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Annotation

Brown, Co-Founder of the Institute on Disability Culture, in the United States, takes an opportunity to review a decade of investigating and promoting disability culture. This piece quotes liberally from previous Brown publications, and attempts to put into perspective both opinions that challenge the concept of a disability culture and those that support it.

Keywords:

Disability culture, disability rights, disability studies.

"POSTER KIDS NO MORE:"

PERSPECTIVES ABOUT THE NO-LONGER EMERGING (IN FACT, VIBRANT) DISABILITY CULTURE

by

Steven E. Brown, 1998
Institute on Disability Culture

They thought we'd keep on smiling for years to come
They thought we'd just be helpless and mild
Without our own opinion they could just cash in on
Their image of the crippled child.

But Timmy and Tammy are rebelling
Their Easter seals have come unglued
They won't be apathetic; they refuse to look pathetic
They're changing their point of view.
They're poster kids no more,
Poster kids no more!

Throw away those images of yesterday
They don't reflect our lives today
Don't tug at the heartstrings, that's not a smart thing
That's not the enlightened way.

It's time to change these ancient attitudes
And show the world a thing or two
If you've got a disability, it's just a different way to be
And you can be proud of it too!

Now the poster kids are living life in their own way
They're everywhere doing it all,
You'll find us in real life, not in a still life
Not with our backs to the wall.

"Poster Kids No More" (title, thanks to Shelley Tremain) is from the cassette entitled, "The Fishing is Free," by Jane Field, a Canadian folksinger with a disability. Jane is only one of a burgeoning group of musicians with disabilities, many of whom are writing about the disability experience. What makes her distinct is the large doses of humor in her songwriting.

It is simply impossible (at least for me) to discuss disability culture from a purely scholarly viewpoint. Despite (or perhaps because of) my academic training as a historian I am unwilling to remove the concept of disability culture from the context of cultural expressions.

Disability Culture was the theme of the Fall 1995 issue of Disability Studies Quarterly, for which I served as guest editor. My contributions to that issue consisted of an introduction; a short, annotated bibliography; and a poem. I purposely chose not to include an essay in that issue because I felt I had become ubiquitous in promoting disability culture. Although I do not regret that decision, I have been both excited and frustrated at times by the evolution of the discussion. I hope in this article to retreat a bit in time, review the history of this discussion, and describe its current status.

As always, I begin with caveats, expressing my own biases and shortcomings: 1) When discussing disability culture I focus on cross-disability culture, meaning a movement that crosses all disabilities and all cultural groups. I do not do this because I believe that the meaning of disability culture is the same for everyone, but because I (and the discussion) have to start somewhere; 2) I write about disability culture primarily in the United States, because, once again, one has to start somewhere. There is a thriving, energetic, intellectual discussion of disability culture in England. One of these days I hope to experience it firsthand and write about it. But, the concept of disability culture has also excited people of every nationality that has encountered and discussed it; 3) I examine primarily a British-influenced middle class history and culture. The reason for this is endemic to American history. This background has permeated our national history, politics, culture, and most importantly, the people who have recorded it. It is in part a reaction to this characteristic of our academic settings that disciplines such as social and cultural history, ethnic studies, and women's studies developed. It is also one of the primary motivations for the development of disability studies. The need for discussions of disability culture from a non-British-based, non-middle class perspective are as needed as they are for other topics; and, 4) I am a white, middle class male and am writing from that perspective as well as any other one.

The deaf have got sign language,

the blind have got their dogs
Their loyal trusted guides are at their sides.
Well everyone has their vices, but we've got our devices
Oh, don't you envy us our privileged lives?
(from Jane Field, "The Fishing is Free")

> "This is culture--it runs deep and embodies perceptions that appear "natural" only to the insider....In fact, a method for identifying cultural elements taught to anthropologists-in-training is that whatever in a culture is stated as if it were *natural* is precisely what is *cultural*." (Scheer, 248)

Three years ago, I wrote:

> Sometime in my personal identity search and its context within the heightening flame of my incendiary involvement as a participant in the Disability Rights Movement I became intrigued, then impassioned, with the notion of a disability culture.
>
> In reconstructing this process during the past year or two I have found a 1985 article in the Disability Rag which began to hint at this idea: "Those of us with the capability to communicate are finding that we can channel our frustrations outward to our brothers and sisters, who really *do* understand disability. I think it's that understanding that defines, for me, The Disability Community." (Hooper, 1985, 5). Several subsequent articles also discussed this concept. (Hirsch, 1987, 38-39; Johnson, 1987; Peters, 1986a, 25; Peters, 1986b, 20)
>
> I also remember the magazine's continuing search for "Disability Cool." But I have no memory of what first sparked my ongoing need to search for the meaning of disability culture. I remember quite clearly, however, the first two times I publicly approached these notions. They both occurred at conferences held within a week of one another in May of 1990.

In Tulsa, Oklahoma, I facilitated and participated in a panel called simply "Disability Culture." A group of about six of us informally discussed the idea of a disability culture. None of us had prepared talks. Rather we spent the panel time examining our own questions and ideas about the notion of a disability culture. Did such a culture exist? If it did, was it beneficial? What characteristics comprised such a culture? How did it affect our lives? How might it impact nondisabled people? Each participant wrestled with these queries and offered some tentative answers.

> Earlier in the week, another panel I had conceived, facilitated, and participated in transpired in Washington, D.C. at the annual conference of the National Council on Independent Living. Called "Speakers of the Independent Living Movement: Voices of Independence," three panelists shared our stories for about forty-five minutes with an audience of a couple hundred people. When we finished the exciting part began. We left plenty of time for audience participation. But it was not enough. Everyone in the audience, it seemed, had a story they wished to share. The energy in the room and in the halls after we concluded was overpowering. There was no question that people were hungry for an abundance of stories--their own and others. (1994, 75-76)

Not long after these experiences, I moved to California to take a job at the World Institute on Disability in Oakland. The San Francisco Bay Area is well-known as a place that accommodates differences of many kinds. One of its charms is a distinct physical presence, sometimes defined by the fog coming in off the Bay. In a very real way, my previous ideas of a concept of culture found location in this area.

One of my first assignments was to work with a planning committee for an international conference which would celebrate the twentieth anniversary of the founding of Berkeley's Center for Independent Living and look at the role of disability themes in the next century. The conference itself was entitled, "Independent Living: Preparing for the Twenty-first Century." I facilitated and presented on a panel about the "History and Mythology of Independent Living." Paul Longmore presented his findings about the League for the Physically Handicapped, a 1930s group of disabled protesters, who engaged in picketing, sit-ins, and boycotts because New Deal programs excluded people with disabilities. Jeanette Harvey discussed the importance of storytelling in her life and others with disabilities. Actor Neil Marcus shared some scenes from his creative perspectives on life. I delivered a paper entitled "Creating a Disability Mythology," which was later published in the International Journal of Rehabilitation Research. I argued that:

> We must also embrace ourselves. As we are. With our disabilities. With our varied needs. With our diverse strengths and weaknesses. To embrace ourselves as we know ourselves--with our disabilities.
>
> I propose, in fact, even more. I wish to see us not only recognize our disabilities, but to celebrate them. To sing clearly and out loud our praises, our struggles, our failures, and our successes: our lives. (229)

Once again, the response of the audience was overwhelming. They wanted to hear more, to know more, to be a part of this experience.

> I began exploring the subject in a variety of ways, reading as much as I could get my hands on, writing about my evolving thinking of the concept, and speaking about it whenever possible. One reaction, in particular, seemed surprising.
>
> Had I encountered this particular response only once it probably would have vanished from my memory. But it came up several times. Each time this specific argument was submitted it was by people with disabilities, of both genders and many different ethnic, racial, and presumably religious backgrounds. Every person who offered this rejoinder said almost exactly the same thing: they could not be a part of a disability culture because they were Americans.
>
> Simple observation indicated that many of those who proffered this rebuttal would have no trouble identifying with numerous other cultures--racial, ethnic, feminist, religious, geographic, sexual preferences--the list seemed innumerable. But the theory of a disability culture harbored some kind of threat to their national identity that none of their other cultural traits betrayed. The most plausible explanation seemed to be that the role of people with disabilities in this society is so denigrated that these individuals feared identification with disability would threaten whatever their sought-after social goals might be. (1994, 79)

Disability culture was simply a concept that I had to explore in more depth. At the same time, I learned about the Mary Switzer Rehabilitation Research Fellowships awarded by the National Institute on Disability and Rehabilitation Research (NIDRR). I applied and received funding to investigate disability culture. Both my proposal and the year-end Investigating a Culture of Disability: Final Report began in similar ways:

> 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.
>
> 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.
>
> The debate over the establishment and desirability of a culture of disability engages the minds of people who wrestle with disability issues on a more and more frequent basis. Dr. Kirk MacGugan, a recent scholar of disability rights and history, who passed away in late 1993, declared that, "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." (MacGugan, 1991).
>
> In 1984, the Association on Handicapped Student Service Programs in Post-Secondary Education (AHSSPPE, recently changed to Association on Higher Education and Disability, or AHEAD) sponsored papers addressing "Is There a Culture of Disability?" The presenters, David Pfeiffer of Suffolk University and Andrea Schein of the University of Massachusetts-Boston answered this question in the affirmative. Conference Proceedings, which include both papers, represent the first documented exploration of the idea of disability culture. (Pfeiffer, 1984; Schein, 1984)
>
> The first concrete realization of the existence of a culture of disability occurred on the campus of the University of Minnesota where a group of disabled students parlayed a research project about the meanings of disability issues into the establishment of a Disabled Student Cultural Center. (G. Chelberg, personal communication, April 1992).
>
> As discussions concerning the existence of a disability culture and implementation of organizations like the Disabled Student Cultural Center and the more recent Institute on Disability Culture are in their nascent stages, and while many of the most recent leaders of the disability rights movement still live, it is an opportune time to investigate its parameters and delve into future meanings. (9-10)

The introductory section of the *Final Report* continues:

> When I began to investigate the culture of disability I believed that it existed, that it was an important component of living with a disability in this world, and that the benefits of its existence would outweigh any deleterious effects. I still subscribe to these values.
>
> The greatest surprise during the period of this study has been the complexity of issues and the proliferation of examples. I have endeavored to address at least some of the complexities throughout the text. But the mushrooming examples seem endless.
>
> The *Disability Rag & ReSource* arrived in the mail today. In it is the second installment of Cheryl Marie Wade's column, "Disability Culture Rap." My pile of reading has grown exponentially while I have been writing. I reluctantly stopped reading about disability culture when I began to write because every time I turned around it seemed like there was something additional to document, to read, to analyze, to observe.
>
> The Disability Culture Movement is running full steam ahead. While I write, and you read, multiplying numbers of people are creating rapidly increasing examples of disability culture....

> I realized quickly after I submitted a literature review as one method of research inquiry that I had neglected art, music, movies, and other examples of cultural artifacts that abounded. As is apparent from the text of this work, I have continued to explore those alternative forms of cultural exposition. And I have immersed myself in literature. But every day, as I look around my office and my home, I see more to read. And, every day, as I read, I am introduced to new materials to read. The list seems endless.
>
> The field of disability writing is not an easy one to assess, or to access. Books about the subject of disability, and disability culture, are to be found in diverse sections of libraries and bookstores. In the past few months, I have taken to wandering into new bookstores and inquiring about a disability section. A few have such a beast, but what one finds in it ranges from self-help books to autobiographies to disability-specific stories to a conglomeration of other topics. Any of these subjects might be found in other sections as well.
>
> To further complicate matters, some of the best information about disability, and disability culture, is found in neither books nor journals, but in newsletters, brochures, fliers, and other kinds of media that are difficult to locate in any systemic way. The result of this miscellany of materials has been an attempt on my part to read, view, hear, and locate all I could. But in this process, I have overlooked journal articles, missed books, and certainly missed much of what is out there to be found about disability culture. (10-11)

During the year of researching and writing the Final Report, my wife and partner, Lillian Gonzales Brown, and I moved to Las Cruces, New Mexico and created the Institute on Disability Culture, a not-for-profit organization, which specializes as our purpose states in "promoting pride in the history, activities, and cultural identity of individuals with disabilities everywhere." During our first two years we presented many trainings and workshops about disability rights history and philosophy and organizational development. Always from a perspective of promoting pride in who we are as individuals with disabilities and usually beginning with poetry (because that is my most accessible art form) and including music, overheads, and other cultural representations. We were also asked once during those first two years to present a workshop about disability culture at a conference that was geared toward diversity. Three people showed up and two were friends.

But all that has changed in our third year, 1996! We have been asked to present three workshops on disability culture all over the country and have made speeches about the subject at two other conferences. In August of 1996, I was a panelist at a Paralympic Congress workshop on disability culture, hosted by longtime disability rights activist, John Kemp, newly appointed President and CEO of Very Special Arts (VSA). VSA then held a Disability Culture Focus

Group, in which we participated, in October of 1996, to discuss the concept and ways in which it might be incorporated into that organization.

> No one knows just what to call us
> which label should befall us,
> And they're some dandy terms from which to choose.
> My favourite's "wheel-chair bound" cause it has a
> bondage sound
> Oh its fun to guess what term they're going to use.
> (from Field, "The Fishing is Free")

Ten years after discussing and writing about the concept of disability culture people started asking over and over again for a concise definition of disability culture. I could not respond. I had no way of taking all the ideas that had been percolating for so long about so many different aspects of disability culture and boil them down to a handy definition. But people kept asking. And one day I gave it a shot:

> People with disabilities have forged a group identity. We share a common history of oppression and a common bond of resilience. We generate art, music, literature, and other expressions of our lives, our culture, infused from our experience of disability. Most importantly, we are proud of ourselves as people with disabilities. We claim our disabilities with pride as part of our identity. We are who we are: we are people with disabilities. (Brown, 1996c, 32)

Between the time the preceding definition was written and its publication, the Summer 1996 issue of Disabilities Studies Quarterly arrived. Devoted to the theme of Developmental Disabilities, the concepts of identity and culture kept recurring.

Steve Taylor of the Center on Human Policy at Syracuse University wrote "...the concepts of disability culture and a disabled identity are foreign to people labeled mentally retarded." He argued that "If the starting point for inquiries into the disability experience is the point of view of disabled persons themselves, then we must take seriously the perspectives of people defined as mentally retarded....the concept of culture carries negative meanings....Whereas many leaders of the disability rights movement claim pride in an identity as a disabled person, representatives of the growing "self-advocacy" movement reject the mentally retarded tag and insist on being defined as "people first.'" The very next sentence is: "What draws people labeled mentally retarded together is a recognition of their oppression and determination to oppose how they have been defined and treated in society. Coming together represents an affirmation and celebration of common humanity." (5)

As I read and reread Taylor's statements I remain befuddled by the distinctions between the definition I have offered and his notion of affirmation and celebration. The only barrier between the two perspectives that I can grab concern the phrases "people labeled mentally retarded," "people first," and "disabled person."

And so I return to my beginnings fifteen years ago and follow more than a decade of contemplation about identity (the subject of another essay in the same DSQ by Susan Gabel).

> I read as much about independent living and disability in general as I could get my hands on. In the early 1980s, that led to an immediate immersion into debates about the use of language.
>
> The crux of the verbal dispute appeared to be about usage of the words "handicapped" and "disabled." Two aspects of the controversy seemed to be highlighted in what I read and talked about with my new colleagues.
>
> First, many people struggled with both of these terms. But the associations of the word "handicapped" seemed to remind people of a time they despised. It might, for instance, have represented being institutionalized in a school for the handicapped. Or it might have been connected with laws or programs which people with disabilities were rebelling against were used.
>
> In addition, "'handicapped' connotes the miserable image of a person on the street corner with a 'handy cap' in hand, begging for money. The word 'disability' may not be perfect, as it still implies a negative: what a person cannot do, but it has become the most widely used and accepted [term] among people with disabilities." (Kailes, 1992, 3)
>
> Organizations most sensitive to this debate tended to change their names in the mid to late 1980s. Examples include the President's Committee on Employment of the Handicapped which became the President's Committee on the Employment of People with Disabilities (PCEPD) or the National Council on the Handicapped which became the National Council on Disability.
>
> The key to unlocking the crux of this dispute is to recognize that disabled people must choose appropriate language

of our own volition. A great American author and social critic, James Baldwin, famed for his passionate analyses of the black civil rights movement, wrote:

> When I was young...it was an insult to be called black. The blacks have now taken over this once pejorative term and made of it a rallying cry and a badge of honor and are teaching their children to be proud that they are black." (189)

Which leads us directly into the second bone of contention of the language debate: that it doesn't matter anyway. Disability policy consultant June Kailes wrote that:

> Some people say that language is a trivial concern and the disability rights movement has much more pressing problems to solve. Language structures our reality.... Disability advocates must become aware of the power of language." (2)

As I continued my own early reading and discussions I discovered that the debate over language seemed not only important, but essential to a more complete investigation into the meaning of disability. As I struggled with what I called myself and how I fit into what seem like a brand new world of disability I also struggled with coming to terms with a different identity. I began, in fact, to realize that I was coming to identify myself as a person with a disability superseding all my other identifications--as husband, father, historian, friend, etc. (Brown, 1986, 9-10)

What was there about recognizing my disabling condition and the status I now felt from it that hit me with such a wallop? It was a fiery combination. My newfound disability awareness led to a profound and extremely positive reevaluation of my own personal identity. (Ibid.) But with that awakening also came the realization that I was making a choice to live as a disabled person in a nondisabled world.

> To return to Baldwin: "To be liberated from the stigma of blackness by embracing it is to cease, forever, one's interior argument and collaboration with the author's of one's degradation." (Brown, 1992, 229; Baldwin 1972, 190)

Baldwin realized that the oft-heralded goal of integration contained a seldom detected pitfall: a desire not only to be equal in status with the dominant white culture, but to become, for all intents and purposes, a member of that group. The evil underside of civil rights integration for black people was to so thoroughly neglect one's black heritage that one did not only attain equality with white Americans, one became, in all but skin color, white. How does a black person become a white one in contemporary American society? By forgetting, or purposely rejecting, one's black roots.

Baldwin's incisive, angry, and agonizing plea for his black sisters and brothers to remember their cultural legacy is a mandatory lesson for disabled people:

> Living in a society which forces us to examine ourselves by inapplicable standards is the plight in which every individual with a disability must find ourselves. The very word, disability, implies in some way a difference from the more positive word "ability." We all know, however, people with disabilities who are both more and less capable in various areas than our nondisabled peers. Rather than continuing to fight to fit into a nondisabled world, many of us have argued for decades that that world must be changed to embrace and adapt to us....As long as we buy into the mainstream notion of success through overcoming we are submitting to an ideal to which we cannot possibly remain true. No matter what we do, we remain disabled. (Brown, 1992, 229) (entire quote in Brown, 1994, 70-72)

In 1996, I consider myself a person with a disability, meaning that I am a person first, but that my having a disability is one of the most important components of my person. It affects every aspect of my life. In the phrase "a person with a disability," "with a disability," is an adjective modifying the "person." So, too, in the phrases "people labeled mentally retarded," "people first," and "disabled person," the "person" is the noun being modified by "labeled mentally retarded," "first," and "disabled."

I object to none of these phrases. My resistance comes in when the disability becomes the noun as in "there go the disabled," here come "the mentally retarded," "the handicapped are destroying the school system." Although there are many discussions of language regarding people with disabilities I still like June Kailes' analyses in "Language is not a Trivial Concern!" the best.

I have quoted liberally from the <u>Final Report</u> because many of my views in it still hold and because it remains the most extensive discussion of the culture of disability. But it is no longer one of the few.

> Well don't you wish that you were disabled?
> Disabled is the better way to be
> There are special entrances in stores, they let us in
> through the back doors
> Oh don't you wish that you were just like me?
> (from Field, "The Fishing is Free")

When Lillian and I founded the Institute on Disability Culture in early 1994, a handful of names arose when the phrase Disability Culture entered a conversation, including Carol Gill, Gene Chelberg, Cheryl Marie Wade, Neil Marcus, Bruce Curtis, David Pfeiffer, Karen Hirsch, Paul Longmore, Victoria Ann-Lewis and us. Individuals who crossed academic, arts, and activists backgrounds, all of us were discussing the culture. Many more people were out there actually practicing the culture. So I could write in the same article in which I offered a definition that "while we may argue about its existence or characteristics the culture itself goes on with or without us." We are no longer a handful. "Art is burgeoning. Writing is increasing. Teaching is taking place. Children are learning about their history. Values are being explored. Music is being composed. Humor is generating laughter. Members of the culture are being born and dying. Life goes on." (Brown, 1996c, 32)

As does the debate. Anthropologist Jessica Scheer, whose comments about anthropologists-in-training are quoted at the beginning of this article, has been one of the most vociferous skeptics about the idea of a disability culture. In a recent article, entitled "Culture and Disability: An Anthropological Point of View," Scheer offers several concerns about the existence of a disability culture.

Before quoting her directly, let's review excerpts from the first two known articles written about disability culture. David Pfeiffer and Andrea Schein both traced the roots of the meaning of the word, "culture," to anthropological origins. Schein contended that "culture" has taken on various meanings over the past hundred years, including an appreciation of the finer things in life, a distinctive body of customs, and a learned body of traditions within a society. (Conference Proceedings, 135). She then linked this evolution of terminology to an evolution of thinking about disability in stating that "The issue of disability has passed through a mirror from being perceived as an unfortunate medical problem to a new recognition of the denial of basic citizenship rights to a disenfranchised minority group." (ibid., 137). Schein's conclusion was that "All over the United States, there are people with a wide range of disabilities who understand and share the central concepts of the disability sub-culture." (ibid, 137).

Pfeiffer argued that the culture of disability is learned. "In conclusion, when the artifacts, the mental products, the social organizations, and the coping mechanisms of disabled persons are brought together, it is seen that the culture is learned, shared, interrelated, cumulative, and diverse. A culture of disability does exist." (ibid, 132).

Pfeiffer and Schein both paid tribute to anthropologists and their definitions of culture. Scheer contends that "Although the concept of culture has not been used to analyze the disability experience in American society, the identification of cultural patterns such as disability subcultures and social liminality has provided useful insights about the social consequences of having a disability that have been accepted by most social scientists." (245)

One cannot discuss the above paragraph without bringing up Robert Murphy, with whom Scheer studied and wrote. In The Body Silent, Murphy emphasizes the status of disability as a liminal condition, halfway between life and death. Yet, "Murphy's own description of the liminal status of disability might just as aptly apply to his own work--standing at the crossroads between perceptions of disability as a negative condition making it difficult to function in society and today's refined idea of disability as a natural process of life which is not only *not* completely negative, but has characteristics non-disabled society could benefit from emulating." (Brown, 1996a, 274)

> In The Body Silent, he merged his scholarly training and personal examinations of disability into a strange combination of perceptive commentary and frustrating inability to move past disability's traditional negative images. He opined that, "Disability is not simply a physical affair for us; it is our ontology, a condition of our being in the world." (1987, 90)
>
> Murphy died in 1990. The Body Silent was first published in 1987. It was reproduced in 1990 following many positive reviews.
>
> Murphy is admittedly not a detached witness, but he does claim his academic discipline of anthropology provides a viable method for documenting a social history of a "social malady." He maintains that the "lessons to be learned from paralysis have profound meaning for" evaluating conflicts between the individual and culture. Murphy gravitates from the specific to the grandiose, finally concluding that, "the study of paralysis is a splendid arena for viewing this struggle of the individual against society, for the disabled are not a breed apart but a metaphor for the human condition." (3-5)
>
> The anthropologist continued that "our shared attitudes as disabled people override the old hierarchies of age, education, and occupation, and they wash out many sex-role barriers as well. (134) No matter how many positive aspects of disability Murphy catalogs in his study, including an awareness of various rights movements, independent living and disability advocacy, he cannot move past his own socialization about disability. This is apparent in his description of the four most far-reaching changes in the consciousness of people with disabilities: "lowered self-esteem; invasion and occupation of thoughts by physical deficits; strong, undercurrent of anger; and acquisition of new, total, and undesirable identity." (108)
>
> Murphy remains an excellent example of someone who comes to an understanding of one aspect of disability,

> but misses how it might have profound positive consequences for someone. What he was apparently unable to do is make the leap from the oppressiveness of disability to its potential for liberation. (Brown, 1994, 95-96)

Scheer contends that "This process of understanding shared life experiences and learning to identify oneself as being like others is not what anthropologists technically define as culture, but it is what disability activists mean when they use the term *culture* in the vernacular." (253) Once again I am failing the test of making distinctions in an author's arguments. In the anthropologists-in-training quote, Scheer states that "whatever in a culture is stated as if it were *natural* is precisely what is *cultural*." When does "understanding shared life experiences" stop becoming *natural* and start becoming *artificial* (my word) and not *cultural*?

I would argue that there are at least three difficulties in the anthropological denial of disability as a culture. The first is that the definition of "culture" itself is slippery, whether attempted by anthropologists, historians, sociologists, or any other discipline. There is in fact a new academic discipline called "Cultural Studies." Many different facets of life are explored by practitioners of this new field of study. I will not attempt to define culture here. I have discussed the concept in detail in the Final Report. (76-109) Suffice it to say that there are almost as many definitions of culture as there are people writing about it.

The second difficulty is fear. Scheer expresses this well: "...people with disabilities who do not have shared institutional experiences often do not come into contact with many other people with disabilities, and when they do, they often tend to avoid each other as a way to minimize their shared stigma." (246)

When Lillian and I train, she often describes a journey from disability shame to disability pride. (Perhaps this is the time to say that I am the writer in the team, but that much of what I say and think has come from conversations with Lillian and discussions that arise during our trainings). As Scheer states people with disabilities have learned a shared stigma. "[This] has been the most common concept used by social scientists to analyze the devaluation and marginality of people with disabilities in contemporary American society." (245) I don't think anyone would argue that people with disabilities have been discounted, marginalized, and, in fact, killed because of our disabilities and for no other reason. We have also been institutionalized, segregated, and oppressed. As a group we have a common history of being denied education, employment, marriage, children, and decision-making. Who among us could live with that historical litany and not feel stigmatized or shamed?

Marginality. Stigma. Shame. Commonalities that would prevent many people from associating with peers. Especially when one buys into the stigma and shame that our society has presented to people with disabilities since the beginning of our history. Whether one is disabled or not, we have all been taught that disability is a negative, devalued condition. The phrase, "I'd rather be dead than disabled," has been stated so often that one does not question its origin, but accepts that it is the underlying attitude toward disability in American society.

So when someone with a disability talks about their condition as something that could instill pride, is it surprising that the majority of Americans have difficulty assimilating that concept. Of course not. That is why we discuss a journey from shame to pride, a journey that is not one-way, but reversible. A journey that has many forks in the road; a journey that most of us stumble upon only if we are lucky, and a journey on which the majority of Americans have yet to embark.

The fact that this fear exists is not in and of itself a reason to deny the existence of a culture. I would contend instead that this very fear is a reason to consider disability experience and values as ones that are characteristic of the culture. An outsider, a nondisabled person, may fear disability and its consequences, but only a person with a disability knows how "deep [this fear is] and [how it] embodies perceptions that appear "natural" only to the insider." (Scheer, 248)

The third fear relates to:

> Who has the power to create and apply definitions? In this specific case, who has the power to create and apply definitions of culture? For the most part, the people who have claimed and proclaimed that power have been academicians in the fields of anthropology, psychology, history, sociology, and other so-called social sciences.

> There may be all sorts of reasons for this act of power. People who are formulating definitions may believe that they have the most knowledge about the concept and therefore the most right to implement their own beliefs. They may just as easily believe that they have spent many years of their life acquiring this knowledge and because of it the position to formulate definitions. They may also believe that others who have not experienced their long quest for knowledge and position have little right to question their judgment. Or they could just as easily fear that when someone questions their judgment they will lose their power.
>
> In any case, the motivation for claiming expertise is power. The power to name, the power to define, the power to proclaim, the power to place people into a context, an order which fits the vision of the person doing the naming, claiming, and proclaiming. (Brown, 1996c, 30)

Scheer states that "Most anthropologists believe that the concept of culture is their unique contribution to the social science tool kit..." (247) It may be, but the significance of the statement itself in relation to a group of outsiders, that is, people with disabilities, creating their own definitions of culture, seems apparent in relation to notions of power and expertise.

Scheer expresses concern that "The cost of promoting a disability culture is that it reinforces the broadly shared cultural belief that people with disabilities are different from others." (259) People with disabilities do have differences. This is not debatable. What is debatable is what conditions become liabilities or stigmatizing in different settings. My favorite example is those of us who wear glasses. Some of us would have liabilities so stigmatizing that we would be considered disabled in this society without our lenses. Yet I never hear the phrase "spectacle-bound."

I am far less concerned with the cost of acknowledging difference than of suppressing it. I thought I could get through this article without mentioning Jack Kevorkian, but that is not possible. He is the current popular (populist?) extreme of what happens when we try to place values on lives that are different. Rather than building level entrances, funding communication access, or providing transportation for everyone, Kevorkian suggests that we kill people with disabilities whose lives are not worthwhile and harvest their organs for others whose lives have more value. Kevorkian merits an article all by himself, but the point is that he is an example of what happens when we try to hide differences rather than acknowledge, accept, and celebrate them.

You know sex is in your head
It's only partially in bed,
And getting there is half the fun.
If you think we're not sexual,
Or our love is ineffectual,
Well, you can't be my honeybun!
(from Jane Field, "Disabled People Do It!)

I don't expect the debate over the existence or efficacy of a disability culture to end. But I predict the discussion will quickly move from arguments over its reality into ones about its costs and/or benefits. As has been stated previously, the culture itself continues, regardless of our analyses of it.

In fact, the Disability Culture Movement not only continues, it thrives. For the entire decade of the 1990s I have ceaselessly promoted the concept of a disability culture. While this has occurred I have had the luxury of researching and writing mostly in a vacuum. That empty space has vanished into what could become an engulfing vortex. Magazines, books, newsletters, organizations, conferences, and government bureaucracies are recognizing the need to look at, if not endorse, the concept of disability culture.

My honest reactions to this success are mixed. It is gratifying to see the Disability Culture Movement becoming entrenched in the lives of so many. It is also scary to witness a concept that I have played with so lovingly for ten years being dissected by so many others. Letting go is not as easy as perhaps it ought to be.

But at the same time the exploration of the idea of a disability culture by so many others offers opportunities that would not have been realistic just a year ago. Chances to study the culture in much more depth than once would have been possible. An ability to present workshops that discuss more than the surface of a culture of disability, but actually explore its breadth and works. Recognition that the art of the culture is a vital one that will garner more attention from audiences of all kinds. Perhaps, most importantly, investigations of some of those neglected arenas mentioned in the introductory caveats.

In our own lives and work we are forging ahead in the Disability Culture Movement in two big ways. First, during 1996, we developed the NEXT

RENAISSANCE: a catalog of disability art, culture & collectibles. Included in this catalog is music, visual art, publications, videos, bumper stickers, and T-shirts. A small sampling of the energy that is going into the no-longer emerging culture.

Second, another Switzer Fellowship has been awarded to begin work on a book about the life and times of Ed Roberts. Tentatively titled, "The Godfather of the Modern Disability Rights Movement," one purpose of this endeavor is to demonstrate the impact and historical importance of a person with a disability who displayed pride in the experience.

The next-to-the last words about disability culture come from the late, disabled sociologist Irving Kenneth Zola, friend and mentor to many of us, one of the fathers of disability studies, and a respected scholar. His first comments about a disability culture were tentative ones. "Activists and organizers know that it is only when there is a realization that one is not alone, that the feelings one feels, the oppressions one suffers are not unique but shared, that a social movement, and perhaps a culture, becomes possible." (1988, 12)

Six years later Zola discussed disability culture as an established reality: The authors honor a history, a culture and the unsung (to the general public not the insiders) heroes and heroines who have learned the political lessons of their predecessors [prior social movements] so well. (1994, 62)

Finally, I conclude as I must, with another sample of the culture, one of my more recent poems:

SONATA IN THE LINGERING KEYS OF LIFE

I.

Found Jim Morrison wailing at me on the radio last night:
"C'mon, baby, light my fire,"
Soothed-voice, throaty, alive,
except, of course, he is not...

1969, a magical year in so many of our lives,
A number tipping the consciousness only after meditating upon those thirty years gone,
except, of course, they are not quite thirty years gone...

Morrison, Joplin, Hendrix,
Candles dying through flames bright.

Memories intense,
Lives vivid,
Whole notes remain.

II.

Idol conversations?
Wordphrases streaming daily now
If only I would listen--
But I am.

Voices searching, seeking me out,
Not those of gods and goddesses,
but frail and mighty warriors.

Sometimes screaming from beds
as tightly bound, as completely free,
as prisons.

Sometimes screaming from conferences,
festivals of the soul;
An only outlet
for many of thy voices.

III.

Ali Baba's magic words barely open
any doors
for my people,
whose voice do we have?
the lame and the halt,
the biblical meek,
the Reagan rejects
roaming the streets.

Some slaves of old
Found comfort in the words
of glorious spirituals
and glory in the future
of the spirit.

Their gateways
handed down

to the trodden
of a new century.

Shimmering hope--
heaven unbridled by earthly restrictions.

IV.

The greatest compliment you could once bestow:
"You don't seem any different to me"--
In my eyes you are normal--
meaning you are like me
somersaulted into an insult
while you weren't looking.
What makes you,
white man, black man,
red woman, yellow woman,
brown child, rainbow race,
Believe that putting two feet on the ground,
Waving two arms in the air,
Having a face unmarred except caked,
Thinking in a straight line
Or famed, artistic, eccentric convolution
Spells normality,
Meaning if you are not like me
You had better want to be like me...
Normalized?

V.

Rocky, jagged outcroppings
Snagging us.
One-liners dropped into a history book or two
Ed will one day make it into your seventh-grader's notes
But Morrison, Joplin, and Hendrix I don't see replaced by
Zola, Zanella, or Follin-Mace.

VI.

The world has begun to give me
a gift of recognition of my poetry,
my zeal and carefully-planned idolatry.

Pain poems magnify, intensify
Perhaps they'll never rinse away;

Perhaps my purpose, or a part of its part,
Is to have this conversation
To hear this voice
which has found others' listening
and others' straining to hear
and others' needing to hear
and face their own fear.

VII.

Naked truths don't lie...
Still who will believe this difficult excursion?
Not paint it with sugar-coated
candied explanations
of good-heartedness,
god-plannedness?
Who will just listen
nod their head in acknowledgement, contemplation, recognition?

Who will not listen
rush to aggravation, defense, censorship?

"Break on through to the other side."

VIII.

BREATHING

My poetry,
like my body...
survives.

(Brown, 1996b, 3-6)

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