

W . I . D . FAX

Date: 9/23/92 Time: _____

To: Janne Angoff

Fax Number: (202) 457-0473 Pages: 5

Dear Janne,
Thanks for your report. Here's a copy of the
introduction as promised. Thanks.
x thanks for the contract.

Steve

NIDRR. Rehabilitation Research Fellowship
for 1993.

Dear Dr Graves

Steve
① Gene from
Conference
Disability
Culture
Center
② Send
Council on
Ind.

INVESTIGATING A CULTURE OF DISABILITY

INTRODUCTION

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.

So begins Cheryl Marie Wade's powerful "Disability Culture Rap," first presented as the keynote address of the Northern California Chapter of the Corporation on Disabilities and Telecommunications meeting in February 1992 and published in the Disability Rag's September/October 1992 edition (37).

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," etc. Scholars would be hard-pressed to discover terms of hope, endearment, or ability associated with Disabled People. But as rights and social standing have become more available to Disabled People 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. The Society for Disability Studies, the most renowned group of

scholars who study disability hosted a heated exchange about the existence and value of a culture of disability at its 1991 Annual Meeting in Oakland, California.

Dr. Kirk MacGugan, a recent scholar of disability rights and history 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." ("An Interpretive History of the Disability Rights Movement, 1920-1990, 5-6, unpublished paper, July 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) presented 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.

Their analyses dissected the heart of one of the objections to the theme of a culture of disability when they explored the meaning of the word, "culture," in describing this topic. 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. (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).

The most recent and concrete realization of the existence of a culture of disability has 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. (Conversation with Gene Chelberg, Coordinator of the Center, in April 1992).

As discussions concerning the existence of a disability culture and implementation of organizations like the Disabled Student Cultural Center 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 their future meanings.

The hypothesis to be examined in this proposed study is that a culture of disability does exist and that its reality has implications for every aspect of the lives of people with disabilities, including the rehabilitative process. Research methods to explore this hypothesis, which will be discussed in more detail, in the section on Research Methods, will include literature reviews, personal interviews, and focus groups.

QUALITY AND LEVEL OF FORMAL EDUCATION

Qualitative research is the standard structure of many scholarly disciplines, including my own academic field of history. As a student of United States intellectual history, I earned a doctoral degree from the University of Oklahoma in 1981. As a partial requirement for the degree, I wrote a dissertation study entitled, "Henry James, Sr. and the American Experience." This was not a biography, but an endeavor to establish how the themes of this iconoclastic writer and theologian intertwined with the values of his time, the heart of the nineteenth century.

The quality of my academic pursuits, in both research and teaching, were recognized when I was appointed Instructor in History at the University of Oklahoma for the 1981-82 academic year. This was the sole appointment during that year and only the second time that position was filled.

As my career has moved in the direction of the field of disability studies I have continued my education through a