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Brown, Co-Founder of the Institute on Disability Culture, in the United States, reviewed the history of disability culture and its artifacts.

"Oh, Don't You Envy Us Our Privileged Lives?"

A Review of the Disability Culture Movement

by Steven E. Brown

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(Page numbers are given in round brackets and footnotes in square brackets.)

The fishing is free with your disability
You don't need a licence like the rest.
Movies are half the price, well isn't that nice?
And the parking spots are nothing but the best.

Well, don't you wish that you were disabled?
Disabled is the better way to be.
With crutches, canes and braces, wheelchairs to run races
Don't you wish that you were just like me?

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? [1]

Incubation

Thirty people met in October, 1996 surrounded by the grandeur of Santa Fe, New Mexico, to discuss the concept of disability culture. One comment in particular from these two intense days begs preliminary consideration in a review about disability culture.

The individual who made the statement is a woman of color who observed that white people with disabilities might need to create a culture out of disabling conditions because we are so lacking in other cultural identifications. Several of us remarked that we knew a number of women of color who also have disabilities who consider their primary culture to be that of disability. The

woman simply could not fathom that these women were being completely truthful about themselves.

As I continue to mull this commentary about white people with disabilities I believe it has some merit. Some, but not complete validity. As I have wrestled with the question of identity for most of my life, I do believe that my background as white has been somewhat limiting in my cultural identification. Somewhat, but not totally confining.

In my brief interactions with my colleague from this meeting I surmised that her identity emerged not only from being a person of color, but also a product of a large Eastern city with a large population of people of color, who continues to live in a similar urban situation. As those of us from the middle and western parts of the U.S. will attest there is often a vast difference in style, if not more fundamental aspects of our lives, from one area of the country to another, including but not encompassing the changes one experiences going from larger metropolises to smaller cities to rural areas.

The woman who prompted these reflections is also someone who works in an academic environment, which in and of itself, has engendered so many descriptions of difference it would be overkill to add to them here. But to throw in some irony, this woman's academic situation is unusual. She works at an institution geared toward people with disabilities different than her own.

I have no desire to attempt an amateur analysis of this woman. But I think her resistance to the concept of a disability culture is instructive. Most fundamentally, there seems to be an almost inevitable gut response to first hearing of the notion of disability culture--either in favor of or opposition to the idea. But the intense, emotional response itself is a sign that the concept is a powerful one.

I suppose this should not be a surprise. Culture and disability are both value- and identity-laden core beliefs. When they are discussed and challenged people respond with a vehemence that values and identity demand.

Second, no one is a product of just one culture, although many of us choose to identify with--or are, from no initiative of our own identified with--a primary culture. It may be religious, ethnic, skin color, occupation, geographic location, or many other possibilities. I know of no proponent of disability culture who argues that we belong to only one cultural group.

Third, because disability and culture are such value- and identity-laden terms that at least potentially impact us all, any discussion about them becomes open to everyone. Embodied in these discussions are our hopes and fears, our dreams and nightmares, our realities and illusions.

I begin this article with the preceding discussion because as academic as we might wish to make and dissect the concept of disability culture it remains an extremely personal vision. Because of this inescapable fact and because of my own training in the academic discipline of history I always try to incorporate as clearly as possible 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;

4) I have always been a fan of both high- and low-brow culture. I am also an advocate of blending academic research and knowledge with non-academic research and knowledge and endeavor to write from that slant;

5) I am a white, middle class male and am writing from that perspective as well as any other one; and, finally,

6) I have discussed my reflections about debates over the terms "disability" and "culture" in detail elsewhere and will not repeat them here [2].

Infancy

Well, don't you wish that you were disabled?
Disabled is the better way to be.
When we go out it's really neat,
we're always sure we'll get a seat
Oh, don't you wish that you were just like me?

In the mid-1980s sporadic discussions about the existence of a culture of disability surfaced. The first two documented publications about disability culture appeared in the PROCEEDINGS that followed the 1984 Conference of the Association on Handicapped Student Service Programs in Post-Secondary Education (then AHSSPPE, now AHEAD, Association of Higher Education and Disability).

David Pfeiffer of Suffolk University and Andrea Schein, then of the University of Massachusetts--Boston, each presented papers entitled "Is There a Culture of Disability?" Both scholars 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. (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." (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." (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." (132). [3]

The Disability Rag & ReSource (formerly the Disability Rag and now revived as The Ragged Edge), MAINSTREAM, Mouth, New Mobility, Accent on Living, and other representatives of what might be labeled the "disability press" [4] have historically been the primary vehicles for exploration of this topic. "But despite the dubious statistics about our numbers, there are many among us who *do* understand, who are of common purpose: they are the Disabled Community....If we don't vigorously acknowledge disability to ourselves, and forge the Disabled Community, we will never be acknowledged." [5]

The most consistent, passionate, and persistent voice initially promoting the concept of disability culture has been that of psychologist Carol Gill: "If we neglect the cultural aspects of our movement, we will fail. There's only so far you can get with intellectual ideas, or even political clout. If you don't have your people fed and charged up, liking who they are and liking each other, wanting to stand by each other, you will fail." [6]

Childhood

The Disability Culture Movement began to assert itself, like a child exploring their world, in the early 1990s. Five notable actions occurred within three years of each other. First, Cheryl Marie Wade of Berkeley, California, one of the most recognized disability culture poets and performance artists in the United States delivered a thundering welcome to our culture in an address to an organization devoted to the promotion of disability art and artists with disabilities. Her presentation began:

Disability culture. SAY WHAT? Aren't disabled people just isolated victims of nature or circumstance? Yes and no. True, we are far too often isolated. Locked away in the pits, closets, and institutions of enlightened societies everywhere. But there is a growing consciousness among us: 'that is not acceptable.' Because there is always an underground. Notes get passed among survivors. And the notes we're passing these days say, 'there's power in difference. Power. Pass the word.' Culture. It's about passing the word. And disability culture is passing the word that there's a new definition of disability and it includes power. Culture. New definitions, new inflections. [7]

Two events occurred in 1992. First, David Hevey of London authored The Creatures Time Forgot: Photography and Disability Imagery. No one had approached disability, disability art, and disability rights in a like manner. In the book's first chapter he states that he has, "attempted to register photographically the energy in the fightback of individual disabled people and the disability movement." (2-3) As a photographer, Hevey is intensely conscious of how people observe the world and how the world observes back: "How the observed begin their own observing is a crucial question in all radical cultural practice and its relevance is critical for new disability photographic practices." (6) He contends that arbiters of social mores cannot be permitted to maintain a stranglehold on images of disability. Disabled people can utilize photography to analyze how they are portrayed and generally oppressed. Hevey concludes that "oppressed people's culture is always undervalued and misrepresented by the dominant culture." (113) Radical disability imagery must admit the panorama of experience, life and action. The permanent route out of oppressive imagery begins with dismantling by caricature. An empowering, truly positive disability imagery must contain signs of pain, of reclamation of the body, marks of struggle and overcoming, and signs for a future. [8]

Error! Not a valid filename.The second landmark of 1992 was also the first of two concrete manifestations of disability culture in the United States: the establishment of the Disabled Student Cultural Center at the University of Minnesota. This resulted from a research project among a student group studying disability issues that discerned the necessity for such an organization, then successfully convinced the University to seek funds to sponsor it. (G. Chelberg, personal communication, April 1992) The program has been an enormously successful one which not only continues to exist, but has branched out into other endeavors, most notably an annual Leadership Conference targeted to students with disabilities.

The second concrete manifestation was two-pronged: a 1993-94 Research Fellowship I received to conduct research into disability culture, the first funding of its type, by the U. S. Department of Education, which culminated in a 250 page document, Investigating a Culture of Disability: Final Report; [9] and the 1994 founding of the not-for-profit Institute on Disability Culture, by my wife and partner, Lillian Gonzales Brown and myself, whose purpose is "promoting pride in the history, activities and cultural identity of individuals with disabilities throughout the world."

Coming full circle, in the finale of these five notable events, the National Endowment for the Arts recognized Cheryl Marie Wade's artistic contributions with an Arts Solo Theatre Artist's Fellowship in 1994, the first award of its kind to someone promoting disability culture.

Adolescence

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 it's fun to guess what term they're going to use.

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?

Modern teenagers lead complicated and confused lives striving to assess their own life's values and goals. Such is also true of the topic of disability culture. A bewildering array of sources either devoted to or tangentially addressing this subject are in existence and growing every day.

One of the most difficult aspects of researching disability culture has been the propensity for it to show up in non-traditional areas, such as organizational newsletters, or music, art, or writing that is not distributed in conventional ways. This has become even more true with the advent of the Internet and the multiplication of World Wide Web sites literally addressing millions of different people and topics.

When Investigating a Culture of Disability was published in 1994 I wrote that it had the most extensive bibliography to date about disability culture. It included a total of more than 250 citations, including 65 books; 24 anthology articles; 99 magazine and journal articles; 20 newspaper and newsletter articles; 11 unpublished manuscripts; 50 films; 5 musical entries; and, 8 cultural artifacts, including comics, calendars, and a poster. Yet, this too, was only a selected bibliography, highlighting the most important of 929 citations entered into twenty-four computer database categories of "Books: Non-fiction;" "Books: Fiction;" "Fiction: Short Stories;" "Books: Photography;" "Books: Poetry;" "Poetry: Tapes;" "Poems;" "Books: For Children;" "Articles from Anthologies;" "Journal, Magazine and Newspaper Articles: Non-Fiction;" "Newspapers, Newsletters;" "Monographs;" "Unpublished Works;" "Letters;" "Films;" "Videos;" "Radio;" "Music: Tapes/Compact Discs;" "Music: Songs;" "Comics;" and, "Cultural Artifacts: Calendars, Catalog, and Posters.;" As I write, the bibliographical count is 1181. [10]

Still, much is missing, including volumes of magazines and journals I have not yet been able to locate, books to be read, music to be listened to, videos to watch, resources that have escaped my attention, and, I am certain, a plethora of international commentaries unknown to me. [11]

So, as I contemplate ways to integrate vast bibliographic building blocks into my previous remarks about the evolution of the concept of disability culture, I decided to discuss a combination of the lesser-known and most important entries from each of three broad topic areas--Art, History, and Identity--that seem to scratch the surface of disability culture. One caveat must be included here as well. Several years ago, I decided that I would not include items in my bibliography that I had not yet had a chance to read or review. The reason for this is that, until quite recently, too many people writing and furnishing critiques about disability products have done so from the older perspectives of viewing disability as a condition to be fixed or cured, rather than accepted and perceived as a natural process of living.

Art

I have integrated the words of Jane Field's song, "The Fishing is Free," throughout this discussion because many people are able to accept the idea of a disability culture much more easily if they are able to feel it. There are so many examples of living with a disability infused into art that it is most difficult to choose a sampling. In a way that is good news. The culture is alive and well.

In alphabetical and categorical order, I begin with cartoonist John Callahan. He is noted for wickedly satiric depictions of all kinds of subjects. He is also a quadriplegic and recovering alcoholic who describes his life in an excellent autobiography, Don't Worry, He Won't Get Far on Foot: The Autobiography of a Dangerous Man (New York: Vintage, 1989), taking the title is taken from his cartoon of a posse coming upon an empty wheelchair in the desert and making the salient observation. [12]

An unusual, if not unique, figure in both art and disability was the Mexican painter Frida Kahlo. Her pictures, including many self-portraits, are devoted to themes of disability and pain. Kahlo's life is portrayed and much of her art included in Hayden Herrera, Frida Kahlo: The Paintings (New York: Harper Collins, 1991).

David Hevey's analytical abilities in The Creatures Time Forgot: Photography and Disability Imagery, are not the only highlight of his book. He is also adept at his art of photography and showing why certain pictures and photographic exhibitions and campaigns do or do not reflect a modern consciousness about disability rights.

It has gotten to the point where I am almost unable to turn on the television without happening upon a program or movie that includes a disability-related theme. A fairly recent compilation that attempts to be comprehensive in listing and providing short descriptions is Lauri Klobas, Disability Drama in Television and Film (Jefferson, N.C.: McFarland, 1988). If there were to be a second edition, in the course of just ten years I have the sense that the book's size would double. That is a commentary on how common disability themes have become in the most recent of times.

The closest comparisons to Hevey's analytical forays about disability and society in the United States come from Frank Moore. I often begin presentations with the following excerpt from his long prose poem, "Out of Isolation:"

I lie here in my universe of the mat, my bed. I always have been here lying in my universe forever, forever. My mat, my pillow, my sheet, my blanket...for countless force-fed meals, enemas, baths,

shaves, haircuts, pissed-on sheets...many many harsh-lighted days, many, many semi-dark nights. Outside my universe there are bony fingers, blotch-skin creatures. Sometimes they invaded my universe...the sickly-sweet smelling ones. They "take care of me"...they handle me like they handle my pillow. Their voices are high, loud, flat. Sometimes they lie on beds beside mine, moaning and crying for alone many many, then they get quiet and others of them carry the still ones away. There are always new ones, but they are always the same. There are different bony fingers who invade my universe, who strip me, probe me stretch me until it hurts...do strange things to me like rubbing ice on my body then brushing me hard. They talk to me in funny ways...loud and flat. They say, "We are doing this for your own good." They don't think I understand what they are saying. I don't understand most of their words. But I understand enough, I understand I am not a Mister, a Mrs., a Miss, a Nurse, a Doctor. I understand I am not bony fingers. They can keep their universe of bony fingers. I am not going out of my universe of the mat. I understand enough. A long long, when I cried out, they made me numb. I do not like being numb. In my universe of the mat, I am not numb. But they said crying out was not "appropriate behavior". I do not think appropriate behavior is good.

Everything that is not appropriate behavior makes me feel. But I understand enough to stop crying when the bony fingers are around. Stop making any sound, any move when they are around. They stopped making me numb. I understand enough. I discovered a way of rubbing myself that makes me warm, makes me feel good. Bony fingers slapped me away from feeling good. Not appropriate behavior. I understand enough. I do appropriate behavior in the harsh light when they are around. I am still, quiet. In my universe of the mat. I do not even look into their world. I am busy creating within me. But when the harsh light goes and the semi-darkness comes...when only the still or moaning bony fingers are around...I move, I laugh, I cry, I rub my body and good feeling comes. Not so loud or so much that the harsh light, the bony fingers, and their numbness come back. But just enough. And by rubbing, I know I am not bony fingers. [13]

When I finish I describe Frank as a performance artist from the Berkeley, California area who has significant cerebral palsy and for much of his life has been described as non-verbal! In a lecture given at New York University in the 1980s and then published as Art of a Shaman (Berkeley: INTER-RELATIONS, 1990), Frank says, "It was just my luck to be born into the long tradition of the deformed shaman, the wounded healer, the blind prophet, and the club-footed 'idiot' court jester." (6) [14]

Two books of photography stand out. The first is Lydia Gans, To Live with Grace and Dignity (Horsham, PA: LRP Publications, 1994). Gans has been taking pictures of individuals who use Personal Assistance Services (PAS) for many years and has compiled a book that presents

twenty-three stories of work, friendship, and living with a disability or with someone with a disability.

In a similar vein, Suzanne C. Levine journeyed to Project Projimo in rural Mexico, a community of people with disabilities who live and work together. Her book Volver a Vivir/Return to Life (Berkeley, CA: Chardon Press, 1996), includes narratives written in Spanish (and later translated into English) by those she photographed. [15]

Many individuals have also dramatized their lives with disabilities through poetry. Some of the best full-length publications are Karen Fiser, Words Like Fate and Pain (Cambridge: Zoland Books, 1992); Laura Hershey, In the Way, ADAPT Poems (Denver: Dragonfly, 1992), On the Lawn: Nairobi Women's Conference Poems (Denver: Dragonfly, 1994), and Dreams of a Different Woman: New Poems by Laura Hershey (Denver: Dragonfly, 1994); and, Mary McGinnis, Listening for Cactus (Santa Fe, NM: Sherman Asher, 1996). I am also partial to my own Pain, Plain--and Fancy Rappings: Poetry from the Disability Culture (Las Cruces, NM: Institute on Disability Culture, 1995) and Voyages: Life Journeys (Las Cruces, NM: Institute on Disability Culture, 1996). [16]

In addition to Jane Field, some of the best singer-songwriters are England's Johnny Crescendo, Mike Higgins and Ian Stanton; and from the U.S., Elaine Kolb, Jeff Moyer, and Blue O'Connell. [17] All but Crescendo sing in a folk style. Like his adopted name implies, Crescendo rocks. Field, as I've tried to demonstrate throughout this article, fills her music with humor.

Three articles about theater and dance are good examples of disability culture in those areas. Actress Victoria Ann-Lewis wrote, "The Secret Community: Disability and the American Theater," Disability Rag & ReSource, 16 (5), (Sept./Oct. 1995), 23-26; Eric Backman explores a variety of art forms and disability culture issues in "Amazing Grace," MAINSTREAM: Magazine of the Able-Disabled, (Aug. 1994), 40-43; and dancer Charlene A. Curtiss discusses her craft in "The Integrated Dance Movement," Disability Rag & ReSource, 16 (6), (Nov/Dec. 1995), 30-32.

In recent years, videos have begun to be made by people with disabilities about our issues. I have included a list of my favorites representing various subjects. (Most recent prices included, when known):

Able to Laugh (1993) [27 minutes] Produced by Michael J. Dougan. (Available from Fanlight Productions, 47 Halifax St., Boston, MA 02130). \$195.

Six professional comics who have disabilities shown onstage.

Black Diamond 9 1/2 minutes] (Available from Melanie Media, 2951 Derby St. #101, Berkeley, CA 9470)] \$25.00.

Afi-Tiombe Kambon performs story of a child born with a disability to a woman in slavery.

Dancing from the Inside Out. (1993) [Approximately 40 minutes] (Available from Fanlight Productions, 47 Halifax St., Boston, MA 02130). \$195.

The video of this dance troupe, which formed in 1987, combines interviews of three dancers with disabilities with footage from a performance using the group's combined talent of people with and without disabilities.

Exploding myths: Exploring the emerging culture of disability. (1993). (Available from Corporation on Disability and Telecommunications of Northern California, PO Box 1107, Berkeley, CA 94704)

A look at Bay Area artists, including Cheryl Marie Wade, Neil Marcus, and Bruce Curtis.

Here--A poetry performance. (1992). [Video and cassette--13 1/2 minutes]. (Available from CM Wade, 1613 5th St., Berkeley, CA 94710-1714). Video: Institutions: \$35.00; Individuals: \$25.00; Low-income individual: \$15.00. Cassette: \$5.00-10.00 Sliding Scale.

Cheryl Marie Wade performs her poetry.

Max and the Magic Pill. (circa 1995) [60 minutes] (Available from Paraquad, 311 N. Lindbergh Blvd., St. Louis, MO 63141). \$15.00.

A look at Max Starkloff, the founder of Paraquad, the Center for Independent Living in St. Louis, which focuses on both his disability and his zest for a typical American life out of a nursing home and in his community.

No Apologies. (1995). [28 minutes]. (Available through the Next Renaissance: a catalog of disability art, culture & collectibles, 2260 Sunrise Point Rd., Las Cruces, NM 88011). \$25.00.

Moving, humorous performances from a 1990 show, interspersed with interviews with group members. Open captioned.

Mr. Roberts. (circa 1988). Sixty Minutes. [Approximately 15 minutes]. (Available from World Institute on Disability, 510 16th St., Oakland, CA 94612). \$20.00.

Harry Reasoner interviewing Ed Roberts and his mother, Zona, discussing Ed's early years, his experience with polio and his decision to live, and the founding of the Physically Disabled Student Program, Center for Independent Living, and the World Institute on Disability.

Positive Images: Portraits of Women with Disabilities (1988) [58 minutes] (Available from Harilyn Rousso, Executive Director, Disabilities Unlimited, 3 East 10th St., Suite 4B, New York, NY 10003).

Follows the lives and careers of three women.

"Redefining Ourselves." [Video package--83 minutes]. (Available from Corporation on Disabilities and Telecommunications/Northern California, PO Box 1107, Berkeley, CA 94704). Two week rental prices: Non-profit organizations and schools: \$90.00; Governmental agencies and businesses: \$100.00.

Includes Here; The Moving Body, featuring Bruce Curtis in experimental movement and dance; The Commercial, a comical look at how to avoid someone with a disability performed by Wry Crips Disabled Women's Theater; Black Diamond, Afi-Tiombe Kambon performs story of fate of a child born with a disability to a woman in slavery; Migraine 2000, featuring art work of Peni Hall; Melvin's Brat, a satirical look at TV tele-a-thons for kids with disabilities featuring Pamela Walker; and Into the Echo Chamber/DreamWeave, featuring six disabled artists collaborating on exploring the creative process and combining their music, dance, and poetry.

Tell them I'm a mermaid. (1982) [23 minutes] (Available from Films Incorporated Video, 5547 N. Ravenswood Ave., Chicago, IL 60640-1199) \$99.00.

Victoria Ann-Lewis and six other women describe life as women with disabilities.

We won't go away... (1981).

A look at the 504 demonstrations in San Francisco and the early independent living movement.

When Billy Broke his Head...and Other Tales of Wonder (1995) Produced by Billy Golfus and David E. Simpson. [Open captioning available-57 minutes] (Available from Fanlight Productions, 47 Halifax St., Boston, MA 02130). \$245.00.

WOW!!! Dare I say it? This *is* inspirational: includes activism, art, bureaucracy, family, friends, and a look at everyday life--all in a very funny hour.

History

Many of us don't know about our history. Not so much because we don't have it, but because until recently it has not been deemed worthy of discussion. That's changing as the following examples attest.

Edward D. Berkowitz, Disabled Policy: America's Program for the Handicapped (Cambridge: Cambridge University Press, 1987) was one of the first works of history to focus on disability policy and explain how it worked (or didn't work) in the United States since the early 1900s. His story is continued in Richard K. Scotch, From Good Will to Civil Rights: Transforming Federal Disability Policy (Philadelphia: Temple, 1984), a look at the crucial demonstrations in San Francisco and other U.S. cities in 1977 which led to the federal government seriously considering Section 504 of the Rehabilitation Act of 1973, which prohibited discriminated in government

funded programs for qualified people with disabilities. [18] Journalist Joseph P. Shapiro has written the most popular chronicle about disability in recent memory, No Pity: People with Disabilities Forging a New Civil Rights Movement (New York: Times Books, 1993). He professes: The disability movement is a mosaic movement for the 1990s. Diversity is its central characteristic....In the last twenty to thirty years, little noticed...another movement has slowly taken shape to demand for disabled people the fundamental rights that have already been granted to all other Americans. it has led to the emergence of a group consciousness, even the start of a disability culture, which did not exist nationally even as recently as the 1970s. (11) [19] I look at the philosophies that led to the development of the independent living movement and symbolism in disability and how they impact the daily activities of an independent living program in Independent Living: Theory and Practice (Las Cruces, NM: Institute on Disability Culture, 1994) and include a long introductory chapter about historical developments in Investigating a Culture of Disability.

One of those individuals who was a part of much of this history, Frank Bowe, wrote Handicapping America (New York: Harper & Row, 1978), which, although dated, remains a valuable tool for understanding the genesis of the disability rights movement and many of its contemporary issues. A second person who was a part of it all is Hugh Gregory Gallagher. He has authored two excellent books, one depicting the original visitation of the Nazi horror on people with disabilities, By Trust Betrayed: Patients, Physicians and the License to Kill in the Third Reich (New York: Henry Holt, 1990), and the other a fascinating account of how Franklin Delano Roosevelt's polio affected him and the nation in FDR's Splendid Deception (New York: Dodd, Mead, 1985).

Paul K. Longmore, who uncovered the League for the Physically Handicapped--a group staging sit-ins, pickets and boycotts in the 1930s, also wrote a critical review of "The Life of Randolph Bourne and the Need for a History of Disabled People: Review of Bruce Clayton's Forgotten Prophet: The Life of Randolph Bourne," in Reviews in American History, (Dec. 1985), 581-87, in which he eloquently states the case for a history of people with disabilities written by people who have an understanding of disability issues. [20]

A book that responds to this need is Philip M. Ferguson, Abandoned to Their Fate: Social Policy and Practice toward Severely Retarded People in America, 1820-1920 (Philadelphia: Temple, 1994), which provides a new look at these institutions and the reasons for their existence and continuance. Ferguson also provides an excellent bibliography of this subject in "Mental Retardation Historiography and the Culture of Knowledge," Disability Studies Quarterly 16 (3)

(Summer 1996), 18-31, as does Steve Taylor, in "Disability Studies and Mental Retardation," Disability Studies Quarterly 16 (3) (Summer 1996), 4-13.

The late Timothy, M. Cook in "The Americans with Disabilities Act of 1990: The Move to Integration," Temple Law Review 64 (2) (1991), 393-469, provides a superb overview of how disability history and issues fit into the broader civil rights agenda.

Karen Hirsch, also writing from a historian's perspective in "Studying Culture," Disability Rag, (May/June 1987), 38-39, was one of the first to call for looking at disability as a culture and in "Culture and Disability: The Role of Oral History," Oral History Review 22 (1), (Summer 1995), 1-27, she makes the case that many historical analyses are less accurate than they might be with the inclusion of a consciousness about disability issues. Finally, two satisfying historical reflections about disability culture occur in Ruth Brannon, "The Use of the Concept of Disability Culture: A Historian's View," Disability Studies Quarterly 15 (4) (Fall 1995), 3-15 and Paul Longmore's "The Second Phase: From Disability Rights to Disability Culture," Disability Rag & ReSource, 16 (5), (Sept./Oct. 1995), 4-11.

Identity

Autobiographies are rampant in describing how someone has lived with a disability or impairment. But many remain in the genre of the inspirational-- "how I overcame my disability and did..... Fill in the blank with almost any field of endeavor you can conjure. Perceptions of disability from today's civil rights perspective remain few. Some of the best include Frank Bowe, Changing the Rules (Silver Spring, MD: TJ Publishers, 1986), in which the author traces his early childhood as someone who has become deaf, but is not recognized for that difference, Anne Finger, Past Due: A Story of Disability, Pregnancy, and Birth (Seattle: Seal, 1990), a marvelous writer with a disability who describes a personal evolution related to discovering her child will be born with a disability, John Hockenberry, Moving Violations: War Zones, Wheelchairs, and Declarations of Independence (New York: Hyperion, 1995), a paraplegic newsman's slants on life, reporting, and disability, and Jason Kingsley and Mitchell Levitz, Count Us In: Growing Up with Down Syndrome (San Diego: Harvest, 1994), the story of two teenagers who, with the assistance of supportive and hopeful parents, discuss their lives with Down Syndrome. Nancy Mairs is an essayist with multiple sclerosis who takes a magnifying glass to her life and reports about it with extraordinary realism and clarity in several books including Ordinary Time: Cycles in Marriage, Faith and Renewal (Boston: Beacon, 1993), Plaintext (Tucson: Arizona, 1986), and Remembering

the Bone House: An Erotics of Place and Space (Boston: Beacon, 1995, 1st published 1989). [21] Lorenzo Wilson Milam's recent Crip Zen: A Manual for Survival (San Diego, CA: Mho & Mho Works, 1993), is both a handbook for living with a disability and a reflection on doing just that for many years, unlike his earlier The Cripple Liberation Front Marching Band Blues (San Diego, CA: Mho & Mho Works, 1984), which focuses on learning to live with disability and (homo)sexuality while recuperating from polio and maturing at Warm Springs Rehabilitation Center, FDR's rehabilitation and vacation site and his most tangible legacy to future generations of people with disabilities. Connie Panzarino in The Me in the Mirror (Seattle: Seal, 1994), addresses some similar themes from a disability rights, independent living, and Baby Boomer perspective, while Ruth Sienkiewicz-Mercer, I Raise My Eyes to Say Yes (New York: Avon, 1989), describes in detail what it was like to live in an institution where very few people understood her abilities--and how she managed to escape. Judith A. Snow, What's Really Worth Doing and How to Do It: A Book for People Who Love Someone Labeled Disabled (Toronto: Inclusion, 1994), is both encouraging and instructive for assisting someone to get what they want out of life, and the late, disabled sociologist, Irving Kenneth Zola wrote about coming to terms with disability and identity while visiting Het Dorp, a housing complex that provides PAS for people with disabilities in the Netherlands, in Missing Pieces: A Chronicle of Living with a Disability (Philadelphia: Temple, 1982).

Articles with similar and complementary themes include my "Creating a Disability Mythology," International Journal of Rehabilitation Research, 15, (Winter 1992), 227-33; "I Was Born (in a Hospital Bed)--When I Was Thirty-One Years Old," Disability and Society, 10 (1), (1995), 103-110; and "We Are Who We Are... So Who Are We? MAINSTREAM: Magazine of the Able-Disabled, 20 (10), (Aug. 1996), 28-30, 32; "a celebration of disability culture," an entire issue of the Disability Rag & ReSource, 16 (5), (Sept./Oct. 1995) devoted to this theme; Gene Chelberg & Sue Kroeger, "Tenets of Disability Discovery," Disability Studies Quarterly, 15 (4), (Fall 1995), 19-21; Carol J. Gill, "Comments on Disability Culture," Disability Rag & ReSource, 16 (5), (Sept./Oct. 1995), 5; and "A Psychological View of Disability Culture," Disability Studies Quarterly 15 (4), (Fall 1995), 16-19; Harlan Hahn, "The Los Angeles Uprisings of 1992: A Disability Perspective," Disability Studies Quarterly, 13, (1), (Winter 1993), 80-84; Dianne B. Piastro, "Identifying with our culture--ourselves," Disability Rag & ReSource, 16 (5), (Sept./Oct. 1995); and Cheryl Marie Wade, "Creating a Disability Aesthetic in the Arts," Disability Rag & ReSource, 15 (6) (Nov-Dec 1994), 29-31 and "Culture Rap: Why Do We *Need* a Culture?" Disability Rag & ReSource 17 (3) (March/April 1996), 28-32.

I would be remiss not to include some of the finest fiction about disability in this section including Patricia Armstrong's Kate (Toronto: Harlequin, 1995), a romance novel about a heroine who, like the author, has Myasthenia Gravis; Andre Dubus, Dancing After Hours (New York: Knopf, 1996), a collection of short stories, many of which feature characters with disabilities, in particular two protagonists whose disabilities are essential to their stories; Anne Finger's collection of short stories, Basic Skills: Stories by Anne Finger (Columbia: University of Missouri Press, 1988); and her novel, Bone Truth (Minneapolis: Coffee House Press, 1994); the second novel of which I'm aware written by a person with a disability focusing on disability themes from a rights perspective, following Jean Stewart's The Body's Memory (New York: St. Martin's Press, 1989).

Many anthologies over the past decade or so have proven to be some of the most fruitful sources of discovering information about all of these subjects in a variety of formats. One of the first, and still one of the best is Susan E. Browne, Debra Connors, Nanci Stern, eds., With the Power of Each Breath (Pittsburgh and San Francisco: Cleis Press, 1985). A more recent one, Lois Keith, ed., "What Happened to You?" Writing by Disabled Women (New York: New Press, 1994), a compilation from England is also excellent. Harilyn Rousso with Susan Gushee O'Malley and Mary Severance, Disabled, Female and Proud: Stories of Ten Women with Disabilities (Boston: Exceptional Parent Press, 1988), is a wonderful collection from someone who has devoted much of her life to instilling pride in girls and young women with disabilities. Cheryl Marie Wade has edited two of the best collections of writers and artists, both in and out of the mainstream in Close to the Truth (Berkeley, KIDS Project, 1989) and Range of Motion: an Anthology of disability poetry, prose and art (Albany, CA: Minuteman, a KIDS Project/Squeaky Wheels Press, 1993). Mary E. Willmuth and Lillian Holcomb, eds., Women with Disabilities: Found Voices (New York: Harrington Park Press, 1993) have assembled an anthology which combines scholarly and popular voices. Irving Kenneth Zola, ed., Ordinary Lives: Voices of Disability and Disease (Cambridge: Apple-wood, 1982) includes fiction, nonfiction, and poetry in a more consistently interesting way than the more well-known Vassar Miller, ed., Despite This Flesh: The Disabled in Stories and Poems (Austin: University of Texas Press, 1985).

Conclusion

Unlike the previous sections, I did not give this one a title analogous to a stage in human development. This is because I think we are, and will remain in, adolescence for the foreseeable

future, while we continue to sift through the various characteristics and debates about the Disability Culture Movement.

No one questions the idea that disability may be perceived in different ways depending upon what culture a person is born into. The most comprehensive endeavor to look at disability in this way comes from Benedicte Ingstad and Susan Reynolds Whyte, eds., Disability and Culture (Berkeley: University of Berkeley, 1995), an anthropological compilation which focuses on how disability meshes with various societies throughout the world. [22] Although the concept of disability culture does not emerge in this book, it has been anthropologists who have articulated the most vocal disagreements with this notion.

Robert Murphy was an anthropologist who became disabled through illness and described his experience in The Body Silent (New York: Henry Holt, 1987). Although Murphy found much to dislike, indeed, even hate, about his disability, he also managed to acknowledge the disability rights movement and its necessity. I have described elsewhere my feeling that Murphy's place in the context of the evolution about thinking regarding disability reflects his own notion of disability as liminal--for Murphy, the man, an intermediate stage between life and death, for Murphy, author and observer, an intermediate stage between disability as something horrible that happens to someone and disability as something that happens and can have positive or negative ramifications, depending upon how the individual chooses to respond. [23]

One of Murphy's students and colleagues, Jessica Scheer, has been most eloquent in voicing concerns about a culture of disability. She wonders if such a culture would not be counterproductive and separatist in "Culture and Disability: An Anthropological Point of View." [24] I argue that rather than being separatist, disability culture is a way to become integrated with other segments of society. If neither people with disabilities nor nondisabled people are able to view disability with any kind of realism, then how can we expect either group to truly integrate? I don't believe it is possible. The Disability Culture Movement's recognition of our history and identity is the most important recent development in our pursuit of being valued in society. [25]

Truthfully, it does not matter what we think about the concept. The Disability Culture Movement is alive and well and continues with or without any one person.

I begin to conclude with examples of this statement from my own life and work. In Investigating a Culture of Disability I made a number of recommendations. Many of them concerned continuing to collect data and stories about the people who have shaped disability rights in recent memory. One of my arguments was that we are losing our leaders to death with too much frequency. In 1996, the Department of Education made the unusual granting of a second Switzer

Fellowship to continue my research about disability culture exploring the life of the outstanding, and late, international disability rights leader, Ed Roberts.

Finally, I have felt the presence of the Next Renaissance: a catalog of disability art, culture & collectibles to be ubiquitous throughout this article. Lillian and I met many wonderful artists while we traveled around the country presenting workshops and trainings in past years. But few of them had outlets outside of their immediate geographical area to distribute their work. In early 1996 we began the catalog and now have over 70 entries in it--a small, but significant sampling of the Disability Culture Movement.

Needless to say, one of our favorite items is Jane Field's tape. I conclude as I began: with her wit and wisdom:

Disabled is the better way to be.
With all these benefits and perks that's
how the system works
Oh, don't you wish that you were just like me?

Oh the fishing is free with your disability
You don't need a licence like the rest.
Movies are half the price, well isn't that nice?
And the parking spots are nothing but the best!

Footnotes

1. Lyrics throughout the article are from Canadian Jane Field's song, "The Fishing is Free," which is also the title of her 1994 cassette. (Available from the Next Renaissance: a catalog of disability art, culture & collectibles, 2260 Sunrise Point Rd., Las Cruces, NM 88011).
2. See , "Deviants, Invalids, and Anthropologists: Cross-Cultural Perspectives on Conditions of Disability in One Academic Discipline: A Review of Disability and Culture," *Disability and Rehabilitation: An international, multidisciplinary journal*, 18 (5) (May 1996), 273-75; *Investigating a Culture of Disability: Final Report* (Las Cruces, NM: Institute on Disability Culture, 1994, Available from the Next Renaissance: a catalog of disability art, culture & collectibles, 2260 Sunrise Point Rd., Las Cruces, NM 88011); "We Are Who We Are... So Who Are We? MAINSTREAM: Magazine of the Able-Disabled, 20 (10), (Aug. 1996), 28-30, 32, and "Poster Kids No More:" Perspectives about the No-Longer Emerging (In Fact, Vibrant) Disability Culture." (Forthcoming, *Disability Studies Quarterly*).
3. Pfeiffer, David "Is There a Culture of Disability?" 1984 and Beyond, Proceedings of 1984 AHSSPPE Conference, 1984 and Schein, Andrea, "Is There A Culture of Disability?" 1984 and Beyond, Proceedings of 1984 AHSSPPE Conference, 1984.
4. Examples include abilities: Canada's Lifestyle Magazine for People with Disabilities, Canadian Abilities Foundation, 489 College St., Suite 501, Toronto, Ontario M6G 1A5,

Web Site: <http://indie.ca/abilities>; Accent on Living, PO Box 700, Bloomington, IL 61702; Disability International, Disabled People's International, 309-175 Hargrave St., Winnipeg, MB, Canada R3C 3R8, E-mail: die@dpi.org, Web Site: <http://www.dpi.org/di.html>; MAINSTREAM: Magazine of the Able-Disabled, PO Box 370598, San Diego, CA 92137-0598; Web site: <http://www.mainstream-mag.com>; Mouth, 61 Brighton St., Rochester, NY 14607; and New Mobility: Disability Lifestyle, Culture, & Resources, PO Box 15518, North Hollywood, CA 91615-9773, Web Site: <http://www.newmobility.com>, and Ragged Edge: The Disability Experience in America, PO Box 145, Louisville, KY 40201, E-mail: rgarr@iglou.com, Web Site: <http://www.iglou.com/why/edge>.

5. Ed Hooper, "Seeking the Disabled Community," Disability Rag, (Aug 1985), 1, 4-6, 8. Quote is on page 8.

6. In Mary Johnson, "EMOTION AND PRIDE," Disability Rag, Jan/Feb 1987, 1, 4-10. Quote is on page 9.

7. Published in Cheryl Marie Wade, ed., Range of Motion, 25.

8. Hevey, David, The Creatures Time Forgot: Photography and Disability Imagery (London: Routledge, 1992).

9. (Las Cruces, NM: Institute on Disability Culture, 1994).

10. See "A Celebration of Diversity: An Introductory, Annotated Bibliography about Disability Culture," Disability Studies Quarterly, 15 (4) (Fall 1995), 36-55, for what I considered the most important entries at that junction in time.

11. This is not to say that I am in total ignorance of international discussions relating to or specifically about disability culture. Two examples, which do not show up in the text of this article, but cover a number of different countries are Barbara Duncan and Susan Brown, eds., Personal Assistance Services in Europe and North America (New York and Oakland: Rehabilitation International and World Institute on Disability, 1993) and Diane E. Woods, ed., Traditional and Changing Views of Disability in Developing Societies: Causes, Consequences, Cautions (Durham, NH: International Exchange of Experts and Information in Rehabilitation, 1993).

12. See also his cartoon books, Digesting the Child Within (New York: William Morrow, 1991), Do Not Disturb Any Further (New York: William Morrow, 1990), Do What He Says! He's Crazy (New York: William Morrow, 1992), Freaks of Nature (New York: William Morrow, 1995), The Night They Say, Was Made for Love plus My Sexual Scrapbook (New York: William Morrow, 1993), What Kind of God Would Allow a Thing Like This to Happen?!! (New York: William Morrow, 1994), and his fairy tale, The King of Things and the Cranberry Clown (New York: William Morrow and Company, 1994). Another cartoonist who has compiled a book, and whose humor is far less caustic, is Frank Warner, Dis"ability" Joke Book (available for \$7.95 from Dis"ability" Magazine, 5910 77th St. East, Palmetto, FL 34221 (941) 723-6308, 1995).

13. "Out of Isolation," (Berkeley: INTER-RELATIONS, 1985, Available from the Next Renaissance: a catalog of disability art, culture & collectibles, 2260 Sunrise Point Rd., Las Cruces, NM 88011). The poem was also made into a video with the same title in 1989. Like most of Moore's visual art, it contains lots of nudity. It, too, is available through the Next Renaissance: a catalog of disability art, culture & collectibles, 2260 Sunrise Point Rd., Las Cruces, NM 88011).

14. Available from the Next Renaissance: a catalog of disability art, culture & collectibles, 2260 Sunrise Point Rd., Las Cruces, NM 88011. For much more from and about Frank and his work see his World Wide Web site: <http://users.lanminds.com/~fmoore> 15. Available from the Next Renaissance: a catalog of disability art, culture & collectibles, 2260 Sunrise Point Rd., Las Cruces, NM 88011.

16. All except Fiser are available from the Next Renaissance: a catalog of disability art, culture & collectibles, 2260 Sunrise Point Rd., Las Cruces, NM 88011. 17. Diane Coleman, "Free Our People," Elaine Kolb, "We Are Everyone," Jeff Moyer, "Special Ed Ranger," "We're People First," and "Good Medicine," Blue O'Connell, "Lines of Change," and, of course, Field are available through the Next Renaissance: a catalog of disability art, culture & collectibles, 2260 Sunrise Point Rd., Las Cruces, NM 88011. Johnny Crescendo, "Easy Money," 1990, "Pride," 1993, Mike Higgins, "Thank You for Your Application," and Ian Stanton, "The Incredible Shrinking Man," 1989, and "Freewheelin'." 1992, have been available in the United States from Mouth, 61 Brighton St., Rochester, NY 14607.

18. This is quite an oversimplification of both the demonstrations and how Section 504 has affected people. Although Scotch is the most comprehensive analysis of this transformation, not everyone who played a role in these activities agreed with his assessments and analyses. See John Hessler, "Letter to Editor," Disability Rag, Sept. 1985, 3.

19. Shapiro also has his critics, particularly of his emphasis on the Berkeley area. But his account is very readable and has begun to fill the broad gap of no mainstream publications about the disability rights movement.

20. Longmore has yet to publish about the League for the Physically Handicapped, but he has discussed it in speeches, eg. at Independent Living: Toward the 21st Century in Oakland, CA in October, 1991.

21. I've included in the text the ones I've read so far, but see also Carnal Acts (Boston: Beacon, 1996); Voice Lessons (Boston: Beacon, 1994); and forthcoming, in 1997, Waist High in the World.

22. See, "Deviants, Invalids and Anthropologists: Cross Cultural Perspectives on Conditions of Disability in One Academic Discipline: A Review of Disability and Culture," in Disability and Rehabilitation: An international, multidisciplinary journal, 18 (5) (May 1996), 273-75, for my detailed review.

23. Ibid., and in Investigating a Culture of Disability, 95-96.

24. In Edison J. Trickett, Roderick J. Watts, and Dina Berman, eds., Human Diversity: Perspectives on People in Context (San Francisco: Jossey-Bass, 1995), 244-60.

25. This is a subject which deserves much more detailed discussion and is only just beginning. For more detail on it and my disagreements with Scheer, see "We Are Who We Are... So Who Are We?" MAINSTREAM: Magazine of the Able-Disabled, 20 (10), (Aug. 1996), 28-30, 32.