Disabilities in the United States.”¹¹ A year earlier, journalist Joseph Shapiro, published *No Pity*, a journalistic analysis of some aspects about U.S. disability rights history.¹² Another journalist, Sonny Kleinfeld, actually wrote about us fifteen years earlier than that.¹³ The primary difference between Kleinfeld and Shapiro and what has followed has been that it has been us—people with disabilities ourselves—who are doing the writing.

Paul Longmore, perhaps the preeminent historian researching disability today, who himself has a disability, has become the co-editor of a New York University Press series about disability. The first volume in that series is appropriately called *The New Disability History*.¹⁴ Longmore also recently published a collection of essays with the intriguing title of *Why I Burned My Book*.¹⁵

A few years ago, in 1999, I had the privilege of co-facilitating a teleconference with Longmore and others, sponsored by ILRU (Independent Living Research Utilization) called "Freedom of Movement."¹⁶ The teleconference and the monograph that accompanied it discussed disability history as we knew it at that time. I recall a caller asking if we knew much about minority disability history, like that of Hispanics or African-Americans. I responded that no, we knew almost nothing about the disability history of any groups beyond those of white Americans.

Longmore disagreed. He said we had barely scratched the historical surface of any groups of people with disabilities. He further contended that he knew of no area that would not benefit from more research, including the group of middle-class white Americans with disabilities.

While Longmore's statement may still be accurate, it's a little less accurate than it was four years ago. That's because we have been researching and writing about ourselves. As an indication of that trend an alphabetical list follows of just some of the books about disability, from the viewpoint of people with disabilities, that have been published since 1994:

Barnes, Colin and Geof Mercer, *Disability*, (Cambridge, UK, Polity, 2003).

Bauby, Jean Dominique, *The Diving Bell and the Butterfly* (New York: Vintage, 1998).

Bowe, Frank G., *Physical, Sensory, and Health Disabilities: An Introduction* (Upper Saddle River, NJ: Prentice-Hall, 2000).

Bragg, Lois, ed., *Deaf World: A Historical Reader and Primary Sourcebook* (New York: NYU Press, 2001).

Brown, Steven E., *Movie Stars and Sensuous Scars: Essays on the Journey from Disability Shame to Disability Pride* (New York: People with Disabilities Press, 2003).

Burch, Susan, *Signs of Resistance: American Deaf Cultural History, 1900 to World War II* (New York, NYU, 2003).

Charlton, James I., *Nothing About Us Without Us: Disability Oppression and Empowerment* (Berkeley: California, 1998).

Crutchfield, Susan and Marcy Epstein, eds., *Points of Contact: Disability, Art, and Culture* (Ann Arbor: University of Michigan, 2000).

Davis, Lennard J., *Bending Over Backwards: Disability, Dismodernism, and Other Difficult Positions* (New York: NYU, 2002).

- Epstein, Susan, *We Can Make It: Stories of Disabled Women in Developing Countries* (Geneva, Switzerland: International Labour Organization, 1997).
- Fleischer, Doris Zames and Frieda Zames, *The Disability Rights Movement: From Charity to Confrontation* (Philadelphia: Temple, 2001).
- Fries, Kenny, *Body, Remember: A Memoir* (NY: Dutton, 1997).
- Fries, Kenny, *Staring Back: The Disability Experience from The Inside Out* (NY: Plume, 1997).
- Hockenberry, John, *Moving Violations: War Zones, Wheelchairs, and Declarations of Independence* (New York: Hyperion, 1995).
- Husson, Therese-Adele, translated and with commentary by Catherine Kudlick and Zina Weygand, *Reflections: The Life and Writings of a Young Blind Woman in Post-Revolutionary France* (New York: NYU Press, 2001).
- Jacobson, Denise Sherer, *The Question of David: A Disabled Mother's Journey Through Adoption, Family, and Life* (Available from Creative Arts Book Company, 833 Bancroft Way, Berkeley, CA 94710, 1999).
- Johnson, Mary, *Make Them Go Away: Clint Eastwood, Christopher Reeve and The Case Against Disability Rights* (Louisville, KY: Advocado, 2003).
- Linton, Simi, *Claiming Disability: Knowledge and Identity* (NY: New York University, 1998).
- Mackelprang, Romel W. and Richard O. Salsgiver, *Disability: A Diversity Model Approach in Human Service Practice* (Pacific Grove, CA: Brookes/Cole, 1999).
- Mairs, Nancy, *Waist-High in The World: A Life Among the Nondisabled* (Boston: Beacon, 1996).
- Pelka, Fred, *The ABC-CLIO Companion to Disability Rights* (Santa Barbara: ABC-CLIO, 1997).
- Priestley, Mark, *Disability: A Life Course Approach* (Cambridge, UK: Polity, 2003).
- Russell, Marta, *Beyond Ramps: Disability at the End of the Social Contract: A Warning from an Uppity Crip* (Monroe, ME: Common Courage, 1998).
- Saunders, Kathy, *Happy Ever Afters: A Storybook Guide to Teaching Children about Disability* (Staffordshire, England: Trentham Books, 2000).
- Shakespeare, Tom, Kath Gillespie-Sells & Dominic Davies, *The Sexual Politics of Disability: Untold Desires* (London: Cassell, 1996).

Stone, Karen G., *Awakening to Disability: Nothing About Us Without Us* (Volcano Press, PO Box 270, Volcano, CA, 95689, 1997).

Thompson, Tracy, *The Beast: A Reckoning with Depression* (NY: G.P. Putnam's Sons, 1995).

Titchkosky, Tanya, *Disability, Self, and Society* (Toronto, University of Toronto, 2003).

Wisehart, Cynthia, *Storms and Illuminations: 18 Years of Access Theatre* (Available from Emily Publications, 2428 Chapala St., Santa Barbara, CA 93105, 1997).

These thirty or so books represent the tip of the iceberg. There are many more magazine and journal articles, websites, newsletters, movies and videos, music, and other examples of disability culture from the past decade. Some of the commonalities of the preceding list, in addition to disability, include expanding our discussions to include all disability groups from all over the world.

Although we certainly have yet to arrive at an international cross-disability culture, as the world gets smaller in size because of our increasing communication advances we are moving toward that direction. With the institutionalization of academic programs, classes about disability, Internet sites, and presentations about our culture I can imagine only that these products will increase in the coming years.

What Hasn't Changed?

I entitled a section of *Investigating a Culture of Disability*, "There Can't Be a Disability Culture, Because..." and then listed some of the reasons why people in the early 1990s balked at the idea.¹⁷ The most intriguing argument concerned people from diverse ethnic, geographic, racial, and gender backgrounds who all claimed they would not want a disability culture to exist because they were Americans.

That response puzzled me for a long time. Especially since the individuals who made these statements clearly fit more than one cultural group, and were proud of all of them. An example close to an actual person would be an Asian-American, lesbian, Christian. I finally concluded that the reason these persons resisted the idea of disability culture was because they did not want one more negative label.

I think this analysis has been borne out by the changes people with disabilities in general have undergone since the early 1990s in our perceptions about ourselves. The results of the Google search, described earlier seem to bear witness to this. And, yet... I wonder?

I think about the article in this forum written by Gilson and DePoy.¹⁸ They argue that in a survey of people who for the most part do not fit into either the academic or the Movement world of disability studies or disability rights, the idea of disability culture is meaningless. They speculate that disability culture may have more of an impact on academia than elsewhere. My first inclination is to argue with this conclusion and cite the kinds of data I've listed previously in this article. But, perhaps that would be too hasty.

Shame and Pride

I recently watched an Oprah Winfrey show where she described her experiences in traveling to South Africa about a year ago. She quoted pop singer, Bono, who has called the rate of HIV infection in South Africa the greatest moral issue of our time. As a student recently taught me, the U. S. Courts have declared HIV to be a disability under the Americans with Disabilities Act. So one could say by that definition the rate of disability is the greatest moral issue of our time.

I don't know if that's accurate. But I do know this. While we bandy about figures about how many of us have disabilities, most people do not identify with disability as a culture, a movement, or a right. Most people still see disability as an impairment.

How do I know this?

Because whatever figure is used: 54 million Americans; half-the-planet; 1 in 5; whatever, most people who have what we call disabilities still find themselves discussing whatever their condition might be as an impairment.

I know this because of studies like Gilson's and DePoy's. I know this because if 54 million Americans actually considered themselves to be part of a disability rights movement and acted upon that, we could not have the horrendous figures of un- and under-employment that we all know about. We could not have the equally appalling figures of educational or income disparity.

Paraphrasing something a friend of mine said long ago, if all people with disabilities realized the enormous substandard of living many of us put up with, we'd be marching in the streets. But most of us are not.

I know most people with disabilities don't identify with disability rights or culture because independent living centers have a hard time recruiting people to be on, and stay on, their Boards of Directors. I know this because actors with disabilities have a hard time finding roles. I know this because writers with disabilities have a difficult time finding mainstream publishers. I know this because Oprah Winfrey, the same person who has now dedicated herself to the children of South Africa, has a hard time acknowledging disability beyond stories of inspiration.

My wife, Lillian Gonzales Brown, who's lived with a lifelong disability and who has been involved with the disability rights movement longer than I, made a salient observation several years ago. She talked about how people with disabilities, if they were lucky, made a journey from shame to pride.

Shame, because that's how we've been taught to view ourselves as people with disabilities from the time we were born.

Pride, because as we've learned more about ourselves, and how strong we have had to be to survive as a person with a disability in a decidedly disability-unfriendly world, we have come to recognize our own skills and fortitude. Pride because at long last some of us, at least, have been able to recognize what we, both as individuals and as groups, have been able to accomplish.

Like all paths, the one from disability shame to disability pride has pitfalls. Like disability itself, it's a dynamic journey, not a static one. Some days we remember to hold our heads up high and be proud of who we are. Other days the shame that has been ingrained in us for so long takes hold.

I continue to believe that disability culture is important because it is one way we can convey to the world that we are proud of who we are. This does not mean that I want to separate myself from the nondisabled world because I'm proud of who I am as a person with a disability. But it does mean that I want the nondisabled world—and people with disabilities, too—to

recognize that in order to benefit from what I have to offer, the world needs to change to integrate me into it, with my disability(ies); and not visa versa.

I continue to argue that this path is the one that's good for the world for a very simple reason. I, like every other living creature, have something to offer—the benefit of my life's experience, my knowledge, my passion, myself. If you—or anyone else, is not willing to make the leap to include us, who loses out more—me or you?

I know the nondisabled culture. It's everywhere. You are much less likely to know disability culture—so far.

When looked at in this light, where is the shame? And who should be proud?

Endnotes

¹ Brown, Steven E., *Investigating a Culture of Disability: Final Report* (Las Cruces, N. M.: Institute on Disability Culture, 1994), 9.

² *Ibid.*

³ MacGugan, K. (1991). *An interpretive history of the American disability rights movement, 1920-1990*.

Unpublished manuscript. Quoted in Brown, *Investigating a Culture of Disability*, 9.

⁴ Brown, *Investigating a Culture of Disability*, 12.

⁵ www.vsarts.org/gallery/exhibits/disability/disabculture.html

⁶ www.disabilityhistory.org/dwa/edge/curriculum/cult_contenta8.htm

⁷ <http://www.amazon.com/exec/obidos/tg/listmania/list-browse/-/2HD21W4CPA64G/002-7131589-2403247>

⁸ <http://disabilities.temple.edu/programs/ds/culture.htm>

⁹ <http://www.english.upenn.edu/CFP/archive/Cultural-Historical/0117.html>

¹⁰ www.dimenet.com/disculture

¹¹ 20-65.

¹² Shapiro, Joseph P., *No Pity: People with Disabilities Forging a New Civil Rights Movement* (New York: Times Books, 1993).

¹³ Kleinfield, Sonny, *The Hidden Minority: A Profile of Handicapped Americans* (Boston: Atlantic Monthly Press, 1979).

¹⁴ Longmore, Paul K. and Lauri Umansky, eds., *The New Disability History: American Perspectives* (New York: NYU Press, 2001).

¹⁵ Longmore, Paul K., *Why I Burned My Book and Other Essays on Disability* (Philadelphia: Temple, 2003).

¹⁶ Brown, Steven E., *Freedom of Movement: Independent Living History and Philosophy* (Houston: ILRU, 2000; Available from 2323 S. Shepherd, Suite 1000, Houston, TX 77019, <http://www.ilru.org>).

¹⁷ Brown, *Investigating a Culture of Disability*, 76-78.

¹⁸ Gilson, Stephen French and Elizabeth DePoy, "Disability, Identity, And Cultural Diversity," *Review of Disability Studies* I (1) (January 2004), 20-22.