

INVESTIGATING A CULTURE OF DISABILITY

FINAL REPORT

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This is dedicated to all the martyrs, who have gone before us,
and especially, to Kirk MacGugan, whose words and passion I very much miss;

and to Helen Kutz, who I am proud to call a friend and mentor;

and to my wife and partner, Lillian Gonzales Brown, who understands and
shares my passion for the work, if not my obsession with it,
loves me in spite of myself, and encourages my poetry

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PREFACE

"Investigating a Culture of Disability" is both the culmination and the beginning of a scholarly passion and a lifelong obsession. Like many people, I have struggled with the need to belong within a community of my choosing and to be able to express my need for individual character. I have found such a role in the disability community.

As I explored why I felt so welcomed within this community I began to sense the blossoming culture of disability. As I talked with people about my feelings I found others too either had, or longed for, this sense of identity.

As I pursued my professional career in disability rights, my personal passion in disability advocacy, and my lifelong interest in scholarship, I discovered a fellowship program named after Mary E. Switzer and sponsored by the National Institute on Disability Rehabilitation and Research (NIDRR).

I decided to apply to the fellowship program to follow my dream of studying disability culture. I was successful.

At the same time, my wife and partner, Lillian Gonzales Brown, and I decided to leave our home in Oakland, California and start anew in Las Cruces, New Mexico, where we have created the not-for-profit Institute on Disability Culture.

The past year has been a whirlwind of moving, creating, and studying. As Lillian says, the success of our endeavors has been because the disability community has supported us. In addition to NIDRR and a wonderful set of friends from our old homes, and our new, we have been bolstered by financial, emotional, and peer support by the Arkansas State Independent Living Council, Austin Resource Center for Independent Living, Independent Living Research Utilization, National Council on Independent Living, New Mexico State Independent Living Council, Region VI Rehabilitation Continuing Education Program, Southern New Mexico Center for Independent Living, University of San Francisco, World Institute on Disability, and many individuals who have contributed their time, knowledge, and enthusiasm to this and other projects during the past year.

I would like to thank particularly Dan Blake, Ann Cupolo, Bruce Curtis, Paul Longmore, Neil Marcus, David Pfeiffer, Ed Roberts, Cheryl Marie Wade, and Pamela Walker, who consented to take the time for personal interviews, and those individuals who responded to the survey form.

Ann Cupolo and Helen Kutz have joined Lillian and I on the Board of Directors of the Institute on Disability Culture and their support and friendship has been invaluable.

Acknowledgement of the many people who are quoted in this work is also appropriate. I thank them all for the contributions they are making to this work.

Finally, Lillian contributes in so many ways that a simple thank you is hardly enough, but I have neither enough words, wealth, or time to say more than may we always dream with poets and angels.

EXECUTIVE SUMMARY

"THE BLOSSOMING CULTURE OF DISABILITY"

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.

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.

The accelerated speed of the Disability Culture Movement renders some of the hopes I harbored when I began this study as irrelevant. When I proposed to research disability culture, I suggested that I would review the literature, facilitate focus groups, and conduct personal interviews. One by one, each objective has been modified, deleted, or replaced.

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.

This would apply to movies and media as well. And my guess is the day is not that far in the future when music will join this list.

Focus groups fell by the wayside after much contemplation. I discussed the process of focus groups with several colleagues and independent living center directors. I sought people who were not that familiar with the concept of disability culture, because I had been involved in so many conversations with people who had already heard me express my own viewpoint.

As the fellowship year proceeded, it began to dawn on me that informal focus groups had been happening at conferences around the country for several years. When those of us who talked about disability culture did so at various meetings, we were generally greeted with perplexed expressions or cries of enthusiasm. But in either case, the idea was most often a new one to audiences across the country. Lively discussions always occurred. As I reviewed these experiences, it seemed to me that they already served the purpose that any current focus groups would offer. I forged

ahead with the personal interviews.

All save one interview has worked its way into this text. That particular interview did not seem to fit into the context of the material. I am hopeful that it will see the light of day as an article. But as the year rolled along unstopably I despaired of interviewing everyone I wished.

As a result of this frustration, I developed a survey form which was completed by twenty individuals. The form is included in Appendix A and survey results in Appendix B. One survey respondent described disability culture as squishy, which seemed as appropriate an appellation as any.

Another respondent offered two definitions of disability culture. "First it is the filter through which we people with disabilities experience the world (shared experiences, & thoughtfully developed concepts). 2nd our expression of ourselves in writing, words, art, etc. as well as organizations, etc."

Those two sentences concisely summarize the status of disability culture as it exists today.

FORGING AHEAD

One purpose of the Switzer fellowship is to influence the business of rehabilitation and of the National Institute on Disability Rehabilitation and Research (NIDRR). I would suggest that the information contained in this study should be alarming to both groups.

The 1992 Amendments to the Rehabilitation Act finally recognizes the status of people with disabilities as a minority group, but this has occurred many years following, to use one example, the 504 demonstrations. While the rehabilitation world is catching up with the disability rights aspects of life with a disability in the United States, the disability community itself is forging ahead into new territories.

The next grand paradigm change in disability has already happened. It is the

Disability Culture Movement. But my guess is that few people within either the Rehabilitation Services Administration (RSA) or NIDRR are aware of the extent or impact of this development. And without this awareness, tension from an inability to provide services that meet the needs of disabled people will continue indefinitely.

One avenue of diminishing these tensions between the disability rights and the rehabilitation communities may be acknowledgement and support of the Disability Culture Movement. With that in mind, a series of recommendations prompted by this investigation have been developed.

RECOMMENDATIONS

1. Funding numerous in-depth personal interviews, to be audio- and videotaped, preferably in every state, along the lines of the Works Progress Administration (WPA) interviews of surviving slaves during the Great Depression. I use this analogy because like the slaves, many of recent history's key players with disabilities are, and will be, dying before we have a chance to record their stories. For that reason this is the most important, and most immediate, recommendation.
2. A thorough review of identifiable literature, including alternative publications such as Accent on Living, Disability Rag & ReSource, Mainstream, Mouth, New Mobility, and others as discovered.
3. A selected bibliography is included as a part of this study. It is incomplete, as it must be, since both traditional entries are constantly being uncovered as well as untraditional categories, such as calendars, event programs, and posters. Funding, or support, to continue to develop, and distribute a dynamic, annotated, bibliography about disability culture, would be a major contribution to the field.

4. Funding for an annotated compendium of films and videos specifically relating to cross-disability culture.
5. Funding for an annotated compendium of music specifically relating to cross-disability culture.
6. Funding to develop a comprehensive Resource Directory about disability culture and disability art.
7. Funding to develop an annually updated directory of artists involved in the creation and production of disability culture artifacts.
8. Funding to survey a segment of the disabled population over a period of time, spanning no fewer than five years to assess views about the topic of disability culture.
9. Funding for the research and writing of a comprehensive history of people with disabilities in the United States.
10. Funding for investigation of disability culture on an international scale.

Each recommendation made in this summary could provide work for any number of people for years to come. Yet those of us who are doing the work of disability culture, both in the arena of scholarship and in the production of the culture itself, are barely eking out an existence. What we are doing is changing the face of disability in society forever. To that everyone should pay attention.

A WORD ABOUT AUTHOR BIAS

This particular of exploration of disability culture reflects my own training and biases. Some words on those subjects:

My academic training is as an historian of United States intellectual history with a preference for focusing on reform and the period from the American Revolution until World War I. My knowledge about people with disabilities has come from the experience of being an individual with a disability who has experienced discrimination, participated in the Disability Rights Movement, and been primarily self-taught in the roles and history of people with disabilities.

In the course of writing this report I have referred to people with disabilities as a distinct group. At times, I include myself in that group and talk about "our people" or "our movement." This is not a typical scholarly approach. But, this is not an objective, unbiased study. This is a work which reflects both my scholarly training and my life passions. As such both are reflected in the report. And both are legitimate. We all bring our individual biases to everything we do, including scholarly attainments. My decision is to acknowledge them as best I can and move forward from there.

For many years I have had an opportunity to speak to a variety of groups about the history and philosophy of the independent living movement. I am hopeful that the approach I have undertaken in the first section, which as far as I am aware is a unique perspective, will contribute to the sadly lacking history of our people.

My belief is that disability culture is comprised of many attributes, one of which is our heritage as a people. For that reason, this study of disability culture includes a lengthy section about one aspect of disability history. My hope is that as this work progresses the interwoven roles of history and culture will become ever more apparent.

This is a cross-disability study. There could, and should, be cultural, and historical, studies of specific disability groups, such as people who are deaf, blind, deaf-blind, have head injuries, cognitive disabilities, and so forth. There could also be studies of specific ethnic or racial groups and how disability is treated in those environments. There have been some studies accomplished in these areas, but few of them

are informed by the disability consciousness of the late twentieth century which ideally respects equality and difference.

But there have been no cross-disability studies of disability culture. This work is the first of its kind. It is a beginning, not an ending. Many other explorations could, and hopefully will, follow this report. In fact, as I have become more immersed in the study of disability culture, my belief has grown that there are many cultures of disabilities.

This statement recognizes not only the diversity of disability, but the many other facets each of us brings to our disability identity--geographic, racial, religious, ethnic, cultural, gender, and I'm sure other traits. All have a place in the eventual studies of disability culture.

Each recommendation proposed in the Executive Summary could also be applied to specific disability groups and probably to other aspects of the cultures of disabilities as well. But we must start somewhere. I've chosen to begin with a study of cross-disability culture.

One final caveat: this paper is being written by a white, middle-class U.S. citizen and it reflects the limitations and advantages of that category.

SECTION ONE:

HISTORY LESSONS

Knowing that there is a disability history is a stunning revelation to anyone who thinks he or she is the only one affected by disability. This knowledge connects us to something much bigger than ourselves and opens our lives to shining possibilities. In our history we will confront our oppression and find communal resolve to overcome it. Recognition of our shared historical experience can help us find pride in ourselves and affirmation of our worth.

(William G. Stothers, 1992, 50)

CHAPTER ONE:

DEVIANTS, INVALIDS, AND FREEDOM FIGHTERS:

HISTORICAL PERCEPTIONS OF PEOPLE WITH DISABILITIES

IN THE UNITED STATES

INTRODUCTION: A RECOGNITION OF OPPRESSION AND GROUP IDENTITY

Another American revolution occurred during the first year of the last decade of the twentieth century. In July of 1990, the month Americans most associate with freedom and independence, a crowd gathered on the White House lawn with President George Bush. Three thousand cheering citizens, many with significant disabilities, comprised the largest crowd ever to observe a White House Bill signing. ("Independence Day 1," 1990, 6)

The law that attracted this crowd of several thousand was the Americans with Disabilities Act, widely hailed as the most significant legislative victory in the civil rights history of individuals with disabilities. The act, familiarly known as the ADA, provides legal protection to people with disabilities in employment, transportation, and public accommodation.

A mere thirteen years prior to signing of the ADA, people with disabilities from across the United States gathered to demonstrate in numerous federal offices because President Jimmy Carter's administration adamantly refused to recognize a short paragraph in a long law which called for discrimination protection primarily in federally-funded employment arenas. (Ervin, 1986, 17)

The overwhelming change in Presidential attitude toward people with disabilities mirrored a social, political, cultural, educational, and economic revolution as profound as previous successes in other human rights movements. The ADA is meaningful not only in its specific requirements, but also by its recognition of people with disabilities as a minority group which has been historically oppressed by social standards, laws, and stereotypes. (Americans with Disabilities Act of 1990, Sec. 2)

The initial purpose of this chapter is to provide insight into traditional attitudes and practices concerning people with disabilities. The second objective is to suggest a new kind of insight, with some introductory thoughts on how it will impact the future of people with disabilities and society as a whole.

This approach is designed both to describe and to assess five perceptions and

their resultant social conventions. This historical analysis places beliefs about people with disabilities in the context of diverse time frames and in perceptual contexts that transcend historical eras.

Neither historical time frames nor attitudinal slants are prone to tidy boundaries regarding their content. Indeed, both are thoroughly fragmented and pervasive throughout time and subject matter. They are presented in this analysis as somewhat monolithic because there are characteristics typical of the time periods to which they are assigned, and because of the logistical requirements of organization for both author and readers. One of the instantly recognizable characteristics of each of these five perceptions, listed in Table A, is that they all still exist, despite assignation to specific historical periods.

TABLE A:

**HISTORICAL PERCEPTIONS OF PEOPLE WITH DISABILITIES
IN THE UNITED STATES**

General Time Frame	First Perception	Second Perception	Third Perception	Fourth Perception	Fifth Perception
COLONIAL PERIOD	Paternalism, Or, Attics, Closets, and Almshouses				
EARLY NINETEENTH CENTURY		Competition and Deviance, Or, Schools, Prisons, and Asylums			
EARLY TWENTIETH CENTURY			Dominance and Fragility, Or, Purity, Reform, and a President in Disguise		
MID-TWENTIETH CENTURY				Rehabilitation, and Independence, Or, Movements, Sit-ins and Disability Rights	
LATE TWENTIETH CENTURY					Charity and Celebration, Or Telethons, Paradigm Shifts, and Disability Culture

PRECURSORS: VETERANS, INSTITUTIONS, AND CHARITIES

As long as there have been people there have been people with disabilities. This is logical. There have always been injuries and diseases.

Archaeologists have repeatedly uncovered evidence of individuals with disabilities as far back as the Neanderthal period. Perhaps more pertinent to this discussion is the long history of attempts to confront disability issues. One such example from ancient times is that Roman law provided assistance to people with disabilities with the expectation that those individuals would then be peaceful citizens. (Mackelprang and Salsgiver, [1993, 2])

With a glimmering of such a long history of perceiving disability as a potentially troublesome issue, it may not seem too unusual to select thirteenth century France as an appropriate time and place to focus on actions that sustained an impact in the United States of the twentieth century.

Simply put, in Paris in the year 1260, an order of monks organized the first known institution for a group of people with disabilities. It was established for blinded veterans of military campaigns. (Scotch, 1984, 15)

The lasting import of veterans, institutions, and charities will become obvious as we proceed.

FIRST PERCEPTION: PATERNALISM, OR, ATTICS, CLOSETS, AND ALMSHOUSES

From thirteenth century France to seventeenth century colonial America. Much of colonial America's law and tradition were natural continuations of European precedents, particularly from England and the Netherlands, the two countries that colonized the eastern portion of what would become the United States. This held true

for people with disabilities.

Disability first became institutionalized in Elizabethan Poor Laws (1598-1601). The Poor Laws, developed in England during a time dominated by the monarchical presence of Queen Elizabeth I, were in part a reaction to the changing conditions of the times. The beginning states of England's world dominance included an increase in commerce and industry, and the creation of a group of unemployed and discontented workers. As the economic focus of the land changed from an agrarian to an industrial society, so too did the onus of unemployment. Once a society of landholders committed to providing work for everyone, the move to industrialization created entrepreneurs who believed that each individual harbored personal responsibility for their unemployment due to some character defect. These perspectives were exported to the colonies along with other English customs. (Connors, 1985, 93-94)

A disability would be considered a character defect if it prevented someone from supporting themselves. Although this sentiment was not confined to disability, there was a profound difference between those with and without disabilities. Any individual who was considered ill or physically impaired was legally defined as being an unemployable social dependent. (*Ibid.*, 94)

The common perception of this time frame was that people with disabilities were not exactly people, but burdensome characters whose disabilities required them to be taken care of in some way. The Jewish scholar, Moses Maimonides, in his 1539 The Guide for the Perplexed proclaimed that all disabling conditions were hereditary. Combined with the social stigma of disability, this attitude led to families sheltering their disabled relatives from public view. (Benavraham, 1985, 327)

In the nicest of settings this meant that families and communities shared a voluntary responsibility for ensuring that their relatives and neighbors with disabilities were treated with respect and perceived as part of community life.

When this did not happen, the burdensome nature of individuals with disabilities became an unwanted and often unhappy part of a family or community. This perception combined with the belief that family and community responsibility took precedence over individual autonomy led to many of the horror stories which pervade our national

consciousness: tales of people locked up all their lives in closets or attics, treated like animals, and doing little more than waiting for death since life held so little. (Ibid.; Lenihan, 1976-77, 2-3)

When families were unavailable or unwilling to harbor the burden of their relatives with disabilities, these people became the community's responsibility. This often led to institutionalization in almshouses, a setting that probably resembles today's homeless shelters, more than any other aspect of present-day society.

Almshouses were constructed in New Netherlands early in the seventeenth century and built in Boston as early as 1662. They provided a minimum of shelter and food to those in the community who were considered unable to fend for themselves. (Ibid.; 5, Connors, 1985, 94]

One other pattern that continues is probably worth mentioning. Aid for those who were injured in combat occurred as early as 1636 in Plymouth and continued with the development of seamen's hospitals and laws applying to those injured in combat. (Lenihan, 1976-77, 8-9)

The prevalent theme of these early American years is that the person with the disability is deemed incapable of primary responsibility for their own life. Instead, it is a familial or community role to care for individuals with disabilities. This first perception, which could be called paternalism, or a need to take care of those who cannot care for themselves, continues unabated throughout most of U. S. history.

SECOND PERCEPTION: COMPETITION AND DEVIANCE, OR, SCHOOLS, PRISONS, AND ASYLUMS

English attitudes towards people with disabilities, summed up in the word, "paternalism," corresponded in some ways with their governmental interactions towards the American colonies. England's monarchy and governing Parliament saw itself as a benevolent ruler which brought stability and prosperity to its colonists who were childlike

and unruly creatures incapable of self-governance.

In return for military assistance, increasing wealth, and civility, England requested only deference and taxes. As is often the case when one entity requires another to be deferential towards it, rebellion ensued.

American colonists perceived this relationship with England quite differently. They resented being treated as incompetent and inexperienced after almost 150 years of governance on American shores. They too had sacrificed their lives in incessant military conflicts, many of which were viewed as England's battles more than their own. What right, they wondered, did England have to coerce taxes from their hard-earned livelihood to a government across a wide ocean?

As all Americans learn in their school books these divergences led first to rebellion and rioting, then onto the Declaration of Independence and the American Revolution and finally to establishment of the United States.

There were individuals with disabilities who participated in significant ways in the Revolutionary War and the success of the early United States. Stephen Hopkins, one of the signers of the Declaration of Independence declared, "My hand trembles, but my heart does not," an apparent reference to his cerebral palsy. Gouverneur Morris, often described as the financier of the Revolution, lost a leg as a result of a carriage accident in 1780. Although both men were Revolutionaries, they were not social rebels who perceived disability any differently than the majority of their American brethren. (*Ibid.*, 11-12)

The overthrow of the English monarchy signaled a period of great change in the nascent United States. Politically, the nation both solidified its own government and attained recognition from others. Militarily, the country realized the need for an army as it continued battles with the first Americans, Indians, and entered a second war with England, the War of 1812. Economically, the newly created state began its own transition from an agrarian to an industrial economy.

The early 1800s both reflected these enormous changes and was a chronological precursor to further social upheaval. On the political scene, the War of 1812 led to the so-called "Era of Good Feelings," beginning with the election of

President James Monroe. Our fifth President attained his second term of office with only a single dissenting vote in the Electoral College. Popular legend maintains that this particular elector cast such a vote because he felt that only George Washington deserved the honor of unanimous election. (Davis, 1990, 113-14)

This era of seemingly little conflict ended quickly. To telescope the history of the period enormously, Andrew Jackson, the hero of the War of 1812, lost one Presidential election when the balloting sent the choice into the House of Representatives and that body elected John Quincy Adams. Never a quitter, Jackson ran again four years later and won. (*Ibid.*, 117-18) His Presidency symbolized the rise of the self-educated, self-made man, a rough-hewn soldier, a representative of the common man, and the individual entrepreneurial spirit.

This rise of the individual also represented a threat to the previously entrenched establishment. In political and economic terms, this threat took one of its most concrete avenues in Jackson's opposition to a national bank. an institution developed by the first Secretary of the Treasury, Alexander Hamilton, to ensure the economic support of the nation's well-to-do. (Ward, 1955, *passim*)

The purpose of this all-too-brief synopsis of a fascinating and complex time is an attempt to establish the flavor of multitudinous and intensely conflicting messages and activities that bombarded people in the United States during the early nineteenth century. Unsurprisingly, these great political, economic, social, and cultural upheavals impacted everyone, and marked a discernible change in social attitudes towards people with disabilities.

The impact of the changes of the early nineteenth century upon American life is difficult to overemphasize, not only for those years, but continuing on until today. A more detailed examination of four specific characteristics of the period will assist in integrating the social constructs of the period into a specific disability perception. They are: economic advances, medical notions, gender divisions, and social reforms.

ECONOMIC ADVANCES: Many contemporary Americans move unthinkingly

from one destination to another in an automobile. If we should stop and ponder the development of the car we are aware, from those same schoolbooks that taught us about the Revolutionary War, that these vehicles became a household acquisition only after the implementation of certain technological and organizational innovations. These advances included the standardization of parts, enabling many cars to be constructed and repaired with a modicum of ease; the implementation of assembly lines, rendering the process of production easier and quicker; and mass production, building so many similar cars that the cost fits within the household budget of many Americans.

Henry Ford is frequently recognized as the father of these innovations. Although Ford used each of these techniques to great advantage and developed a business which enabled the car to change the way we live, the technological aspects of standardization of parts and assembly lines existed long before he came on the scene. In the early part of the nineteenth century, inventors and refiners of products such as the cotton gin and the rifle both contributed to and benefitted from each of these economic innovations. (Davis, 1990, 113, 263-64)

For our story, the key elements to remember are that both the standardization of parts and the development of the assembly line were considered to be modern and positive reforms. If they had such a beneficial effect on the economy, perhaps they could be constructively used in other arenas as well.

MEDICAL NOTIONS: Medical beliefs rarely exist in a vacuum. Physicians and other practitioners of the healing arts share their society's attitudes and beliefs. During this time period, hospitals continued to be established and social responsibility for veterans retained its thirteenth century sensibility.

An early American hospital of note is the Pennsylvania Hospital established in 1751. It was the first such institution to include people with both physical and mental illnesses. Twenty-two years later, another first occurred with legislation sponsoring a hospital exclusively for people with mental illnesses in Williamsburg, Virginia. The statute was entitled, "Support and Maintenance of Idiots, Lunatics, and other persons of

unsound Minds." (Lenihan, 1976-77, 5-6)

Wars were a constant aspect of colonial life throughout the eighteenth century. But the young country could have no control over national policy towards veterans until the onset of the Revolutionary War. Then the Continental Congress authorized up to half pay for those soldiers who had become disabled while on active duty. (*Ibid.*, 8)

The twin trends of hospitalizations and accountability to veterans continued patterns that are traceable as far back as the thirteenth century. But their evolution in the nineteenth century reflected the strange symbiosis of then-current economic and medical beliefs.

From the vantage of the last years of the twentieth century, medical practices of the last century seem naive at best and unbearably primitive at worst. Our national consciousness assigns to this era the common, but now illogical practice, of bloodletting. There were no antibiotics until the middle of the century. And during the 1800s, phrenology, the scientific study of bumps on the head to determine a person's intellectual abilities, reached new heights.

These three examples, of many possibilities, are cited only to demonstrate that the medical "science" of that day so differs from our own tenets that it is almost unrecognizable. Yet, just as today, medicine had not only a biological impact, but a social one as well. With these illustrations of nineteenth century medical practices, one might appreciate how this knowledge could have an enormous, but from today's standards, a seemingly preposterous influence on the social mores of the time.

A combination of the economic trends of the marketplace and the medical science of the day contributed to an unusual view of the self-made man and entrepreneurial spirit. They were summarized some years ago in a fascinating article, provocatively entitled "The Spermatic Economy." (Barker-Benfield, 1972, 45-74)

The Jacksonian ideal of the market economy held in highest esteem the self-made man. An individual who rose from poverty to become, in favorable comparison with Jackson's own public image, a self-educated, self-supporting, essentially self-sufficient entrepreneur. A man who did not merely survive, but thrived in the cutthroat, competitive marketplace. (Ward, 1955, *passim*; Davis, 1990, 120)

The medical aspect of this theory was that men, the primary competitors of the marketplace, contained a finite physiological supply of sperm. In the space of a single lifetime, a man's limited sperm must be expended wisely and sparingly. If used too often, the supply would be depleted.

This medical belief in a finite sperm supply created a dilemma in the marketplace. Only a virile man, in other words a man who had not wasted his sperm supply, would be powerful and aggressive enough to compete in the dog-eat-dog competition of the day. The logical conclusion of this belief could only be that to succeed in the competitive, market economy a man would have to carefully guard his finite physical attribute so that he would be an energetic and successful competitor. (Barker-Benfield, 1972, 45-74)

In our tale of historical perceptions of disability, the desired strength, virility, and marketplace competitiveness of the ideal individual would be weighed against, at least symbolically, the traditionally and legally established incompetence of the person with a disability.

GENDER DIVISIONS: Since the marketplace was an institution geared to male potency, where did that leave the era's women? The prevalent medical notion of limited male energy and stamina and its subsequent social manifestation in a "spermatic economy," left only unenviable situations for the women of the time. These untenable stereotypes have been documented and analyzed in another excellent article, called, "The Cult of True Womanhood." (Welter, 1966, 151-74)

If men are bound by the limitation of their sperm supply, but still believed to have a supreme social and economic role, then women are artificially inhibited in the parts that they can play. They must either fill a position as a supportive and cooperative helpmate or be placed in the guise of an alluring and weakening burden on a man's ability to compete in the marketplace. This leads to the premise that there are only two types of women--whores and virgins.

Whores are wicked, alluring, and wanton women who entice men to expend their

limited energy. They lack any particular interest in the trajectory of a man's career, but are selfishly in pursuit of their own objectives. These women are to be avoided for they are an obvious detriment to success in the marketplace.

The whore's opposite, the virgin, is the selfless woman who will become a successful man's wife and the mother of his children. This woman is noted by four characteristics: purity, piety, submissiveness, and domesticity.

The true woman is pure in her interpersonal relations, that is, she is a virgin until matrimony, and focuses on intercourse solely for procreation, never for recreation. She is pious; it is her role to rule the spiritual aspects of family life and see that her children are well-raised. If daughters, that means to follow in her footsteps as a true woman, pure, pious, submissive, and domestic. If sons, that means to be taught that competition is healthy and the strongest competitors will be those who make it in the marketplace, but that one should remember to be charitable to those less fortunate and to play fair whenever possible. To be submissive means that men are the unquestioned lords of the home, whether that be father, brother, husband, or son. And to be domestic means that the true woman's job is to attend to household matters and ensure their order.

How does this stereotype affect people with disabilities? Individuals with disabilities deemed incompetent to fend for themselves in the marketplace, at least since Elizabethan times, are more akin to the pure, pious, submissive, and domestic woman than any other persona of the time.

SOCIAL REFORMS: The early decades of the nineteenth century were ones of accelerated progress and massive injustices. A throng of reformers subscribed to the economic, medical, and gender notions described in the preceding paragraphs. They fused these concepts into a somewhat tattered package and presented their society with a recipe that contained ingredients for profound change.

Standardizing mechanical parts and inaugurating assembly lines worked so well in the progressive factory and industrial setting that many people thought these

advances could be transferred to society with equally notable results. Many institutions of the late twentieth century have discernible roots in the social reforms of the early nineteenth century.

Schools, for example, have traditionally placed people of the same age in the same grade, taught them the same subjects, and given them the same tests to see whether they will progress to the next grade or be held back. We allow this pattern in the majority of our educational settings even though we know empirically that people of the same age possess different skill levels, diverse aptitudes, disparate abilities, and distinct identities. The nineteenth century founders of the school system we still recognize today consciously patterned our educational institutions after the newly established characteristics of the profitable factory.

Reformers of the day did not stop with schools. If such a vital component of the nation's resources could benefit from the factory model, then surely other institutions would be improved by integrating the factory model. The early American prison system became another object of the reformers' vision.

American prisons have historically treated people in a similar fashion, whether their primary purpose has been viewed as punishment or rehabilitation. Criminals are removed from society, placed in an isolated institution, clothed in identical uniforms, expected to conform to the same time rituals, and, with a minimum of variation, required to perform comparable menial tasks. The factory model inherent in this description is overwhelmingly apparent.

Schools were primarily for children and prisons were for criminals. Where does that leave the person with a disability?

Like the criminal, the person with a disability was an outcast, someone who did not fit into the traditional notions of society. If an institution modeled after a factory was advantageous for schoolchildren and criminals, it would only be logical to assume that the same kind of reform would benefit the individual with a disability.

Away from family and friends, a person with a disability could not fend for themselves if left alone. The proper thing would be to create an institution just for them. Hence the discovery of the asylum. (Rothman, 1971, passim)

The classic asylum, sometimes better known as a state hospital, was constructed as far away from society as possible. The best location was on a rural road miles from town. The institution would be plopped in the middle of the highest hills if they were available.

The criminal and the person with a disability shared one outstanding, common characteristic. Both were seen as deviants, unable to meld into respectable, middle class society.

Disability had now evolved in the national consciousness from a sympathetic characteristic which rendered its victims unable to meet their own basic needs, to an unacceptable social aberration warranting isolation from proper society. This signals the beginning of institutionalization as we commonly think of it today. Whether a psychiatric hospital, a nursing home, or some other variation of this theme, the individual with a disability is isolated from family and friends, and often forcibly incarcerated, all because society has a belief, a perception, that disability is deviant, therefore harmful to society, and must be isolated.

The second historical perception of individuals with disabilities is part and parcel of the mindset of competition and reform of the first half of the nineteenth century. The reason for analyzing this time period in such detail is that the impact of deviance, isolation, and institutionalization remains predominant for most of the following two hundred years. We will return to each of these themes repeatedly as we continue our course through the remaining three historical perceptions.

BRIDGING THE CENTURIES: THE CIVIL WAR

The volatile fervor and ferment of the first half of the 1800s erupted in the middle of the century with the outbreak of Civil War. The conflict between North and South raged over the ethics and economics of freedom and slavery, and the efficacy and dignity of industrialization versus agrarianism.

These antagonisms were buttressed by the economic and social reforms described in the preceding section. The national bloodletting unleashed in the Civil War, despite its widespread impact on the nation as a whole, had a minimal impact on disability issues.

The primary effect upon disability resulted from the fighting itself. Many combatants were injured. The numbers of people with disabilities increased. Although disabled Northerners fared better than their Southern counterparts, neither section of the country poured massive amounts of aid into healing their wounded.

Some Americans, in and out of government, recognized a need to assist those injured in battle. Public aid, in the form of family and community support as it existed in colonial America, no longer held much appeal. Asylums did not seem to be the proper resort for those soldiers who had put their lives on the line for their country. The government did not favor national relief programs so concerned citizens formed voluntary associations.

The United States Sanitary Commission brought together many of these voluntary groups to offer private philanthropical assistance to disabled veterans. Their efforts led to the establishment of a National Home for disabled Union veterans in 1866. Lodging and medical care were provided in eleven more homes opened during the next sixty years. (Lenihan, 1976-77, 33-35)

The repercussions of Civil War echoed throughout the remainder of the century. Veteran's issues, including those of disability, assumed utmost importance in many of the political debates of the latter nineteenth century. But for people with disabilities, it would take another tidal wave of reform and America's participation in World War I to spark a pivotal change in societal perceptions.

THIRD PERCEPTION: DOMINANCE AND FRAGILITY, OR, PURITY, REFORM, AND A PRESIDENT IN DISGUISE

Robust Theodore Roosevelt became President in 1901, heralding an era of American vigor and vitality. The energetic President, noted for his wilderness excursions and famed charge up San Juan Hill as a "Rough Rider" in the Spanish-American War, had also been a sickly child, who wheezed because of acute asthma and had inferior eyesight. A lifelong devotion to physical fitness may have derived from his childhood illnesses. As an adolescent, Roosevelt possessed a fanatic determination to transform his childhood weaknesses into an adult strength and sterling character which serves as an apt metaphor for his time.

Roosevelt's energy, passion, and conviction embodied an age historians have labeled the "Progressive Era." Reformers throughout the late nineteenth century demanded a halt to abusive business practices, an improvement of the country's morality, and a more direct involvement by the government in the life of its people. (Davis, 1990, 229-30)

As in the first decades of the 1800s, the late nineteenth century was a time of turmoil and unrest for many Americans. The piety explicit in the Jacksonian stereotypes of the true woman evolved into a sense of ladies as arbiters of social morality and males as transgressors of appropriate civil behaviors.

Progressive reform resulting from these principles included, among many other accomplishments, the passage of child labor laws, prohibition of alcohol, and regulation of food products. (*Ibid.*, 229-30, 255-57) Proponents of these efforts sincerely believed they were protecting and improving American life and morality, but there was a malignant underside to this reform effort.

Many late nineteenth century scholars fervently believed in the omnipotence of the scientific method. New disciplines, like psychology, sociology, and political science, advertised themselves as social sciences or scientific disciplines applicable to society. (Stallybrass and White, 1993, 286)

Faith in the social sciences, combined with recently ascertained laws of genetics, led to aspirations of creating a civic utopia. For late nineteenth and early twentieth century Americans this meant a white, intellectually rigorous, middle class society.

These qualities mirrored the racist conviction of the time that white people were a

pure and superior species. The superiority of the white race was not only conveyed through social customs, but by unrefutable scientific evidence and historical analysis. Amidst these multitudinous claims of racial sovereignty, white dominance contained a disquieting fragility threatened by miscegenation, or interracial sexual relations or breeding, with darker, inferior peoples. So the exploration of scientific and cultural evidence in support of white supremacy continued unabated.

Cranial studies demonstrated that whites had larger brains, and therefore, inherently more intellectual capacity than their darker "poor relations." Not only was this proven in study after study, but racial classifications were derived from these tests and other scientific studies. The next most intellectually capable group were those who were somewhat darker in skin color, but lighter than the rest of humanity. They also possessed craniums with the next largest brain mass. The least intellectually able group was also of darkest color, with minimal brain tissue, and usually assigned to peoples somewhere in deepest Africa.

Scientific evidence corroborated and upheld data from the social sciences. Historical and anthropological studies, along with their sister disciplines, explained that the least developed social structures were African. No great civilizations were recognized to have appeared in Africa or to have derived from African origins. This explained why smarter, more civilized, white Europeans easily enslaved black Africans and why freed blacks were incapable of advancing from inferior social stations. This also explained why little enthusiasm greeted a new wave of immigration from Eastern Europe. These darker newcomers, though superior to Africans, would have a difficult time integrating into superior American society. This resulted in passage of immigration laws restricting the numbers of newcomers to American shores and promising to save Americans' vaunted morality. (Fredrickson, 19 , passim)

An early indication of what would become a twentieth century nightmare was the transformation of the word, "defective." Originally an adjective, by the 1880s, defective had become a noun. Defectives, like people with disabilities, were considered threats to genteel society. (Finger, 1985, 295)

Against this backdrop of Progressive reform, middle class morality, pervasive

racism, homage to science, and the rise of eugenics, people with disabilities were a disparate group buffeted about on the seas of change. The ebb and flow of certain tides were decidedly more dangerous than others.

Eugenics, or genetics engineering, in concert with the entrenched certainty of inferiority that characterized people with disabilities proved first to be perilous, then deadly. There is no polite way to describe the horror that followed.

A pioneering attempt to control disability via heredity occurred in 1907 in Indiana where the first sterilization laws were enacted in an attempt to prevent congenital mental retardation. A succession of similar legislation followed in other states. (Lenihan, 1976-77, 47) Individuals with disabilities who were untouched by these statutes often encountered others laws equally repellant. Many cities had ordinances which prevented someone who was "unsightly" from appearing in public. (Longmore, 1985, 584)

The logical and lethal conclusion of the combination of the science of eugenics and the desire to eliminate disability occurred in Nazi Germany. People with disabilities were the first group to face the ovens and encounter genocide. This story is well documented elsewhere, so will not be repeated here. (Gallagher, 1990) But it should be stressed that the attempt to eradicate people with disabilities that failed in Nazi Germany emulated patterns well established in the United States.

Other reform crusades affecting the lives of people with disabilities coexisted with the rise of eugenics. Charity, economic compensation, and rehabilitation all retain premier roles in twentieth century perceptions of people with disabilities . In an endeavor to integrate them all we will begin with a succinct summary of charity and economic compensation.

The veteran's homes developed by the United States Sanitary Commission at the end of the Civil War included shelter and food, just like their colonial counterparts, the almshouses. Residents of these facilities also received medical attention in recognition of their war wounds.

One of the hallmarks of Progressive reform was a realization that all-encompassing change could only occur on the national level. This evolution in thought

from earlier focuses on local political transformations influenced charities as well. The Red Cross may be the most renowned assistance organization. It combined the idea of medical aid with social amelioration. The American branch of the Red Cross incorporated this amalgamation in the creation of rehabilitation facilities. The initial agency, the 1917 Red Cross Institute for Crippled Children and Disabled Men, promoted operation of rehabilitation facilities domestically and abroad. (Lenihan, 1976-77, 50-51)

National Progressive reforms also occurred in business and industry. A belief in safer and more sanitary job conditions and cognizance of workforce unrest led to passage of child labor laws, shortened work hours, and safer conditions.

Labor unrest coalesced into the formation of unions, followed by riots. The most famous of the early labor demonstrations occurred in Haymarket Square in Chicago in 1886. To place union activity in historical context, early demands included the eight-hour day, six-day work week, and regulations of workplace conditions. Fear of worker rebellion in alliance with a legitimate concern about worker welfare led to many early twentieth century reforms. (Davis, 1990, 207-210)

The first modern disability law emerged from this time. Employers were rarely considered responsible for occupational hazards. An on-the-job injury meant unpaid leave and perhaps termination or permanent unemployment. By the early 1900s, many government and business leaders along with reformers, realized that this injustice entailed a social cost as well as immediate damage to the families of injured workers. Acknowledgement of civic accountability in accord with a desire to prevent social unrest led to laws providing a minimal safety net for workers injured on the job. Worker's compensation, which has been called the first modern disability law, began in New Jersey and Wisconsin in 1911. (Berkowitz, 1987, 15)

The innovative idea of worker's compensation and the traditional role of charities were two critical foundations of the rehabilitation bureaucracy. Two other developments must be addressed prior to narrating the beginnings of rehabilitation.

Education too underwent a transformation during Progressivism. Early American education targeted only those who were most zealous in their desires for learning.

Although standards in education like grade divisions and testing occurred, they were not applied to everyone because not everyone attended school. Those who did enroll often went for a few years, but no longer.

Fear of civic unrest, concern about social impurities from inferior immigrants, and a sincere desire to inculcate everyone with fundamental American notions of government and civility led to required educational attendance. At the same time, university education began to divide branches of knowledge into specific degree disciplines. But school for everyone did not mean that most Americans moved on to higher education. The labor force remained the destination of most Americans.

The desirability of more schooling, reformist tendencies of the age, and concern with workers keeping up with the vast changes in knowledge and workplace production, led to a new kind of instruction, vocational education. One more marked change in an already discussed field holds the final key to the development of rehabilitation.

The healing arts, as practiced in the early twentieth century, were almost unrecognizable from the turn of the preceding century. Nineteenth century discoveries in antibiotics, bacteria, and causes of diseases highlighted a medical revolution.

Modern medicine commenced treatment for injuries and illnesses which enabled people to live longer with disabling conditions. Offsetting the condition of disability fell under the new idea of "rehabilitation."

Vocational rehabilitation meant that at least some people with disabilities should enter or reenter the workplace. Neither the most lucratively funded program for people with disabilities nor necessarily the most successful, vocational rehabilitation has been one of the most influential.

President Woodrow Wilson declared United States entry into World War I a mission to "make the world safe for democracy" and to fight a "war to end all wars." On a less idealistic level, World War I, like all wars had a profound impact on disability. Additional numbers of veterans with disabilities, continuing reformist actions, and a desire for disabled veterans to reenter the peacetime workforce, all contributed to a spate of legislation creating vocational rehabilitation.

During the final year of World War I, Congress passed the Smith-Hughes Law

(Vocational Education Act) of 1917. This legislation established the Federal Board for Vocational Education (FBVE) which was authorized to serve men with disabilities in hospitals and encampments. The following year Congress unanimously ratified the Soldier's Rehabilitation Act, designed to assist returning World War I veterans to join the labor pool. (Lenihan, 1976-77, 51; Walker, 1985, 25]

Transformation of soldiers with disabilities to civilians proved to be a difficult task. The Surgeon General of the Army and the FBVE disagreed about vocational options for servicemen with disabilities. The Surgeon General thought they should stay in the Army in non-combat jobs. Many soldiers were discharged unaware of the FBVE.

Two years after the Soldier's Rehabilitation Act, President Wilson signed the first federal act to provide vocational rehabilitation services to civilians with disabilities. A federal-state cooperative program, vocational rehabilitation became an immediate fixture of most state governments. Four years after the 1920 passage of the Vocational Rehabilitation Act only twelve of the forty-eight states did not participate in the program. (Walker, 1985, 33)

The FBVE, the umbrella agency to which vocational rehabilitation belonged, consisted of the three Cabinet Secretaries of Commerce, Agriculture, and Labor, as ex-officio members, and three salaried members responsible for its operations. John Kratz, Vocational Rehabilitation (VR) Chief in 1924, managed to convince both the FBVE and Congress to renew the office for six years. In an early agency nightmare, Congress adjourned prior to appropriating any funding.

State agency directors had to try to survive from June to December of 1924 without any funding. Missouri was the only state which could not keep its program alive. Federal staff remained on the job with deficit spending approved by petition to President Calvin Coolidge. After the debacle of no funding, states organized a national conference. This led to the 1927 founding of the National Rehabilitation Association which intended to make vocational rehabilitation more than an extension of vocational education. (*Ibid.*, 26,33-35)

Early statistics maintained by VR indicated a modest expenditure of \$12,000,000 had rehabilitated 45,000 people between 1921 and 1930. This averaged out to a cost

of about \$300 per person. Although still a bureaucratic stepchild without a comfortable home, VR's apparent efficiency led to its renewal in both 1930 and 1932 with increased levels of funding support.

By 1930, nine more states participated in the program. A total of 143 rehabilitation workers were employed in 44 states. Vocational rehabilitation became a permanent program in 1935. (*Ibid.*, 39, 58)

In the early thirties, VR had been transferred to the Office of Education in the Department of the Interior. It did not thrive in this setting. Rehabilitation workers felt their role in placing people with disabilities in the workforce was quite distinct from a narrow focus on education. They longed to be housed in another agency. The Federal Security Agency created in 1939 became the home for both the Office of Education and VR. Rehabilitation continued to be dissatisfied with its place in the hierarchy. (*Ibid.*, 102-103)

A year later, in 1940, Congress extended vocational rehabilitation services to people with disabilities working in sheltered workshops, which had been established by charities and paid workers pennies on the hour for assembling piece-meal products; those who were homebound; and those in the workforce who required services in order to remain employed. This significant increase in responsibility set the stage for a decade of greater funding and responsibilities. VR grants increased 75% in 1940 and continued to increase throughout the 1940s. (Scotch, 1984, 21; Shapiro, 1993, 143)

In July of 1943, rehabilitation services were managed by a rehabilitation director appointed by the Federal Security Administrator. For the first time, VR services were broadened to include physical restoration and clients with mental illness as clients. (Walker, 1985, 103)

By this time, the United States had weathered a Great Depression and entered a second World War. Major shifts in the ways that people with disabilities were perceived were on hand. Yet rehabilitation, in many ways a child of Progressive reforms and the aftermath of World War I, continued its progress toward larger and more significant roles in the lives of people with disabilities. We will return to its story shortly.

Perhaps the best way to conclude this section of Americans' perceptions of

disability is to take a brief glance at the career of Franklin D. Roosevelt (FDR). A pioneering Presidency, held during much of the Depression and World War II, FDR is both one of America's most beloved and most vilified Presidents. Among his many other qualities, FDR was the only President who was elected to the office with a clear and visible disability. Yet he consciously disguised the effects and ramifications of his disability from the American public in a national conspiracy unbelievable in the post-Watergate era of media invasiveness and all-consuming public scrutiny. Labeled by one scholar, "FDR's splendid deception," no account of American perceptions of disability can neglect to examine how and why FDR's disability became a non-issue. (Gallagher, 1985)

Like his cousin, Theodore Roosevelt, FDR was emblematic of his heritage and his time. Born into a wealthy family, he was bred to be a patrician, someone who called upon his natural talents and inherited wealth to serve his less fortunate countrymen.

A personable and vigorous young man, FDR emulated his cousin first in joining the Navy, then in quickly becoming a successful politician. Unlike his older cousin, his first foray into Presidential politics resulted in a losing effort as the Vice-Presidential candidate of the 1920 Democratic slate. Shortly thereafter, with his political future uncertain, he became ill with polio.

Often fatal, polio was a debilitating disease whose survivors frequently acquired permanent disabilities. FDR was no exception. Both his legs became paralyzed and he became a wheelchair-user.

FDR's wealth and contacts enabled him to pursue physical rehabilitation in any place of his choosing. He selected Warm Springs, Georgia. There he poured much of his energy and financial largesse into building a modern rehabilitation facility. He also encouraged other polio survivors to take advantage of the healing properties of Warm Springs.

Most historical accounts of FDR's bout with polio treat it as a brief and isolated incident in his life which probably proved to his political benefit. These narratives contend that the healthy and wealthy FDR was distanced from the common voter. But polio became a great equalizer. It demonstrated that even someone with FDR's

breeding and riches could be brought down a notch or two and in so doing would become more appealing to the voters who would elect him. In addition, FDR turned to his wife Eleanor, whose compassion is now legendary, to keep him in touch with everyday issues and the average citizen. Finally, his long recovery enabled him to write many letters, entertain visitors, and make numerous contacts in a concerted effort to reenter the political scene which he did with great success in being elected governor of New York in the latter part of the 1920s.

As Gallagher eloquently describes in his groundbreaking study of FDR, this scenario is one which has little understanding of disability and its comprehensive effects. Although FDR recovered from the polio virus itself, his disabilities remained.

FDR was a paraplegic who could not control the use of his legs and whose most efficient and comfortable method of moving was in a wheelchair. Although FDR took great pains to hide the extent of his disability from the public, it did not disappear from his own life.

As part of a study about historical perceptions of disability, FDR's need to hide his disability from public view is most instructive. Prior to his encounter with polio, FDR presented a public persona of both wealth and health. His post-polio paralysis and use of a wheelchair were viewed as signs of illness. Even though the polio virus itself had disappeared and the consequent impairments did not technically make FDR "sick" that was how he and the American public viewed disability.

The word invalid has historically been used to describe someone who is incapable of caring for themselves. Throughout most of modern history this has been the perception of a person with a disability. Although illness or sickness is not necessarily a permanent aspect of disability, it is an inherent concept of invalidism. Since no distinction was made between an invalid and a disabled person that individual was considered to be sick.

As a person whose polio had caused paralysis and wheelchair use, FDR fit the classic description of an invalid. Yet he had no intention of letting that erroneous appellation prevent him from resuming his political career. The clear course was to convince the American public that he was not sick, was not an invalid, and could fulfill

the duties of public office. To do that required conscious planning, massive assistance, and from today's vantage, unbelievable media corroboration.

When FDR appeared in public he did not use his wheelchair. He was able to rise from a seated position with the aid of braces and crutches, though he was neither stable nor graceful. He provided an illusion that his recovery from polio was so complete that he did not need the aid of a wheelchair. Once standing, FDR would shuffle along while carried by a complement of strong men. Someone in a crowd would see what looked like FDR walking from his seat to a podium or some other device that he could stand and lean against. Rather than appearing as a sickly invalid FDR gave the appearance of a healthy politician.

The media supported FDR's efforts to hide the extent of his disability. By conscious, yet informal, agreement radio, newspaper and film correspondents simply did not discuss FDR's paralysis. Thirty-five thousand photographs were shot of FDR as President, but only two show him seated in his wheelchair and these were never published. (Hevey, 1992, 102) This conspiracy of image makers extended as far as political cartoonists who would never draw FDR in his wheelchair, but always standing or walking--or running, or flying!

Although many Americans knew on some level that FDR used a wheelchair the disguise was so successful that many other Americans professed their ignorance of his disability. This was his "splendid deception" because it enabled him to rise to the Presidency during a time in which everyone was convinced that no invalid could aspire to that position.

What did FDR's cloaking of his paralysis and wheelchair use mean for people with disabilities. The conclusions are diverse and murky. For many people with disabilities FDR was a hero, a person who had overcome his disability and acquired the nation's most coveted office. In addition, he helped develop Warm Springs into an international rehabilitation facility and had a powerful and beneficial effect on the lives of many polio survivors throughout the world. On the opposite side of the coin his massive coverup not only reflected the perception of his time that disability meant illness and invalidism, but it also contributed to future generations harboring those same beliefs.

The contradictions inherent in trying to assess FDR's impact on disability conditions are a portent of many of the historical tensions about disability which flare into a full-fledged conflagration during the ascendancy of the fourth perception.

FOURTH PERCEPTION: REHABILITATION AND INDEPENDENCE, OR, MOVEMENTS, SIT-INS, AND DISABILITY RIGHTS

Post World War II America exploded into middle class prosperity. Jobs were plentiful and for the first time single dwelling homes were within the reach of a majority of Americans. Despite this newfound wealth for many Americans, the post-war years were far from tranquil.

The United States seemed constantly upset by issues of global politics, embodied in the Cold War; an unprecedented national cynicism, reaching a zenith with the resignation of a President threatened with impeachment proceedings; and, a plethora of social protest movements, including a sometimes violent civil rights movement. In the wake of demands from blacks, women, Chicanos, Native Americans, and many other groups, a Disability Rights Movement also emerged.

Unfolding the evolution of people with disabilities from social misfits, deviants, and invalids to a belief in their rights as a distinct minority group movement requires incorporation of the first three perceptions with a variety of post-war trends. The result is an innovative rights movement which coexists in a less than harmonious fashion with each of the still existing traditional perceptions.

An exploration of several topic areas will hopefully reveal the configurations, antagonisms, and complexities which for the first time characterize a historical perception of disability. The patterns of the fourth perception, like all previous ones, do not exist in a vacuum, so already identified topics will surface before any original activities are recognized.

REHABILITATION: Vocational Rehabilitation continued to amass larger budgets and greater prestige throughout World War II and the post-war years. A career bureaucrat, Mary Switzer, received a coveted appointment as Director of the agency in 1950. A long time advocate of vocational rehabilitation's mission, Switzer spent the next two decades zealously expanding its role and power. (Walker, 1985, 125-26, passim)

Switzer guided a comprehensive legislative package through Congressional appropriations four years after her appointment as agency Director. State vocational rehabilitation grants rose to a budget of \$30,000,000. Additional monies for training medical and rehabilitation professionals established long range agency precedents. Switzer persuaded Congress to fund research and development in medicine and rehabilitation engineering, in-service training programs, rehabilitation centers, and sheltered workshops. Satisfying the long-term agenda of the National Rehabilitation Association, she also managed to obtain permission for creation of separate Vocational Rehabilitation agencies outside of state education agencies. (Scotch, 1984, 22)

In the following decade, rehabilitation became a soldier in President Lyndon Johnson's "War on Poverty." Funding levels continued to increase, greater numbers of individuals became eligible to receive services, and state matching fund requirements decreased. (Ibid., 23) In 1974, Vocational Rehabilitation rehabilitated an all-time high of 361,000 clients. (Berkowitz, 1987, 175) By the late 1970s, disability researcher Frank Bowe praised rehabilitation as one of the best social investments ever made. He cited studies estimating a return of from five to seventy dollars for every tax dollar invested in rehabilitation programs. Bowe's endorsement of the rehabilitation process considered the tax paying contributions of people who had once been tax dollar recipients as well as the boost to their self-esteem as productive social participants. (1978, 164)

DISABILITY INSURANCE: Although rehabilitation steadily continued its path toward greater funding and influence, other disability programs still overshadowed it. A contemporary scholar contends that disability insurance programs have held an almost

hypnotic effect over disability policy. (Berkowitz, 1987, 105)

Social Security Disability Insurance (SSDI) might be considered a hybrid of worker's compensation from the early years of the century and the New Deal program of Social Security guaranteeing an income to older Americans. As first proposed in the late 1930s, SSDI would have been a federal program covering individuals with disabilities of all ages. Congressional negotiations changed the nature of the program. States became the entities making initial eligibility determinations applying only to people age 50 or over. Even in this streamlined form, SSDI quickly became the largest U.S. disability program in terms of people served and operational costs. (*Ibid.*, 141)

As a program compelled to make eligibility decisions, SSDI units had to issue guidelines describing who would be qualified for its services. This began a continuing quest for a common definition of disability.

The first federal definition of disability, in the midst of the Depression, delineated a physical impairment that severed a person with a disability from the labor force for life. Social Security definitions emphasized parallels between disability and age by focusing on the permanence of a condition and on income maintenance over rehabilitation and using the same formulas to determine benefits without distinctions for differing disabilities, except in the case of the blind. (*Ibid.*, 43-47)

Debates about disability insurance continued throughout the years. In 1950, Congress passed Aid to the Permanently and Totally Disabled, grants to states for people with disabilities who fit both the definitions of disability and poverty. Six years later SSDI maintained a narrow definition of disability as applicable only to people who could demonstrate they could hold no job. (*Ibid.*, 70, 41)

More than forty years later, in 1994, Social Security Disability Insurance remains an immense program. Approximately 3,000,000 people come to Social Security annually claiming to be too disabled to work. This represents an increase of 40% each year since 1990. The pending Social Security Administration (SSA) backlog is 800,000. Simply to work the backlog would take three months. Five billion dollars are currently expended in the system to determine who is eligible. Of those who do enter the SSA rolls less than one-half of one percent leave to go to work. Chances of going off SSA

rolls by some means other than death are less than 10%. (S. Daniels, personal communication, May 20, 1994)

PARENTS: The role of parents and families in the emergence of the Disability Rights Movement has been described in more detail in descriptions of advances in developmental disabilities. In the realm of cross-disability rights the role of parents and families is a largely untold story.

Internationally recognized disability rights advocate Ed Roberts recently declared that having parents willing to fight for you and include you in that fight is the most important skill a young disabled person can learn. (Shapiro, 1993, 44) His is the voice of experience. His mother, Zona, a former labor organizer, is renowned throughout the Berkeley area for her spunk and dedication. During a late 1980s interview with Harry Reasoner of "Sixty Minutes," Zona recounted how the doctors had told her that Ed's post-polio disabilities would be so significant that he would be better off dying than living as a "vegetable." Rather than accepting this verdict of her son's life, Zona became an advocate for his reentry into society as a significant participant. ("Mr. Roberts") We will soon have occasion to portray to some of Ed's accomplishments.

A decade later, across the country, another child with a disability, Robert deFelice, entered a mainstream school in the early 1960s because his mother "was a bitch." DeFelice reminisced about this time in a comic performance at a recent Society for Disability Studies Conference. (June 23, 1994) His point was that in a time when no laws protected children with disabilities, parents were almost solely responsible for the educational and social welfare of their children. If they were not up to the task, or knew no better, then the child would suffer from rampant and unchecked discrimination.

PERSONAL ASSISTANCE: Personal assistance is defined as an individual or a system of people assisting a person with tasks that one would normally do for themselves if they did not have a disability. These tasks include, but are not limited to:

personal maintenance and hygiene, such as dressing, bathing, getting in and out of bed or wheelchairs, household responsibilities, including everything from cooking and cleaning to child-rearing; cognitive tasks, like memory prompting, money handling and budget planning; emotional support, for instance, assistance in getting started with the day; and communications access, such as interpreting and reading. (Litvak and Kennedy, 1993, 64)

About 300 people who had polio and used respirators were institutionalized in the United States after the epidemic of the 1940s and 1950s. One-half of these polio survivors were housed at Rancho Los Amigos, near Los Angeles.

The state of California provided residential services including bathing, dressing, and other needs of daily existence. A late 1950s study indicated that dispensing this assistance in private homes would be less costly than institutional care. Thus began California's In Home Supported Services or IHSS, the nation's first publicly supported personal assistance program. Its role in the development of disability rights will soon unfold.

EDUCATION: Several institutions of higher education claim to have been among the first to welcome people with disabilities on their campuses. Perhaps the most well known is the University of Illinois in Champaign-Urbana which encouraged disabled people to enroll in the 1950s. No history of this phase of University life has been written from the viewpoint of the individuals who attended.

Many Illinois alumni participated in the development of the Disability Rights Movement and have divulged both fond memories and bitter recollections about their experiences at Illinois. Although the campus was comparatively accessible architecturally, students were required to be capable of self-care. This meant that if, for example, you used a wheelchair, then you had to be able to push yourself across campus without assistance, sunshine or snowstorm. This limited the number of people with disabilities who could apply due to the extent of their disabling conditions. (Shapiro, 1993, 52-53)

Other universities known for their general accessibility and acceptance of students with disabilities included Long Island University and Hofstra University in the New York City area and the University of California at Los Angeles. But it was the University of California at Berkeley that became the home of the Disability Rights Movement.

Ed Roberts entered the University of California at Berkeley in 1962. The uniqueness of his admission centered around the extent of his disability. Roberts' post-polio disabilities, which doctors believed would leave him better off dead, include high level quadriplegia resulting in the limited limb use of two fingers on his left hand, assistance from a ventilator to breathe during the day, and nighttime rest in an iron lung.

Roberts arrived at Berkeley in the same year that James Meredith broke the color barrier at the University of Mississippi. In Meredith's case, troops were required to ensure his physical admittance to the University and his struggle is routinely documented in history textbooks. Roberts barrier-breaking action is celebrated throughout the disability community, but few outside of this community know of his achievements, despite print and electronic media documentation of his action. (S.E. Brown, 1994, 28-30; Shapiro, 1993, 43-45; "Mr. Roberts;" We Won't Go Away...,")

When Roberts enrolled at Berkeley he accepted a unique living situation. He resided in an on-campus hospital. This enabled him to receive as much personal assistance as he required in a housing situation. It also provided an architecturally accessible domicile. From the University's perspective, it enabled them to keep an eye on a potentially vulnerable student. What it did not do was provide a setting equivalent to those received by other students.

Roberts registration as a student at Berkeley initiated a revolution. Within three or four years about a dozen other students with significant disabilities were living in Cowell, the on-campus hospital. They began identifying themselves as the Rolling Quads.

The group determined that they had to be responsible to obtain and direct services they desired, such as wheelchair repair and more available Personal Assistance Services. This led to the development of the Physically Disabled Students'

Program (PDSP). (Shapiro, 1993, 49-51)

The first such office of its kind in the nation it provided students with needed services and advocated with the University for more access to programs and buildings. It led to similar programs across the nation and eventually across the oceans. It also received widespread local attention and attracted area residents who were not students but who wanted similar services. We will return to their story.

A NASCENT MOVEMENT: Associations *for* people with disabilities began to develop in the late nineteenth century. But organizations created *by* disabled people to address their own needs have been a phenomenon of more recent times.

In the 1940s, Paul Strachan founded the American Federation of the Physically Handicapped, a precursor of later coalitions of disability advocates. (Berkowitz, 1987, 210-11) Government entered the act in the late 1940s with the creation of the President's Committee for the Employment of the Handicapped (PCEH), now known as the President's Committee on Employment of People with Disabilities, which began holding annual conferences in 1948. (Scotch, 1984, 56) In 1959, PCEH sponsored a conference of the American National Standards Institute (ANSI) which led to development of ANSI standards in 1961. These remain the most well known guidelines for architectural access. This was followed in the late 1960s with the Architectural Barriers Access Act of 1968, the first major piece of legislation to promote certain kinds of architectural access for people with disabilities. (Scotch, 1984, 73-74; Bowe, 1978, 32)

While organizational development continued, individual stories pertaining to accessing equal rights were accumulating. A recent memoir by a long time disability activist, Connie Panzarino, describes a local action in her area of New York that serves as an example for hundreds of other similar stories around the country.

In the early 1960s, Panzarino's community constructed a new library building closer to her home than the old one. She was ecstatic because the library was a local hangout and she could find a friend to push her there in her wheelchair. But the

entrance to the library had a dozen steps. She was prohibited from entering.

The library board held its meetings in the basement of the inaccessible building. Panzarino called the library and arranged to have a discussion of the building's lack of access placed on an upcoming meeting agenda. She called the local newspaper to request coverage and arrived with a group of people who also used wheelchairs. Since the Board meeting was in the basement those in attendance lifted the entire group into the library and down the stairs. When Panzarino's agenda item came up for discussion, there was none. There was simply a vote to make the library accessible. (1994, 99-102)

Across the country in the late 1960s and 1970s students with disabilities enrolled on college campuses, regardless of accessibility. Helen Kutz first attended the University of Oklahoma in Norman in 1970.

Kutz had moved from Missouri to Oklahoma shortly after she became a quadriplegic from a car accident. Kutz scheduled all of her classes at least one hour apart. That way she would have time to drive home and go to the bathroom. There were no accessible facilities on the entire college campus.

Kutz found others who had similar problems and experiences and she became an advocate who successfully changed the face of disability on that campus and in the city of Norman. By the late 1970s, accessible bathrooms on the University of Oklahoma campus were no longer an issue. (S. E. Brown, 1992, 231)

MEDICINE: Medicine in the post World War II era has improved so vastly that large numbers of people who would have died in an earlier time do not. This includes people who acquired the polio virus and those with spinal cord injuries.

Perhaps because the medical profession is the first to observe many of these individuals, society has turned to medicine to provide answers as to how to treat longer living people with disabilities. This has caused enormous problems for those of us with disabilities.

Medicine, like all disciplines, has its method. A physician is trained to detect

symptoms, diagnose ailments, and prescribe cures. When working at its optimum, this is a sequence that pleases all involved parties. But this also puts a premium on curing whatever ails a specific patient or group of patients. This leads to a medical conundrum in confronting disability.

A person with a disability is not sick. A disabled person may become ill with a cold, or flu, or measles, or any other ailment a nondisabled person might acquire. But having a disability is not the same as being perpetually indisposed. There are many healthy quadriplegics. There are also sickly quadriplegics. But the quadriplegia itself is simply an inability to use all or part of four limbs. It is a disability; it is not an illness.

Medical personnel are not trained to appreciate this distinction. They are instructed to cure illnesses. When that is not possible, as in the case of disability, medical training is inadequate.

Medical solutions to disability issues have been called a medical model. This model is distinguished by perpetuating the notion that someone who has a disability is broken, in disrepair, or infirm. This perception is easily integrated into medical training.

If a patient is broken they can be fixed. If ill, they can be cured. There is only one viable alternative to this philosophy, and that is death. There is no room for any intermediate position. Ongoing disability does not enter into the equation.

In the medical model, if people can neither be fixed nor cured and will not die, then they are no longer of medical concern, other than easing the inevitable wait for departure from this world.

The medical model validates previous perceptions of incompetence, deviance, and invalidism. Individuals with disabilities have no worth in either the medical or the social hierarchy. As one might imagine, this philosophy leads to confrontation with the notion of capable, valuable human beings with disabilities put forth by advocates with disabilities. (S. E. Brown, 1990, 64)

INDEPENDENT LIVING: Berkeley's Rolling Quads did not limit their exploits to the University. Life went on beyond the confines of campus, yet the city was no more

equipped to handle significantly disabled individuals than was the University.

A clear barrier to wandering around on Berkeley's streets was a lack of ramps or curb-cuts enabling people using wheelchairs to cross from one road to another. Devising solutions to this problem ranged from individuals wielding sledgehammers and pouring tar to make ramps from street to sidewalk in yeoman fashion to submitting requests to the City Council to redress the problem.

As the Rolling Quads increased in number and as the issues increased in quantity the city of Berkeley decided to budget some money for the opening of an office to address these problems and barriers. In the early 1970s, the Center for Independent Living (CIL) was born, partly staffed by members of the Rolling Quads themselves, who believed that without the kind of political action and change that led to the center's establishment disabled people would never rise beyond second-class citizenship and attain equal societal access. (S. E. Brown, 1994, 29; Shapiro, 1993, 47-55)

Several fundamental beliefs combined to form a philosophy of independent living. These premises include the notion that each individual is different and unique; that people with disabilities are the most knowledgeable experts about our own needs and issues; and that programs serving disabled people should be designed to serve all disability groups. This is not to say that a person without a disability is incapable of knowing, understanding, or empathizing with what it is like to have a disability. But it is to say that it's much more likely for a person with a disability to possess these characteristics.

The notion of one person with a disability having some understanding of another person with a disability forms a primary underpinning of independent living philosophy, which is the concept of peer support. In independent living terms a peer is someone with a disability who is a role model and/or support person for another person with a disability. The ideas of peer support and people with disabilities knowing what is best for ourselves leads directly into the concept of people with disabilities running our own programs. Staffs and governing boards of independent living centers were conceived as being comprised predominately of disabled people.

The final philosophical framework of independent living programs is that they

should be designed to serve all disability groups. Cross-disability advocates will agree that different methods may be used to attain the overarching goal of independence, for example a deaf person may need sign language for communication and a person with a head injury may need a tape recorded reminder to do a task and a person whose legs don't work well may need a wheelchair, but beyond the necessity of different tools is the common goal of an opportunity for full participation in the cultural, social, economic, and political aspects of our society.

The driving beliefs of independent living philosophy are a recognition that each person with a disability, like each person, is unique; that because of this uniqueness people with disabilities are in the best position to guide, direct, and control their own programs; and that because all people with disabilities are oppressed independent living programs need to be designed to ensure equal social, cultural, economic, and political opportunities for all disability groups. (S. E. Brown, 1994, 1-5)

CIL was a community-based, grassroots activist organization designed to provide services and political action for people with disabilities in the area. Although it was the first organization of its kind, other groups were implementing similar programs at about the same time in places such as Houston, Ann Arbor, and Boston.

Mary Switzer reluctantly retired in 1970 when she reached the then-compulsory retirement age of 70. (Walker, 1985, 253) Her impact has remained legendary within the rehabilitation community. But she might not recognize the evolution of disability rights that occurred after her death.

Disability activists, like the founders of CIL, empathetic rehabilitation workers and progressive Congressional colleagues worked together in the early 1970s to implement a new and broader agenda for the vocational rehabilitation agency. Aware of the pervasive discrimination against people with disabilities endemic in education, in employment, indeed in all of society, advocates worked to make revision of the rehabilitation act legislation a major shift in the early 1970s. This led to the first real fight of the nascent disability rights community.

Richard Scotch has provided the most thorough scholarly documentation of the struggle that ensued. But it apparently contains gaps. The late John Hessler, who

followed Roberts at Cowell and went on to participate in the founding of PDSP and CIL, wrote a correction to Scotch's narrative in a letter to the editor published in the Disability Rag magazine. Hessler maintained that, unlike Scotch's depiction, a number of activists participated in the concepts and language proposed in the Rehabilitation Act of 1972. According to Hessler's letter, Fred Collignon, a Berkeley community planner who worked with then Rehabilitation Agency Commissioner, Ed Newman, actively involved many Berkeley activists in the planning of the early 1970s act. Hessler wrote that he, along with other advocates with disabilities, worked on language that appeared in the eventual act, including the controversial Section 504, which became the catalyst of the young Disability Rights Movement. (1985, 3)

Hessler and his colleagues across the country thought that they had devised a progressive piece of legislation, which included concepts of independent living, client advocacy programs, and some prohibitions of discrimination. But President Richard Nixon vetoed the legislation, insisting that the Act would be too costly to implement and would be an administrative nightmare.

Nixon's veto sparked demonstrations across the country. Judy Heumann remembered in a 1980 conversation that New York's Disabled In Action organized a demonstration of sixty to eighty people to go to Manhattan's Federal Building. But when they arrived they discovered it was in an isolated section of the city. The demonstrators piled back into their vans and other vehicles, drove to Madison Avenue and stopped traffic on up to four blocks, effectively publicizing their demands. (Heumann in "We Won't Go Away...")

The following year Congress passed similar legislation with changes Nixon approved and the President signed the Rehabilitation Act of 1973 in September. But further struggles loomed ahead. (Scotch, 1984, 56-57)

Many advocates considered Section 504 of the Rehabilitation Act of 1973 the nucleus of all ensuing progress in obtaining disability rights. Section 504 was a short paragraph in the fifth section of the law. In about forty words, programs and activities receiving Federal financial assistance were prohibited from discriminating against otherwise qualified people from participating or receiving benefits from such programs

solely on the basis of their disability. This concise paragraph guaranteed disabled individuals civil rights for the first time in history.

The trouble with Section 504 was not the wording. Although Nixon had signed the law, regulations to guide its implementation were bogged down in the old Cabinet Department of Health, Education, and Welfare.

Frustrated by federal inaction, James Cherry and the Action League for Physically Handicapped Adults sued the government in 1975 for issuance of 504 regulations. The next year, disabled leaders demonstrated in Health, Education, and Welfare Secretary David Matthews office for 504 regulations and threatened to picket the 1976 Republican Convention. A federal notice of intent to publish proposed rules materialized in the May 17, 1976 Federal Register. In July of the same year, the courts ruled 504 regulations should be promulgated, but did not set a deadline. A second federal notice of intent to publish proposed rules was published in mid-July with little change from earlier edition. (*Ibid.*, 93-96)

Passage of 504 regulations became a battle cry of disability activists throughout the country. Two days after President Jimmy Carter's inauguration in January 1977, about fifteen people went to see new HEW Secretary Joseph Califano to advocate for rapid distribution of regulations. The administration received a deadline of April 4, 1977 to issue regulations or disability advocates would pursue an alternative course. Califano resisted for some of the same reasons that Nixon originally vetoed the entire act. He feared that both actual and administrative costs would be more far reaching than anyone imagined. (Eunice Fiorito in "We Won't Go Away...," Scotch, 1984, 104)

Disability advocates scheduled a series of demonstrations to follow the April 4 deadline. Ten cities across the country were targeted. The most successful action occurred in San Francisco. More than 150 people took over the federal building and remained for twenty-eight days. Ed Roberts left his new office as Director of the California Department of Rehabilitation to join the protest. Judy Heumann crossed the Bay from Berkeley to become one of the leaders of the takeover. Early in the action, Heumann, in a statement reminiscent of freedom fighters of all ages, declared that, "we will no longer allow the government to oppress disabled individuals...we will accept no

more discussion of segregation." ("We Won't Go Away...")

The mayor of San Francisco ordered law enforcement personnel to leave the protesters alone. The Black Panthers and the Gray Panthers brought in food donated by Safeway and assisted with personal care needs. (Shapiro, 1993 67-68)

Local news stations aired the story. The most comprehensive reporting was filed by a young newsman named Evan White. He was so new to the field that he did not yet have credentials to file national news stories. But his luck was good.

Heumann left San Francisco during the occupation to travel to Washington to lead a delegation to talk personally with Califano. He refused to meet with them. They decided to camp on his front lawn until he agreed to meet. Evan White traveled from San Francisco to Washington with the group to report the story. At the same time a media strike left a void in national news stories and uncredentialed stringers like White were able to file stories. His coverage of the demonstrations was picked up by national news networks and both the story and his career took off. (P. Walker, personal communication, Sept. 29, 1993)

After twenty-five days, Califano signed regulations. Two days later, victorious protesters emerged from the federal building chanting "We Shall Overcome." The siege remains the longest takeover of a federal building by any group in American history. (Shapiro, 1993, 69)

One year after the demonstrations in San Francisco, another kind of protest group emerged. A fictionalized account of the late Wade Blank's role in the disability movement was highlighted in the 1990 movie, "When You Remember Me," about the fight to remove a young boy with muscular dystrophy from a nursing home to a community-based residence. Blank's role in that action awakened a desire to protest the pervasive discrimination against people with disabilities.

One issue of obvious and symbolic importance was transportation. In the 1950s, blacks protested because they had to sit on the back of the bus, but in the 1970s, disabled people protested because they couldn't get on the bus. People who used wheelchairs had no way of entering a bus, even though equipment such as wheelchair lifts were available, comparatively inexpensive and fairly easy to use. A group of nineteen Denver activists organized with Blank to form a group called American

Disabled for Accessible Public Transit (ADAPT).

The first ADAPT demonstrations were staged on July 5 and 6, 1978, in Denver. Soon other ADAPT chapters and similar organizations formed throughout the country. Their methods of protest included blocking buses so they couldn't move. The theory was that if disabled people could not use the buses then neither could anyone else.

Police quickly arrived to arrest the protesters. But it was not such a simple process. First, police often still thought of disabled people as sick and vulnerable and were either cautious about injuring them or careless about not doing so. Second, the paddy wagons, like the buses were frequently inaccessible, so police had no way to transfer people to jail. And if they did find a way the jails were often inaccessible. The protests continued.

ADAPT was the first long-term United States grass roots movement of disability activists and is now in over 30 states. In 1992, Denver commemorated the first ADAPT action with a plaque which includes the names of all the protestors, except Blank, a nondisabled man who believed that this movement of disability activists should be so represented. (Dunning, King, and Smith, 1994; Hartman, 1993, 2, 8)

The same year that ADAPT began its actions, Congress formally recognized the value of independent living centers by writing them into the Rehabilitation Act with minimal appropriations. The first ten independent living centers funded through this legislation received monies in 1979. (Dunning et al., 1994; M. Shreve, personal communication, Sept. 9, 1994)

In Norman, Oklahoma, United Cerebral Palsy of Cleveland County (UCP-CC) successfully applied for independent living funding. The organization's Board of Directors sought these monies after a previous award of funds to build accessible, low-income housing. Many UCP-CC Board members were parents of adolescents with disabilities and professionals who worked with disabled children. They were extremely cognizant of the need to find shelter for their children when the parental home was no longer an appropriate option.

Helen Kutz was also a member of the UCP-CC Board and an intent follower of the progress of independent living funding. Oklahoma's Vocational Rehabilitation

agency, which had the right to apply for this money, decided against submitting a proposal. This enabled community based organizations like UCP-CC to apply. Kutz informed the Board of this opportunity. A successful grant application ensued.

From the inception of Norman's independent living center, which Kutz directed, problems of personality and politics, headed by issues of consumer control, surfaced. Three years after Norman established its independent living center, every full-time staff member walked out of the organization in protest of the lack of control from disabled individuals. (S. E. Brown, 1985a, 39-40) Similar confrontations occurred throughout country.

A tension between traditional modes of caregiving and the new concepts of independent living remained throughout much of the 1980s. By the early 1990s these tensions had become recognized on a national level with the battle to influence the 1992 Amendments to the Rehabilitation Act.

Early independent living center advocates had begun the process of forming a national organization in 1981. One charge of the new association called the National Council on Independent Living (NCIL) was to bring independent living issues to the forefront of the periodically required amending of the Rehabilitation Act. NCIL began this process quite early in preparing for the 1992 Rehabilitation Act amendments. A result is that the latest edition of the Rehabilitation Act more strongly reflects the philosophy of consumer control, the history of oppression and the desire for personal and group power of disabled individuals more than any previous Act.

There are currently over 50 definitions of disability in federal statutes and regulations. (Pfeiffer, 1993, 729) In the early years of the 1990s, the United States spent more than \$200 billion on programs and services that maintain disabled people in dependent care-giving environments and less than \$1 billion moving people into the

mainstream. (Leon, 1992, 2) In 1994, all of the programs and agencies funded by the Rehabilitation Act totaled 1.8 billion dollars. Of that amount, a fairly paltry \$36 million dollars is earmarked to independent living centers. (P. Spooner, personal communication, August 29, 1994)

Susan Daniels, a recent appointee to the Social Security Administration, discussed the continuing split between the paradigms of the disability and policy communities. Social Security still uses the old paradigm of impairments meaning deficits with no intervening variables. (personal communication, May 20, 1994) It is to these two tensions about the meaning of disability we turn to in the fifth perception.

FIFTH PERCEPTION: CHARITY AND CELEBRATION, OR, TELETHONS, PARADIGM SHIFTS, AND DISABILITY CULTURE

Various talents appeared among the scores of protesters taking over San Francisco's federal building in 1977. Jeff Moyer brought along his guitar and became known as the resident musician of the demonstration. Moyer's stirring voice and ringing guitar are heard throughout the 1981 documentary, "We Won't Go Away...." His composition, "Keep Your Eyes on the Prize," is a musical chronicle of the 504 protests. Years later Moyer produced "Do You See Me as an Equal?," a tape of his songs including his signature title tune.

Moyer's musician role during the 504 demonstration and his later verses represent significant changes in disabled people's self-image. In a complete turnabout from the discounting and devaluation inherent in the first three perceptions of this saga, the Disability Rights Movement has encouraged a celebration of disability.

The very idea of celebrating a condition like disability which has historically been viewed from incompetence to deviance to tragedy remains an anathema to a society guided by the medical model. A more popular view of disability is molded by what many disabled people consider the scourge of the late twentieth century--telethons. We will

spend some time examining the role of these latter-day charities prior to a brief glance at the ways in which disabled people are celebrating their heritage.

Telethons have generated great controversy for the past decade or so. Entertainer Jerry Lewis has become the focal point of this conflict. Best known for his comedy routines and slapstick movie roles, Lewis has been identified with the Muscular Dystrophy Association (MDA) for many years. The MDA has sponsored an annual telethon during the Labor Day weekend since 1981. (Dunning et al., 1994) Each year Lewis takes the opportunity to write an article about MDA in Parade magazine which is distributed with many Sunday papers. Lewis' articles have tended to bemoan the plight of children who have Muscular Dystrophy and to include pleas to support "his children," some of whom are almost as old as he is.

Several years ago Lewis spent some time in a wheelchair to see what it was like. He wrote about his experiences in Parade. His comments were so disparaging that two advocates with Muscular Dystrophy formed a group called, "Jerry's Orphans," to sponsor annual Labor Day weekend demonstrations to protest Lewis' demeaning approach to disability.

The two combatants have waged a public battle, which led to a 1993 article in Vanity Fair magazine characterizing Lewis' personality and the substance of the issues involved. In the article, Paul Longmore, a historian with a disability known for his studies of the media and telethons, described the impact of telethons on the American public.

Four major telethons--Easter Seals, the Arthritis Foundation, United Cerebral Palsy, and the M.D.A.--are the single most powerful cultural mechanism defining the public identities of people with disabilities in our society today, mainly because they reach so many people....The telethon sponsors claim that, collectively, they have a combined audience of 250 million people. That's the equivalent of the population of this country. The message of telethons is that whatever condition people with

disabilities have, that condition has essentially spoiled their lives, and the only way to correct that is to cure them. The message of the disability-rights movement is that it's possible to be a whole person with a disability. (Bennets, 1993, 92)

The final two sentences of Longmore's analysis form a precise description of the models of charity and celebration of disability that have emerged in the late twentieth century.

The most comprehensive assessment of the charity mentality comes from an English photographer with a disability, David Hevey. In his 1992 book, The Creatures Time Forgot, Hevey exposes charities as the most visible appendage of what he calls the "disability industry."

Hevey contends that charities have created a hegemony, an almost complete dominance, of what the public perceives as the one voice of people with disabilities. But in reality, disabled people wait at the end of the line of the disability industry's priorities.

Foremost among any charity's goals are survival and ensuring that those individuals who contribute to the agency's success feel good about themselves. This can be accomplished by attaining the dual objectives of raising money for the organization and determining how to distribute it to those the organization's needy clientele.

One result of this model are that the needs of the charity, or disability industry, must come before all other concerns. A more invidious consequence is that the only way charities and their ilk can continue to exist and to feel good about their selfless contributions to those less fortunate than themselves is to have a perpetual supply of victims of disability's tragic ravages.

The strongest threat to the disability industry comes from the Disability Rights Movement. Not only do participants of the Disability Rights Movement refuse to play the role of victim any longer, many disabled people have taken the traditional prototypes of disability, turned them topsy-turvy, and begun to extol their lives. (S. E. Brown

1985b, 4-5; Hevey, 1992, 22-26, 51-52)

Perhaps the simplest way to describe disability culture is to exclaim pride in the condition of disability. Dianne B. Piastro is a middle-aged woman with a disability. She was once a nondisabled adult. Her experiences in becoming disabled from Multiple Sclerosis created a desire to write. Since the mid-1980's, Piastro has published a syndicated newspaper column called "Living with a Disability." In a 1993 column, she wrote:

Contrary to what you may think, disability culture is not new. It has always existed. But it is the people who know they are well-centered and valuable because they have a disability, not in spite of it, who will bring it into America's consciousness.

The idea of having pride in one's existence as a person with a disability is so novel it begs paradigm analysis. The following chart explores two disability paradigms that include aspects of all five perceptions.

We will use it as a springboard to the next sections of this work--a detailed analysis of the burgeoning fifth perception--disability culture.

TABLE B:

DISABILITY RIGHTS/CULTURE/PRIDE PARADIGM

by

Steven E. Brown¹

	COMMUNITY ASSISTANCE/MEDICAL/ CHARITY PARADIGMS	DISABILITY RIGHTS CULTURE/ PRIDE PARADIGM
DEFINITIONS OF PROBLEMS	Physical or mental impairments; lack of socio-economic, political, and cultural skills	Dependence on professionals, family members, and others; hostile attitudes and environments; lack of legal protections or recognition of inherent worth of disabled people
LOCUS OF PROBLEMS	In individual (who is broken or sick and needs fixing or curing)	In socio-economic, political, and cultural environments and perceptions
SOCIAL ROLES	Patients, clients, charity recipients, non-existent	Family and community members, customers, coworkers, advocates, same as anyone else
SOLUTIONS TO PROBLEMS	Professional and volunteer interventions and treatments	Equitable socio-economic, political, and cultural options
WHO CONTROLS	Professional and/or volunteer	Individual or group of individual's choice
DESIRED OUTCOMES	Maximum self-care; No social misfits	Pride in unique talents and attributes of each individual and positive disability identity

¹Parts of this chart have been extrapolated from DeJong, G. (1978). The movement for independent living: Origins, ideology, and implications for disability research. Boston: Tufts-New England Medical Center, Medical Rehabilitation Institute; *Ibid.* (1983). Defining and implementing the independent living concept. In N. Crewe & I. K. Zola. (Eds.). Independent living for physically disabled people. San Francisco: Jossey-Bass; Racino, J. A. (1992). Living in the community: Independence, support, and transition, In F.R. Rusch, L. DeStefano, J. Chadsey-Rusch, L.A. Phelps, & E. Symanski, (Eds.). Transition from school to adult life: Models, linkages, and policy. Sycamore, IL: Sycamore; and M. Shreve. (1994). In Independent living and the Rehab Act: Regional training. Houston: National Council on Independent Living/Independent Living Research Utilization.

SECTION TWO:

**"THE FILTER THROUGH WHICH WE
PEOPLE WITH DISABILITIES EXPERIENCE THE WORLD"**

Voice is what social movements are all about....denial was regarded as essential to anyone with a disability being accepted into society. Such acceptance was embodied best in two compliments echoed throughout much of the 20th century and occasionally even today: from the other, 'I never think of *you* as handicapped;' from the self, 'I *never* think of *myself* as handicapped.

(Irving Kenneth Zola, 1993, 802)

CHAPTER TWO:

"ONE'S INTERIOR ARGUMENT AND COLLABORATION WITH THE AUTHOR OF ONE'S DEGRADATION "

ONE VOICE AWAKENING

Disability pride equals personal liberation from the handicappism (myths and stereotypes accepted about disability). It is an awareness and analysis of our experience and appreciation of how we have coped with disability and survived. It is a positive view of ourselves.

(June Kailes, 1992, 23)

"A business in Tulsa was looking for someone to write their history....After what seemed like an eternity I learned that I had been hired....All of my contacts with the business were over the phone....A week later we had another phone conversation. He informed me that his company did not believe an individual with my health problems could complete the project in time. This from a man who was first impressed with me because I had completed my dissertation in a shorter time than he....In that instant my radicalism crystallized." (S. E. Brown, 1984, 1)

Thus began my own rude introduction into the world of disability discrimination. The trajectory of a shifting paradigm might be a gradual displacement of old beliefs. Or, as in my own case, what seemed to be an overnight awakening.

I was one of the lucky ones. About six months prior to my devastating experience with such obvious employment discrimination I had been introduced to the staff and mission of my community's brand-new independent living center. I had begun to do some volunteer work for the organization.

When I slammed down the phone, after a forty-five minute argument with the person I now considered my tormentor, I got into the car and drove to the center. They could not find a legal way to assist me. But they did offer moral support. Peer support.

Soon I was spending all my time at the center, volunteering, reading, talking with other people with disabilities. A couple of months later, the center received additional funding to create two new positions. One job description seemed perfect for me. I successfully applied. Soon I was immersed in my new job, my new environment, my new life.

Old habits linger. Although I had left the university setting, I remained a scholar.

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." (1972, 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." (1992, 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. (S. E. 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." (S. E. 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. (S. E. Brown, 1992, 229)

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.

This need to tell and to hear our stories is why I have approached this section of an investigation of disability culture with my own story. Personal stories often embrace solutions to much larger matters. Autobiography, in fact, often plays vital roles in the passage of laws. This situation occurred with the fight to pass the Americans with Disabilities Act of 1990 (ADA).

Justin Dart, a longtime disability advocate, spent a considerable amount of time and money traveling to every state in the union in the late 1980s to collect information demonstrating the need for the ADA. He asked people to write or relate discrimination diaries, experiences that people with disabilities had had in their everyday lives that led to their belief in the desirability of a such a law.

Many stories were collected, so many that they are now stored at the PCEPD offices. Some of the more poignant storytellers testified before Congress. One was a young woman from the state of Washington who has cerebral palsy. She testified that she tried to get into her hometown theater to see a movie, but the ticket taker would not admit her because her speech was slurred. This woman's story touched the heart of many members of Congress and President Bush, who recounted it when greeting celebrants at the ADA signing. (Shapiro, 1993, 105-06, 140)

These anecdotes contain an important element of a culture--a historical tradition. But before we delve further into specific aspects of a culture of disability, we must assess in-depth the concept itself.

CHAPTER THREE:

"OUR OWN FAMILY"

THERE CAN'T BE A DISABILITY CULTURE, BECAUSE...

Several years have elapsed since I realized that disability culture had become my passion. 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.

Carol Gill, an eminent psychologist with a disability who has written with great passion about disability culture, observed that people who deny they are disabled believe:

Disability equals tragedy. They've learned the myth "you're not an OK person if you're disabled." "When you accept that myth, "you're going to have to deny something. You're either going to have to deny that you're OK, emotionally, or you're going to have to deny that you're disabled."

(in Johnson, 1987, 7)

Those individuals with a disability who fear that identification with a disability culture will threaten their broader social status appear to share a common attitude with a cohort of scholars. Two recent Society for Disability Studies (SDS) conferences have served as settings for attacking the idea of a disability culture.

A word about SDS and its informative publication, Disability Studies Quarterly, might be appropriate before relating these two incidents. Sociologist and writer Irving Kenneth Zola, of Brandeis University, continued a newsletter begun in 1981 by a graduate student who lay, and lays still, in a coma from an automobile accident. That newsletter has become a quarterly journal, Disability Studies Quarterly. It is a publication automatically received with SDS membership. (in Brown, 1993, 6)

SDS began in the mid-1980s when Zola and others who were pursuing research and writing in the field of disability studies sensed a need for group support. SDS has grown over the years to an organization of several hundred members, many of whom are disabled. One highlight of each year has become an annual conference.

At the 1993 Annual Conference in Seattle, Simi Linton of Hunter College at the City University of New York, led a discussion to reevaluate the conceptual foundations of the field of Disability Studies. Taking the information from that meeting and later comments, a lengthy definition, a part of which follows, was advanced:

Disability Studies reframes the study of disability by focusing on it as a social phenomenon, social construct, metaphor, and culture, utilizing a minority group model. It examines ideas related to disability in all forms of cultural representations and throughout history, and examines the policies and practices of of all societies to understand the social, rather than the physical or psychological, determinants of the experience of disability. Disability Studies both emanates from and supports the Disability Rights Movement, which advocates for civil rights and self-

determination. This focus shifts emphasis away from a prevention/treatment/remediation paradigm to a social/cultural/political paradigm.... (1994, 46)

This definition would seem to sustain the idea of a disability culture. Yet it has been at SDS Conferences that some of the most vociferous critiques of disability culture have been promulgated.

At the SDS conference in Oakland in 1991, two graduate students delivered a paper discussing "The Search for a Culture of Disability." Audience reaction was heated. Representatives of various academic disciplines, especially anthropology, seemed almost oppressively possessive of the idea of culture. These individuals proclaimed that there could not possibly be a disability culture because people with disabilities lacked a common language, did not pass cultural traits familialy, and had no ritual tradition.

Three years later, after the above definition had been fostered, a new panel assembled to discuss "Disability Community and Disability Culture: What are They and Who Cares?" Moderator Richard Scotch, author of From Goodwill to Civil Rights, an examination of the battle to obtain 504 regulations, indicated that disability culture had been a hot topic and should be addressed. Unfortunately, none of the panelists he convened represented people doing the field work. For the most part, investigators of disability culture languished unheard in the audience, which did not receive much participatory time.

The general conclusion of the panelists was that disability culture did not exist, except in the case of the deaf, who had their own culture, and who were represented by two of the panelists. The most that could be positively articulated was that a disability subculture probably exists which could be a positive mediating force between the nondisabled mainstream and the marginal disabled outsiders. Those of us in the audience representing the daily work of exploring disability culture concluded that the panelists had not rejected the notion of disability culture as we perceived it so much as they did not understand it.

WHAT IS CULTURE?

The contentiousness displayed by the participants in the preceding disability culture debates ostensibly revolved over the interpretation of the meaning of culture. There may be as many definitions as there are people.

When I first realized I wanted to write about disability culture I looked for some definitions. I quickly discovered that scholarly definitions ranged from 500 page tomes devoted entirely to attempts to define the concept, to "you're part of a culture if you think you are." These research efforts on my part occurred before I realized I wanted to write a scholarly paper on the topic, so I did not save the references.

For the sake of scholarly integrity I shall first quote a dictionary definition, then an apparent lay definition, and some academic discussions. The 1973 Random House Unabridged Dictionary, which happens to be the one I use at work, defines culture as "the sum total of ways of living built up by a group of human beings and transmitted from one generation to another."

Shortly after copying this definition I came across another. I had jotted it down on a piece of scratch paper. I don't know its origin, but its definition is a "totality of socially transmitted behavior patterns, arts, beliefs, institutions, and all other products of human work and thought characteristic of a community or population."

These definitions would seem to have only one potential conflict with the notion of a disability culture. Do disabled people transmit the ways of living they have built from one generation to another, if so, how, and if not, why not? I would argue that indeed we do transmit our ways of life from one generation to the next and when we don't it is most often because oppression or stigma has prevented us from so doing. I believe this will become clearer when we examine disability culture in detail.

The study of culture is often associated with anthropology, however, cultural biases are a part of every discipline. Practitioners of those disciplines which do not obviously study culture, like mathematics, are swayed by the cultures of which they are a part. The pervasiveness of cultural influence has led in recent years to the

development of a discipline of cultural studies.

Simon During, Professor of English and Cultural Studies at the University of Melbourne, recently edited an anthology called the Cultural Studies Reader. Twenty-eight essays from all over the world addressed cultural studies issues. All kinds of disciplines and subjects are represented. Disability is almost completely overlooked, yet there is no question that it would fit within the context of the volume.

During's introduction is both a fascinating historical recap of the field and a discussion of the evolution of theories of cultural studies. He indicates that cultural studies is an academic discipline unlike any other—it has neither a well-defined methodology nor clearly delineated fields of investigation. The discipline continually shifts its interests and methods because it is in constant and engaged interaction with its larger historical context and because it cannot be complacent about its authority. (1993, 1,20)

Cultural studies, like culture itself, is an elusive target, defying conventional approaches to human scholarship and behavior. Essayist James Clifford contends that culture is enduring, traditional, structural, a process of ordering, changing and developing like a living organism. (in During, 1993, 64)

A third essayist describes why oppression must be seen in the context of cultural organization:

Indeed, it was the long, painful realization, *not* that all oppressions are congruent, but that they are *differently* structured and so must intersect as complex embodiments that was the first great heuristic breakthrough of social-feminist thought and of the thought of women of colour. This realization has its corollary that the comparison of different axes of oppression is a crucial task, not for any purpose of ranking oppressions, but to the contrary, because each oppression is likely to be in a uniquely indicative relation to certain distinctive modes of cultural organization.

(Sedgwick in During, 1993, 253-54)

Two scholars writing about culture in relation to disability, as opposed to disability culture, in a rehabilitation journal, defined culture as "a system which blends the ideas, values, and beliefs of individuals into commonly shared interpretations of events."

(Fowler and Wadsworth, 1991, 19)

Finally, another cultural studies essayist, Ien Ang, wrote that:

Ideologies organize not only the ideas and images people make of reality, they also enable people to form an image of themselves and thus to occupy a position in the world. Through ideologies people acquire an identity, they become subjects with their own convictions, their own will, their own preferences. (in During, 1993, 410)

And, their own voices.

A LIVELY DEBATE, OR A FAMILY ARGUMENT?

We don't need to be foster children of the "able-bodied" culture. We can have our own family. That doesn't mean we don't still want our majority culture family we were born into; but we also want one that responds more to our experience.

(Carol Gill, in Johnson, 1987, 6)

In some ways the question of whether there is a disability culture is an academic

one in the most ivory tower sense of that word. Countless numbers of people are consciously participating in the culture of disability on a daily basis. Some are doing so simply (though it is hardly easy) by living the life of a disabled person or as part of a community of disabled people in a marriage, a family, a home, an institution, a workplace, and so forth; others are writing, creating different kinds of art, composing, performing, and participating in all of the activities that comprise a culture's outward manifestations.

At the 1993 Society for Disability Studies Conference Gene Chelberg and I facilitated a panel called "Disability Culture: Putting the Philosophy into Practice." Gene is a recent college graduate from the University of Minnesota. As a result of a senior project, he worked with a group to form the Disabled Student Cultural Center at the University. It is the first concrete manifestation or institutionalization of the idea of disability culture. (Weglarz, 1992, 1,8)

Gene discussed the evolution of the Disabled Student Cultural Center and its forthcoming projects. I presented a paper entitled, "A New Renaissance: Exploring the Existing Culture of Disability." We were joined by Anne Finger, who talked about writing and read one of her forthcoming short stories, about an imaginary meeting between Helen Keller and Frida Kahlo. The audience sat spellbound.

Part of the purpose of this panel was to move the discussion about disability culture beyond the question of whether it exists to what is it. We all had lots of examples of disability culture in practice. But the debate did not end. In fact, it may have even picked up steam.

But there is an extremely exciting characteristic of this battle. The most vociferous participants generally tend to be the actual players. There are philosophers of disability, but they are commonly relegated to finding outlets for their contemplations to academic papers and treatises or in underground or alternative publications. The popular press has yet to discover the magnitude of the interest people with disabilities express in finding out more about ourselves.

The sole purpose of the remainder of this chapter is to document the evolution of the idea of disability culture during the past decade. This is the time frame in which the

question has most often been framed and explored.

The principle hypothesis of this work is that a disability culture does exist. One way to demonstrate the validity of this assertion is to listen to many of the people who form that culture. There is a noticeable distinction between the thinking of the earliest espouser of disability and the latest. There is also a recognizable difference in the perceptions of different generations. A colleague of Gene Chelberg, Barbara Robertson, recently discussed her ideas about a disability culture she is certain exists:

People with disabilities have been adopting the socio-political model, resulting in efforts to simultaneously develop a community and to influence the larger society's view of disability. This movement is informed not only by the experiences of disabled people, but by the civil rights movements of African-Americans and other minority groups, the women's rights movement, and by the current movement for gay and lesbian rights. As different as the experiences of members of these groups may be, there are commonalities that they all share: Disenfranchisement, barriers to political and economic power, assignment to marginal status in the larger society, internalization of oppression, and struggles for dignity and pride. All of these movements share the objectives of redefining the meaning of the group's identity of repudiating the stigma traditionally associated with membership in that group, and of demanding equal opportunities within the larger society. (1994, 5)

Robertson concludes that there are two values apparent from a disability culture perspective: first, disability can be a source of pride, rather than shame; and second, that there is a redefinition of independence. (6-7) The ease with which she arrives at these conclusions belies the struggle that has preceded her.

To get a better idea of the flavor of the debate, and its evolution, a number of its

participants will be recorded in their own words. They will be presented in chronological order to enhance the sense of movement that transpires in the debate.

Until someone uncovers an earlier attempt at grappling with the issue of disability culture, we will begin with the first written discussion of disability culture. Two essays were included 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--it has paid attention to the debate). David Pfeiffer of Suffolk University and Andrea Schein of the University of Massachusetts--Boston each presented papers entitled "Is There a Culture of Disability?"

Pfeiffer and Schein had originally intended to present in tandem, but as they prepared their paper they discovered they approached the topic from quite different perspectives. They chose to present separately. (personal communication, Sept. 19, 1994)

Extracts from these initial essays, beginning with David Pfeiffer, introduce this exposition on the topic:

Is there a culture of disability?...The question is neither easy nor trivial....If one turns to the discipline of anthropology to answer the question, little assistance is to be found. Very few anthropologists study disabled persons....Since the term "culture" comes from the discipline of anthropology, it is important to examine its use by anthropologists. When that is done one finds that it is a term more used than defined.... Most anthropologists, however, agree that culture refers to beliefs, value systems, and behavioral norms conveyed over time through an educational process....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 this culture is learned, shared,

interrelated, cumulative, and diverse. A culture of disability does exist.

Schein states:

The question posed here is whether disabled Americans as a group share a common culture....Today, anthropologists generally agree that culture is the learned body of tradition within a society....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....All over the United States, there are people with disabilities who understand and share the central concepts of the disability sub-culture.

The writers that follow do not acknowledge any debt to these two essays. Yet the themes set out by Pfeiffer and Schein dominate much of the future discussion.

The Disability Rag & ReSource (formerly the Disability Rag) has since the early 1980s served as a kind of conscious of the disability movement. Many controversial topics have found a home there. The next quote and many to follow might be deemed the grassroots exploration of disability culture. This may be more important than at first it might seem. Many of the goals and objectives of the Disability Rights Movement have been ones that began as grassroots issues. More than the academic papers quoted above, the Rag may have been the vehicle most responsible for spawning and entrenching the idea of disability culture.

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.

(Ed Hooper, 1985, 8)

Hooper published those words in the August 1985 issue of the Rag. The following month the Rag distributed a larger-than-usual "Independent Living" issue, which for many years was a staple of orientation packets on independent living all over the country. The idea of culture fit well within its content:

The *dream* [Independent Living Movement] has grown beyond the boundaries of any one social institution. It is the dream of a social revolution and its profound redefinition of the value of life: the dream of the ultimate civil rights movement.

(Mary Jane Owen, 1985, 63)

The one consistent, passionate, and persistent voice promoting the concept of disability culture during this entire decade 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.

1985

Two years passed before the next significant call for an investigation of disability culture surfaced, again in the Rag. The author was Karen Hirsch, a professor of education, who wrote an opinion piece called "Studying Culture."

Does there exist a 'disability culture' that is shared
by disabled persons from different parts of the country?
In what ways could knowledge about disability issues
shed light on our understanding of American culture
in general?

(1987, 39)

Hirsch's perspicacity faltered when she predicted that cultural disability studies were likely to find their strongest initial support in anthropology and sociology. She did not comprehend the apparent possessiveness of the practitioners of these academic disciplines for the concept of culture.

But Hirsch fared better as a fortune-teller than the author of one of the best studies of disability policy:

Nor do the handicapped give birth to future generations
of handicapped or promote a handicapped culture. The
lack of this common culture isolated the handicapped from
each other, and the isolation was exacerbated by the fact
that the handicapped differed greatly among themselves.

(Edward D. Berkowitz, 1987, 193-94)

Like many other writers and researcher of disability issues, Berkowitz apparently misjudged his subjects because of their traditional lack of voice. Paul Longmore, now a Professor of History at San Francisco State University, speaks sometimes as the keeper of those unheralded expressions of ancestors past .

A 1988 article described him as "an unofficial curator of the cultural history of disability, with an emphasis on the ways disability is used, or misused, in theater, films, and television." ("Puzzles," 1988, 19)

Longmore represents a generation of disabled people who identify with the movements and coming-of-age of the 1960s. A veteran of an earlier time is disabled sociologist Irving Kenneth Zola, whose first comments about a disability culture are 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)

The city of Berkeley, California has become prominent in the evolution of disability culture just as it was for the development of the independent living movement. Indeed part of the reason is that many people who arrived in Berkeley for its reputation as a "mecca" of independent living have stayed on and become part of the first generation of creators of a vibrant disability culture. One of those practitioners is Pamela Walker, who was quoted in a 1989 article, in a period of apparent despair: "We're emerging as a cultural group, but we haven't gotten acceptance by the mainstream as a cultural group yet. We barely accept ourselves." (Younkin, 1989, 33)

Novelist Jean Stewart has captured the essence of becoming a member of the disability community better than anyone else. Her satirizations of rehabilitation, the medical profession, and caretakers ring true to the collective memory. So too does her description of the pattern, and advice, of avoidance: "Whatever you do when you leave here, don't join any *handicapped groups*. As long as you don't see yourself as handicapped, you won't *be* handicapped. (1989, 250)

Anne Finger created a poster of disabled women because they were hidden from history. ["Disabled Women"] She has also written some of the best books about disability, including Past Due, an account of her difficult pregnancy and subsequent birth to a disabled child. "My friend Vicky says, 'We need to build a disabled culture because

we've been so trained to hate ourselves that we hate each other.'" (1990, 172)

A colleague and a friend to all of us in the Disability Rights Movement and the study of its development died suddenly in late 1993. Kirk MacGugan held a doctorate in education and was working on one in history. She worked at San Francisco State University and her energy and enthusiasm were contagious. Her personal loss is matched by the misfortune of forfeiting her dissertation objective of writing a history of the recent Disability Rights Movement.

In a 1991 paper designed to present her case for writing about the history of disability, she observed that: "The most interesting recent work-in-progress by persons with disabilities is about whether or not the Disability Rights Movement has given rise to a disability culture." ("An Interpretive History..." 20)

I had the pleasure of being both a friend and colleague with Kirk. We were mutually supportive and I knew I had an ardent backer of my own goals relating to disability culture. Although it may seem unusual to offer a personal quote, it is only proper to acknowledge my own leanings and perhaps my role as a player in this discussion:

With the discovery of the disability movement's history, heroes, humor, music, stereotypes and language, the past twenty years have seen a renaissance for disabled people. These shared experiences comprise elements of a culture. People with disabilities are beginning to recognize that we have a culture--one that we can be proud of. (in Leon, 1992, 7)

The World Institute on Disability, where the preceding paragraph first surfaced in a funding proposal, serves as a bastion of pioneering ideas about disability. But my entry into the fray of disability culture only reinforces the much more significant role played by Carol Gill, who once again, turns up with a succinct statement of the import of culture. "Gradually, people with disabilities are finding their history and cultural legacy. They are seeking support and validation in the community--the family--of other disabled

people..." (1992, 13)

Two years after quoting her friend, Vicky, Anne Finger clearly advocates the need for disability culture as an aspect of our liberation: Many disability-rights activists now see that while we need changes in laws and policies, the formation of a culture is a key part of winning our freedom. (1992, 10)

Disability policy consultant June Kailes is in the trenches of disability rights as a sought-after trainer. She is also a writer about the disability experience and a promoter of the concept of culture in an almost matter-of-fact manner: "Disability culture is the commonality of the experience of living with a disability..." (1992, 5)

One of the early manifestations of disability culture was the San Francisco Bay Area's Wry Crips, disabled women's reader's theater. Many area artists were a part of that group before moving on to other activities. This has enabled the group to continually bring in new participants. A high school student who joined the group in the early 1990s and wrote an award-winning classroom essay which eloquently describes the view of the younger generation: "The minority cultural group to which I belong--that of disability culture--is not commonly thought of as a specific culture....it certainly feels like a culture to us." (Sascha Bittner, 1993, 22)

Anthony Tusler holds a place in many different categories of disability rights activities. Involved in the arts, the self-determination movement, and most passionately, drug and alcohol abuse, he has written that: "The final definition is cultural....It is a definition based on experience rather than law. It is a flexible definition dependent on experience and perspective." (1993, 5)

Performance artist Cheryl Marie Wade has offered some of the most expressive representations of disability culture and its meaning. In a short, but feisty definition, she declares: "So what's this disability culture stuff all about? It's simple, it's just 'This is disability. From the inside out.'" (1993, 27)

Journalist Joseph Shapiro has written the most popular chronicle about disability in recent memory. 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.

(1993, 11)

Katherine Seelman became director of the National Institute on Disability Rehabilitation and Research (NIDRR) in 1993. She may be the first person with a disability to have held the position. She is a governmental proponent of the idea of disability culture.

These efforts have also been inspired by an active and vibrant community which sponsors and supports cultural expression such as the National Theater of the Deaf or wheelchair dancing. Increasingly, disability is recognized as a distinct cultural phenomenon which has become a subject of inquiry, ie disability studies.

(1993, 13)

Six years after his tentative assessment that a culture might evolve from disability activism, Irving Kenneth Zola discusses a 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)

Also presenting the existence of disability culture as an uncontested fact of life is a frequent Rag letter-writer:

I'm also not that happy with disabled people who are satisfied living entirely as part of a 'disability culture.'...I don't have to join a 'disability culture.' *I am* that culture. My plays, my poems, my books, my short stories, my newsletter, my on-line Internet Mobility list are all naturally about disability. That is my world. That is my culture. We don't join or reject a culture. It oozes from us. We create it, we mold it, we give it birth. It's not really a matter of choice....It's our very essence.

(Robert Mauro, 1994, 37-38)

Another frequent contributor to the disability press seems concerned about the value and meaning of disability culture and its effect on today's philosophies of disability:

Just what is 'disability culture?' In today's society, many groups have become concerned--some say obsessed--with the creation and nurturing of their own distinct culture.... have set out to identify those common experiences that both set them apart from the dominant culture and define their relationships to it.

(Douglas Lathrop, 1994, 15)

Published in many of the same magazines is another contemporary author with a radically different agenda: "We don't need an occasional disabled performance artist

or a few disabled writers, actors and comics. We need disability culture." (Kathi Wolfe, 1994, 28)

Another recent journalist of the disability press believes that disability culture is here and valuable:

The articulation of a broad-based disability culture will undoubtedly help unify the disability community, as it develops a distinct language to express the experiences and world-view of people with disabilities.

(Eric Backman, 1994, 43)

The last word on the subject--to date-- belongs appropriately to Carol Gill:

I believe persons who live with disabilities come to share not only an experience of social oppression (and varying degrees of personal struggle) but also a similar worldview, values about human worth, orientation to problems, creativity, etc.

(1994, 31)

The quest for disability identity constitutes the heart and soul of the emerging disability culture. That is the subject of the next chapter.

CHAPTER FOUR:

"THE FORCE AND POWER OF IT ALL"

DISABILITY AS SOCIAL MALADY

I would slip
this glove of body off—
humped, bony, sweated, sore--
except the weary thing
shows where I live.

(James Weigel, "Testaments V," in Hooper, 20)

Wrestling with the issues of our singular and collective human experience has occupied philosophers for centuries. In a like manner, unraveling the meaning of disabling conditions has been a recurrent theme for those most affected. Dorothea Lange, a world-renowned photographer who has been described as having had mild, post-polio aftereffects, expressed her intense feeling in a little-known quote:

No one who hasn't lived the life of a semi-cripple knows how much that means. I think perhaps it was the most important thing that happened to me. [It] formed me, guided me, instructed me, helped me; and humiliated me. All those things at once. I've never gotten over it and I am aware of the force and power of it all. (in Carillo, Corbett, and Lewis, 1982, 8)

One of the most articulate recent observers of the circumstance of disability was anthropologist Robert Murphy, who became disabled from a spinal tumor. 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.

Murphy may be the most eloquent modern voice decrying victimization from his disability. But he is not unique. In a 1993 article in Ms. magazine, Ynestra King inveighed against her disabling condition, with the same lack of comprehension of the contemporary disability rights and its inherent dignity betrayed by Murphy:

being disabled is not a socially constructed condition.

It is a tragedy of nature, of a kind that will always

exist. The very condition of disability provides a vantage point of a certain lived experience in the body, a lifetime of opportunity for the observation of reaction to bodily deviance, a testing ground for reactions to persons who are readily perceived as having something wrong or being different. It is fascinating, maddening, and disorienting. It defies categories of 'sickness' and 'health,' 'broken' and 'whole.' It is in between. (72)

DISABILITY AS REFERENCE

James Baldwin's incisive depictions of civil rights and black pride predate most pertinent analyses of disability, but they still find the target's bulls-eye. He remarked that, "no one knows precisely how identities are forged, but it is safe to say that identities are not invented; an identity would seem to be arrived at by the way in which the person faces and uses his experience. (1972, 189) Baldwin also characterized the most fundamental problem with the kind of views expressed by Murphy and King: "it is terrible to watch people cling to their captivity and insist on their own destruction." (*Ibid.*, 195)

Unlike both Murphy and King, Al Mann does not have the credentials or reputation to find his way into a respected publishing house or nationally reputed magazine. Like those two though, Mann wrote that "like all persons with a disability, my condition is the single, dominant force in my life." There is a difference though when Mann makes this pronouncement because it is contained in a spirited, down-to-earth memoir/manifesto, entitled, GIMP: Gutsy Imperfect Maximizing Potential. Mann has moved beyond the limitations of his disability to recognize its positive impact on his life. (1985, 71)

Mann's little-known work fits well within positive sentiments expressed by other

contemporary authors. Anne Finger, scribe of scintillating fiction and passionate nonfiction, recalled a significant moment in her evolution as a person with a disability: The first time I ever spoke on a panel as a disabled person, I talked in part about my journey from self-hatred, from rejecting others who were disabled to finding community. (1990, 180-81)

A second, animated voice of today, performance artist and poet, Cheryl Marie Wade, remembered that learning about the independent living movement altered her reality about disability: "With 'independent living' came a new image of disability to use as a reference: the image of an independent, dynamic human with possibilities." (1985, 59)

Like "black is beautiful" or "disability cool," pride in one's disability identity followed a kindling of the positive spirit of disability. Columnist Dianne Piastro described this feeling:

Disability pride may seem like a euphemism, but it reflects the feelings of many people today who want society to confront its fear of individual differences. Their goal is for disability to be seen as an integral and valid part of an individual's identity rather than as something to apologize about. Disability pride disavows being ignored, or branded as objectionable while it proclaims that being different is OK. ("Which famous")

ACCEPTANCE AND DENIAL

One writer about disability has noted that people with disabilities "generally share only the experience of living in a society devoted to the body beautiful." (in Cherry, ed., 1991, 3) Another essayist proclaimed that "being happy with my disability became my

declaration of total rebellion against what society expected and what my family had prepared me for." (Panzarino, 1994, 161)

Disability activist Barbara Faye Waxman, who seems to thrive in writing about controversial issues has tackled both disability sexuality and hate crimes against disabled people. In one of the latter pieces she wrote that, "successful and assured disabled people violate their 'stigma role requirements of suffering and acknowledged inadequacy'--in other words, they refuse to 'stay in their place,'--and nondisabled people feel their own status threatened." (1992, 7)

Reactions of nondisabled people to those of us with disabilities who are secure in our identities contains aspects of role reversal. Old stereotypes are turned topsy-turvy, but new modes of interaction have yet to be comfortably developed.

The words of William Stothers, editor of Mainstream: Magazine of the Able-Disabled, will be used both to address the personal frustration of this development and to provide a segueway to a lengthier examination of the subject of pride:

Whenever someone tells me they don't think of me as being disabled, I want to scream at them....a friend says that such people mean only that they don't think of me in the way that they think about 'disabled people.' Thus they can accept me on equal terms and still hold fast to stereotypical views of people with disabilities that I find repugnant....Disability is a large part of my life, it shapes who I am. To separate me from it, to deny my disability, is to deny me. (1994, 46)

DISABILITY PRIDE

Harlan Hahn is a political scientist with a disability who has said that disability is a

positive condition because it is epistemologically advantageous. In simpler terms, people with disabilities have a unique worldview expressly because of their disabilities. (personal communication, June 22, 1994)

Bill Bolt, who changed his surname by-line from the original Bolte to reflect his hard-hitting journalistic style, proclaimed that:

There is an as yet unmined strain of golden talent among the severely physically disabled. There is even what I call a disabilities point of view that could be so valuable to our society and economy in its search for innovation. That disabilities p.o.v. comes from our experience in being left out of so many of the institutions in our society--...This goldmine of thought and attitude has been shut out or actively put down. (1994, 17)

Hahn and Bolt communicate pride in their personal disability experiences and in being an individual with a disability. Irv Zola wrote similarly that, "To be prideful means at very least that disability is something to be owned, spoken of, and claimed by oneself for oneself." (1988, 12)

All of these passions fit into the easygoing, but extremely serious philosophical discourses of Berkeley playwright Neil Marcus, who set forth, in his own inimitable style, a disability viewpoint:

if there were a country called disabled, i would be from there.
id have disabled culture, eat disabled food, make disabled love
and id share my country with all other great countries....i did
become a citizen of disabled country since age eight. (1991, 2)

Digesting the concept of possessing disability pride has been grappled with since

about the same time that the notion of a disability culture appeared. Ed Hooper, who struggled with these issues in several Disability Rag articles, concluded that:

Something we've come to call disability pride is important.
Very important. It's helped us see ourselves in a light we
created, rather than the jaded lightshow put on by society's
special-effects department." (1989, 19-20)

Neil Marcus recorded his thoughts about one of our society's most frequent inquiries with a show of disability pride (and an inkling of poor spelling--or typesetting):

Well, what is it that you do? (is a common question).
Let's say that I am a master at what i do. Let's say
i am an expert in this feild [sic]. Its [sic] an unknown
feild [sic]. I don't know anyone else who is doing it.
What do i know? Its [sic] hard to say, but im working
on it. There's no name for it. You can't study it in
school. It comes from my life. (1986, [19])

The mysteries of a life spent investigating disability clearly delineated in the preceding quote reflect the concerns expressed by poet/activist Laura Hershey, in a 1991 article, when she tried to come to terms with pride's place and elusiveness in the Disability Rights Movement. She began by stating that without pride our movement can never develop. But even finding it is no guarantee that it will endure:

The thing about pride is that you can work like
crazy to find it, but when you finally do, that doesn't
mean you have it forever....More and more I have
realized how familiar it is within the disability
community, that feeling of no pride....How many

of us truly live in that place, where everyone has a right to live: a place of power, effectiveness, validation, connection, beauty--in other words, in pride? (5)

CELEBRATION

Diana Viets might have been a classic example of Hershey's description of the struggle between pride and oppression. At a 1989 meeting in Boston, Viets suggested an event to celebrate disability which culminated a year later in that city's first Disability Pride Day. (A. Hasbrouck, personal communication, 1992) Yet Viets herself succumbed to some unknown depression and took her own life in early 1994. (K. Kleinmann, personal communication, 1994) Her legacy lives on, however, in the continuation of this celebration.

In a press release describing the second annual Disability Pride Day in 1991, event organizers elucidated:

Disability Pride Day is patterned after Lesbian/Gay Pride and Black Power movements, which strive to bring a positive self-image to their constituents. 'People with disabilities have been trapped between two false images of themselves,' said Amy Hasbrouck, Director of Education and Advocacy at the Boston Center for Independent Living, one of the event organizers. 'On the one hand we are seen as burdens to ourselves, our families and our society. Or we're evil. All the 'best' villains have a scar or a limp or some visible disability. On the other hand, people with disabilities are often put on pedestals just for living

our lives. Hundreds of movies have been made about 'plucky cripples who overcome their handicaps.' But that's as unreal as the evil, scarred villain. Both images erect barriers between us and the nondisabled population, which deprive us of our rights to equal access and participation in society.

A platform statement issued at the event read as a manifesto for disability rights: It follows in its entirety:

- Disability is a natural part of the human experience.
- We take pride in ourselves as people with disabilities.
- All people, regardless of limitation, are entitled to the maximum quality of life. This includes access to food, shelter, clothing, education, employment, health care, transportation, communication, help with activities of daily living, recreation, companionship, and spiritual and personal development.
- Every human being, regardless of limitation, has the right to self-determination.
- Each person has a right to maintain and express his/her dignity.
- We have a right to maintain our culture, without forced assimilation to the dominant culture.
- It is primarily the physical and attitudinal barriers in this society--not our disabilities--which limit us. As we work to eliminate these barriers, so must the non-disabled society, here and around the world.

- We recognize and embrace the diversity among all people, including people with disabilities.
- People with disabilities must be free from physical, sexual and/or emotional abuse and violence, and fear or threat of same. We must empower ourselves to resist physical and emotional attack.
- People with disabilities must be given information about, and the opportunity to express, our sexuality. We must be granted full reproductive rights and free choice in matters of family planning information and techniques--contraception, abortion, and sterilization--and be free from coercion or force in these matters.
- People with disabilities have a right and duty to participate in the political process. This includes access to information, government activities and meetings, and polling places.

"I SURVIVED"

Disability Pride Day encompasses both the political and the personal in its celebration. Activist Jean Stewart's 1989 novel, The Body's Memory, perhaps an intentional slam at anthropologist Murphy, described a protagonist's experiences with cancer and its disabling consequences. Unlike Murphy, Stewart's hero, Kate, moves beyond her initial despair to a point of celebration. Kate's triumph is described in a party scene:

another dancer has just been added to the group,
an equal and respected participant: the chair....
And now the chair changes occupants with

dervishlike intensity, each rider lifted out by
the next rider, the lifting itself becoming part of the
dance....into the enchanted chair....Kate dances. (217)

Ed Hooper's article, "The Cure," is an impassioned appraisal of whether he would take a cure for his disability if offered. He decides that no he would not: "I roll away knowing that I don't need to be cured. I survived. And I'm proud of who I've become." (1989, 21)

Hooper's personal jubilation about his coming to terms with his disability is transformed in the work of Carol Gill into a movement triumph:

A disability culture movement can foster disability pride. It promotes pride in us; it allows us to project a positive image to the public. We renew each other and our strength through shared experiences and rituals. If we express our culture in some unified way, we're signalling; we're communicating what our values, goals, and identity are. Through our culture we can recruit people. When we present a strong image, it motivates people to want to belong. They want to be part of something that powerful. (in Johnson, 1987, 4)

We can wait no longer. It is time to explore some specifics of our current-day disability culture.

SECTION THREE:

A PLACE TO BELONG AND FIND WHO I AM"

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.

(Cheryl Marie Wade, 1993, 25)

CHAPTER FIVE:

"THE FINAL DEFINITION IS CULTURAL...."

TELLING STORIES

Even though people with disabilities have long been writing about their lives, to a marked degree certain aspects of their lives have been inaccessible even to themselves.

(Irving Kenneth Zola, 1988, 7)

The history of people with disabilities is a long tale with many missing pages. The first section of this work is an attempt to fill some of the gaps in the story. The second section of this study is an endeavor to look at one of the stories of people with disabilities in the context of contemporary times. There are many divisions about how to tell this story and what parts of it are of greatest import, which leads to the debate over disability culture.

Is disability culture a significant aspect of the story of disabled people as it is played out today? Is it any part of the story? And what role do the stories themselves perform?

Betty Friedan is well known from her cutting-edge theories of feminism, which have been a critical ingredient in the way the women's movement has developed. She wrote that: "It seems to me that you can trust feminists--or any other 'ists' for that matter--only when they speak from personal truth in all its complexity. Such truth is never black and white...." (1981, 33-34)

The seemingly microscopic concerns of our own everyday lives contain within them the seeds of universal truths. Journalist Victoria Medgyesi wrote in 1992 that there were four waves of activity affecting people with disabilities. The first wave was that of professionals speaking for disabled people. This was followed by parents who spoke for us. The third wave was people with disabilities speaking for ourselves. The fourth wave, the one in which we currently find ourselves, is people with disabilities knowing that we must take our stories to the whole world if we are going to fight

discrimination. (3)

The purpose of this chapter is to tell several personal stories through the lives of people who have had some kind of impact on the developing culture of disability. Each story is unique, yet certain details will sound similar because each has experienced a pattern of oppression and liberation in their lives. For some the concept of disability culture has been an important one; for others it has been less meaningful. For some they have been a part of the creation and promotion of the culture; for other there is some concern as to whether one exists. All of the stories were told during personal interviews.

As you read about these seven individuals you will note not only the similarities and differences in their remarks, but in the interplay of their lives. They all know, or know of, each other, and have had an influence on one another. There will also be names that recur from these interviews that have been mentioned previously. Part of the function of the emerging culture is to create a path for people with disabilities with similar interests to find one another. Some of the successes of this objective are apparent from the interviews.

Each of these individuals lives in, and the interviews occurred, in the San Francisco Bay area. This is because this is one of the most active regions in the arena of disability culture and because that is where I lived and worked while these interviews were being arranged. There are many other people throughout the country who could have been, and should be, interviewed.

Finally, I have tried to write about the interviews from the point-of-view of each individual discussed. Although little of the narrative is marked with quotations, the ideas and comments are those of the interviewees.

STORM READING

I do not remember hearing about Neil Marcus until shortly after I moved to

Berkeley. A colleague gave me a ticket to see a play called "Storm Reading." It was a thoroughly enjoyable experience.

"Storm Reading" is a one-person play which requires three performers. A largely autobiographical work, Neil plays himself, with both a voice and a speech interpreter. I noticed that there were a number of both disabled and nondisabled people at the fairly small and intimate Berkeley theater. After the play concluded, the cast members and director responded to questions from the audience. There were lots of typical questions about what life is like living with a disability. There were also queries about performing with a disability and its ease and difficulties.

Neil's responses to all of these inquiries, even after working very hard for a couple of hours, were filled with humor. Indeed that quality of quirkiness and irony seemed to be what attracted everybody in the audience to Neil's style and created a zone of comfort for most of the audience.

Some months later I waited in line to see a concert. Sitting in back of me I thought I recognized Neil. I introduced myself. He was very gracious. When I asked him if he was stopped like this in public he indicated that it was a frequent occurrence and one that he liked. We discussed some of our mutual interests. A couple of months later we ran into one another at the Oakland meeting of the Society for Disability Studies and spent some time getting better acquainted. We decided to get together soon. After that we met periodically to discuss the course of our lives, our mutual interest in the culture of disability, and the state of the world in general.

When funds became available to do this study, Neil was one of the first people I called to interview. He eagerly consented.

Neil's disability is dystonia, which he acquired for no apparent reason as a child. It affects his movement and his speech. In outward appearances his movements and speech patterns are sometimes similar to someone who has cerebral palsy. Upon closer inspection, his spasticity seems more susceptible to control and his speech improves with his hand held on his throat and during less stressful times of day.

On the streets, Neil uses a motorized wheelchair which includes a milk crate on the back, which he uses to hold his acquisitions and to distribute his wares. The milk

crate itself makes it into "Storm Reading," as do many other accoutrements of his daily life.

Neil's apartment might be considered part of the culture. Living in an area of Berkeley that is near both the Center for Independent Living and the University, Neil's building is one of those for senior citizens and people with disabilities. Papers and posters are strewn all over the place, with return address labels cut out from envelopes and taped to a file cabinet serving as an address book. Posters from "Storm Reading" and other works are tacked to the walls.

When I asked Neil to talk about disability culture, he responded, "I live it everyday." He indicated that from psychology he learned the importance of telling your own story.

Originally from Ojai, California, Neil spent some time at a college in Vallejo, north of Oakland, as both a student and counselor, before moving to Berkeley in 1979. Once in Berkeley, he got on Social Security so that he would be sure to acquire health insurance through Medicare.

Neil used his active imagination and skills of observation to record daily life as he perceived it. He says he began a diary when he was twenty because he needed a way to record the world in the unique way that he saw it. The diary has continued through the years and is now more than twenty years old.

A little over ten years ago, Neil began to excerpt diary segments and use them to create a newsletter he calls "Special Effects." He chose the title from the movie term for things that are innovative, which is how he perceived his newsletter. He prints up a number of newsletters and hands them out to people he meets on the street or sends them to targeted audiences. The Disability Rag began receiving his newsletter sometime around 1982 or 1983 and wrote a story about Neil under the title of "Disability Cool," in 1985. (27)

Neil's credo might be taken from a statement quoted in that article:

I realized that for the past ten years i have had great
visions for "my people" (I do have a people). And that

i have been working to get OUR spirits free. I've been interested in symbols....[disability art is] art that when I look at it reminds me of my culture--the culture that i come from, the disabled, physically different...one. (Ibid.)

His diary also served as the basis for "Storm Reading." Neil cut out the logo of Access Theatre, a southern California group which stressed theater activities for people with disabilities, put it in his newsletter and sent it to them. Access Theatre then contacted him and they have been working together ever since. "Storm Reading" is directed and produced by Access Theatre and has won numerous awards and continues to tour both nationally and internationally.

The major theme of Neil's work is that disability itself is an art. (Princess & Dragon) He is extremely conscious of the quantity of humor he puts into his performances because he wants to communicate with the audience, to open their hearts and feed them with the idea of how rich life is for everyone. Neil has also developed a non-threatening approach to his art and style. Part of the reason for this is that he perceives his speech problem as unique among performers and enough of a hurdle for an audience to break through.

Midway through our interview the phone rang. Neil's agent was very excited. He had gotten a request to bring Neil to Tennessee to play a character in the television pilot of "Christy." The phone call itself added an exciting flavor to the interview. While we talked about disability culture, we also seemed to be witnesses to it. Although Neil's character did not make it through the final editing, the opportunity is a reflection of his determination to crack the hurdle of disabled people playing themselves in mainstream media productions.

Neil's approach to his life and art is that he would rather be a hero than a victim. He considers his contributions as innovative, as part of a first generation of practitioners of disability culture. Neil perceives himself like the wind, a poetic metaphor that is full of the human heart and human soul.

Mythology of Disability

m/d 101

Styles Hall

7:30-10 weekend evenings beginning new years

TOPICS: current mythology. ancient mythology. cultural mythology.
markets. life stories. life histories. YOU. Interview your classmates.
create own reading lists and literature. set standards. go public.
bring soul.

EVERY BODY WELCOME.

Professor: Neil Marcus ("Mythology," 1993, 3)

QUADZILLA

Ann Cupolo is a forty-two year old woman who was born with diastrophic dwarfism. She is not only short, but her physical proportions are different and she has scoliosis. She is also a bundle of energy, fun-loving, and the kind of person everyone wants for a friend, someone who is always around in times of need.

I first met Ann when I attended a planning meeting for the "Independent Living: Preparing for the Twenty-first Century Conference." At that time she was the Services Coordinator for the Center for Independent Living. I knew right away that she was someone with whom I wanted to become better acquainted.

I did get to know Ann better over the next couple of months. Then when I began to date the person who would become my wife I found out that she and Ann were the best of friends. As I learned more about Ann I realized that she was someone who both exemplified and symbolized the entire concept of disability culture. When I asked Ann if

I could interview her she was agreeable, but couldn't imagine why I would choose her as an interview subject. I hope that will become apparent.

Ann is from Queens, New York. As a child, she attended special education classes. When she reminisced about her early years, camp seemed as important as school. As a young girl, she went to Camp Carolla. The camp, as well as other activities, were run by a Jewish women's philanthropic organization, the Carollean club.

Camp seems to have played a more important role in the lives of young disabled people in New York than in many other places. Judy Heumann, who grew up in Brooklyn about the same time as Ann, recalled that:

I went to camps from age 9 to age 18, and these were the only times I was integrated with disabled people. We lived together for weeks; we bonded; we were comfortable together. I feel this was the only time in my life when I was really involved in cross disability and with people of different races. The system had always separated disabled people by labels. We learned to fear our own because of this separation. Coming together at an early age allowed me to see what we had in common. (1993, 234-35)

Judy's memories of camp are mostly happy ones. Ann's remembrances are somewhat more mixed. She relates that at Camp Carolla girls could attend until they were sixteen, but boys could only go until they were thirteen. She believes the camp managers thought that disabled people were oversexed and didn't want to encourage any unruly behavior.

At seventeen, Ann matriculated to Camp Jenet. She remembers it as a place where freedom and acknowledgement of sexuality could be expressed. This was a new and exhilarating experience and an appropriate transition to college years.

Like Connie Panzarino, Ann enrolled at Hofstra on Long Island. She described her dorm living conditions as semi-accessible. But little more was expected. Ann did

not have ambitious career goals either. As a music-lover, she decided to make that her major, with the intention of becoming a piano teacher in the home upon graduation.

Although Ann did not have a lot of militancy in her background, this was the late 1960s and early 1970s. Protest was in the air. She remembers distributing petitions on behalf of Judy Heumann when Judy was denied a teaching position. Ann also remembers participating in blocking the streets in downtown New York with hundreds of other people advocating signage of the Rehabilitation Act of 1973.

Perhaps more important to Ann than the camp run by the Carollean group was a club they sponsored that opened on Saturdays in Manhattan. The club, open to people of all ages, had activities like drama, music classes, and arts and crafts. There Ann met many people who would play an essential role in her life in a few years.

Immediately following college, Ann married a young man she knew from camp and high school. They lived across the street from her mother and Ann worked at a utility company while her husband tried to sell life insurance.

In the mid-1970's Ann's marriage disintegrated and she looked for a new course in her life. She was terrified that if she did not leave New York she would wind up living with, and being too dependent upon, her parents. Several of her friends from New York, including Neil Jacobson, whom Ann had met at the Carollean Club, had emigrated to Berkeley, which was becoming known as a haven for disabled people. She remained in contact with them and they encouraged her to join them in the heady California atmosphere.

Ann arrived in Berkeley in the fall of 1975. She quickly obtained state and federal services so that she could remain in the area, then she hunted for a job. She found one as a notetaker for someone with quadriplegia who attended the Disabled Computer Training Program, which Neil Jacobson had played an integral part in developing.

Late in October of that same year, Ann attended a Halloween party at the Center for Independent Living (CIL). For the first time in her life, she saw people with disabilities calling attention to their bodies and she liked that. It began to change the way she perceived her own body and her disability and her life. She began working as

a volunteer intern at CIL in 1976 while completing a Master's Degree in Health Services Administration from Antioch West College.

After graduation, Ann left CIL to work at DREDF (Disability Rights Education and Defense Fund--which had started as a legal arm of CIL and branched out separately). There she became involved in a women's role model project.

Corbett O'Toole (then Katherine Corbett) convinced DREDF to develop a book that would be used as a support tool for young disabled women. At the time no work of, by, and for disabled women existed.

DREDF hired a diversified staff of women to research and write the book. No More Stares, whose title was a play on words that confronted both environmental and attitudinal accessibility, was unique in the early 1980s. It contained lots of pictures of disabled women going about their everyday business. It also followed the fictional story of a young woman named Anna, interspersed with true accounts of women with disabilities.

Publication of the book was followed by three No More Stares conferences. They were held in Berkeley, Idaho, and Minnesota and had great influence on many of the young women who attended. We will catch up with one of them soon.

In the meantime, Ann's perception of her own role in life was changing dramatically into a growing militancy. In the late 1970s, she attended a local club with a group of friends. She was ejected and told that her wheelchair was a hazard. In her early life, she may have quietly acquiesced to this turn of events. But her newfound advocacy from her work at CIL and DREDF and her own growing self-esteem would not permit her to ignore this affront. She sued the establishment, who then settled with her out-of-court. That effort began a history of civil rights litigation which continues through today.

Finding a significantly disabled person who cannot recount horror stories from airplane trips at the drop of a hat would be an exceedingly difficult task. The final straw for Ann occurred when American Airlines informed her that she could not fly alone. Ann realized her civil rights were being violated and requested DREDF take her case to sue the airline. They did and again an out-of-court settlement was reached. She has

recently joined a class action suit against United Artists Theaters for discriminating against disabled people in its segregated placement of wheelchair seating. That case is still pending.

Ann is unable to sit still. The litany of activities just described barely touches the surface of her pursuits. While working at DREDF, Ann first became involved with Little People of America (LPA). The annual conventions, which she attends each year, are mostly social, with dancing and music every night; some topical workshops, and some sightseeing. Ann first met another dwarf who's diastrophic at LPA. She also describes the convention as a great opportunity for parents to see what possibilities are available to their children. Most telling is her depiction of the annual convention as a fix of being with her peers.

Ann has served on the Board of Directors of the Bay Outreach Recreation Program (BORP) for a number of years. The small, not-for profit, organization, which promotes sports and recreation for people with disabilities, began in the 1970s. It sponsors a number of activities for kids and adults, including whitewater rafting, camping, trips to sports activities, swimming classes, and other activities.

A few years ago, someone at BORP heard about quad rugby. They researched it and decided to start a team.

Although it is not as well known as wheelchair basketball, it is played throughout the country by people with more significant disabilities. Ann has been a member of Quadzilla, the rugby team for many years. The players, both men and women, have many different kinds and levels of disabilities. The team is very competitive, usually playing in the tournament for the national championship and winning it one year.

Quadzilla is sponsored by St. Mary's Rehabilitation Center in San Francisco, another of Ann's previous places of employment. She worked there during the time we conducted the interview. Ann compares her experiences at St. Mary's and at CIL in a way that seems an apt metaphor for the tension that exists between different camps of the disability culture issue. St. Mary's is a place where people who are newly injured are sent. She says that those who go to St. Mary's are in agony about being disabled, which is appropriate when first disabled. But CIL encourages pride in the commonality

of disability. Pride in both being okay with who you are and recognition of pride in group identity.

THE GODFATHER

Trying to establish any kind of context for disability rights issues without including Ed Roberts would be like trying to analyze civil rights without discussing Martin Luther King, Jr. I remember hearing about Ed almost as soon as I became involved with independent living. Ed combines his pioneering advocacy with thoughtfulness and a penchant for attracting attention.

I also remember the first time I saw him in action. It was at the first national conference I attended, "Beyond Survival," in Denver in 1983. The theme of the conference was that many of us with disabilities had made it past the life-threatening stages of our injuries and illnesses and past the rudimentary levels of whatever form of rehabilitation we had either been coerced into or voluntarily undertaken. Now it was time to look beyond our injuries and our immediate survival to living a life in whatever manner we desired, filled with the same kinds of quality available to everyone else.

I met many colleagues during that time who have remained a part of the independent living movement. Linda Tonsing Gonzales, from Santa Fe, described "Beyond Survival" as the Woodstock of the disability movement. An appropriate analogy. For many of us it was the first time we were ever around hundreds of other people with significant disabilities of all kinds. Ed remembered the event as one of many wheelchairs.

I recall Ed delivering a rousing speech. But mostly I remember that he did it while using a respirator to aid his breathing. That too was a new experience for me. I had never seen anyone using any kind of breathing apparatus until I attended that conference.

That's the kind of impact Ed has on people. While in California I co-taught a

class at San Francisco State University. Ed came in once a semester as a guest speaker. If any students missed class they could catch it later on videotape. One student did just that after Ed's presentation. She said she laughed, she cried, and then she stood up and applauded. That's the nature of effect Ed has on people.

Ed has been called both the father and the grandfather of independent living and these days he likes to call himself the godfather. The broad details of his life have been documented in numerous places besides the early section of this work. (Levy, 1988; Shapiro, 1993;) We will not rehash them here.

One of his accomplishments that is sometimes overlooked is his degrees in political science. In fact, he is an ABD--one of those students who completed all the work toward a doctorate with the exception of a dissertation.

When he left Berkeley after studying political science and helping to set up the Physically Disabled Services Program and the Center for Independent Living he taught school in the barrios of Los Angeles. The discussion that I had with him emanated from those experiences as much as his more well-known exploits.

I interviewed Ed in his Berkeley home. For the first time I saw him laying in his iron lung. A phone was nearby and constantly ringing, and people were in and out of the house at his direction. Although I had just spent close to three years working at the World Institute on Disability (WID) I did not know what to expect when we started to discuss disability culture.

Ed ruminated for a while about the concept of disability culture. He began by saying that when he first heard of the idea of disability culture he had not thought about it in a broad context. But the more he thought about it, the more sense it seemed to make. He reminisced for a moment about his days at Cowell, the on-campus hospital where he lived when he first attended Berkeley. The development of a group calling themselves the Rolling Quads and the idea of peer support was the key concept in those early movement days. Ed speculated that peer support is such a powerful component of our lives that it must have some cultural context.

As Ed played with the idea of disability culture it was easier for him initially to pick up on some of its negative aspects, particularly the continuous and belittling

stereotyping resulting from centuries of attitudinal devaluations. Reinforcing a theme discussed in the first chapter, Ed described how people with disabilities become almost instantaneously stereotyped as patients and therefore labeled weak. There's a constant struggle not to lose one's complete identity when typecast as a person with a disability because we've been led to acknowledge its devastation without any kind of preparation or recognition for the strength we encompass. Most of us readily follow the image we've been led to believe is the true one—of a helpless cripple.

Part of our role, as movement advocates, is to change the negative image to a positive one. Independent living shines on more positive images. It tries to change the cultural context from a negative to a positive one. No matter what happens, no matter the disability, the issues and struggles are similar ones.

People with disabilities are perceived with little or no power. Ed warmed to one of his favorite subjects.

Power is out there to be taken. He often relates how as a teenager returning to the world after his bout with polio he saw lots of people staring at him. He decided then and there that if he was going to be that noticeable he would be a star. And he has been. But Ed has also used his own personal and professional power to try and show others the power that is there for the taking. He also understands and discusses that sharing power is a way of gaining power.

During the interview Ed explored how anger is an essential part of our culture and our power. Yet the concept of anger itself is terribly misunderstood in our society. People who are angry frequently use that feeling as fuel for taking power. But the oppression of disabled people is so pervasive that no matter how personally powerful one becomes the anger doesn't seem to dissipate. The process of anger that everyone with a disability undergoes toward a positive identity is a part of our culture.

Disabled advocates, Ed believes, fit within a liberation mentality. In that context, we are redefining culture, both the prevailing attitudes of our own culture and the larger culture.

It makes sense to discuss disability in terms of culture. It's perhaps hard for people to see because they see the disability, not the person.

Part of disability culture is to feel, to challenge yourself, and others to create new roles for disabled people. This process of changing is about as rewarding as life gets. Having a cause is a reason to exist. It's important to have dreams and shared visions.

"I DON'T KNOW IF I CAN ENDURE IT"

I still recall the exhilaration I felt when I read about Paul Longmore. It was the first time I heard about another historian with a disability who analyzed data from a disability rights perspective. I immediately wrote to ask him about his work. He sent a fairly large packet of material and I responded in kind. Then we lost touch.

In 1988 I read about him again. Royalties from his book, The Invention of George Washington, threatened his eligibility for Social Security, health insurance, and Personal Assistance Services. The cost of these items was well over \$30,000 per year, yet any income that Longmore made would render him ineligible for these benefits. Book royalties would not be plentiful enough to make him a wealthy man, but they would be enough to push him further into poverty. (Shapiro, 1993, 28)

As the story goes, Paul conferred with Doug Martin, who has long been known in the disability rights community as the expert on disability and Social Security. They decided to publicize the problem with a media event--a book burning. Press were alerted in Los Angeles and the national news wires picked up the tale of the author who was forced to set fire to his own work because of the inherent unfairness of the laws.

Media attention from the event helped change some of these unjust and archaic regulations.

In reading about the conflagration I learned that Paul had moved from Southern California to teach at Stanford University in the San Francisco Bay Area. I hoped that when I moved to California to work at WID that we would have an opportunity to connect.

We soon did. Two historians with disabilities who share an interest in both

academic scholarship and disability rights is not a unique occurrence, but it is a rare one. We reinforced each other's interests and explorations. I looked forward to my interview with Paul and anticipated a thoughtful examination of the issues. I was not disappointed.

As befits two people focused on the past we began with his childhood years.

Paul became ill with polio about forty years ago when he was seven. He attended a special education class in the fourth grade and the first half of the fifth grade, then he missed a year of school while undergoing a spinal fusion.

Some distress was evident still in his recollection of special education as inferior schooling from second rate teachers. The kids were no better with constant taunting. Even the cafeteria was segregated. They ate at a special table.

Paul's sixth grade teacher, Miss Gustafson, was one of his early mentors. Toward the end of that school year, Paul remembers Miss Gustafson using her influence to get him admitted into a mainstreamed seventh grade class at the junior high school.

Before Paul matriculated from sixth grade, Miss Gustafson took him aside and explained that he was a pioneer. He must succeed, or else others like him would not have the same chance.

Paul remembers clearly understanding this role, but not feeling terribly burdened by it. In a way he felt it his destiny to be a pioneer.

At about the age of twelve, it dawned on the young Paul that he was being treated differently by adults than other kids his age. He got away with doing less than his peers. He resented this treatment and it made him quite angry.

Like many adolescents, he felt smarter than most of the adults surrounding him, yet he was the one who was being treated as emotionally fragile. He sensed a lack of honest feedback from everybody with whom he came into contact.

By the tenth grade, Paul perceived the falseness he detected in his environs as a form of prejudice. None of his family or friends would validate this observation when he broached them with it. No one, in fact, would confirm this sense for the next twenty to twenty-five years.

Alone and alienated by the feelings he possessed, he decided that if anyone was going to feel sorry for someone else it would not be him. Paul realized that people formed impressions within the first three to five minutes of meeting each other. As a teenager he responded to this pattern by consciously discarding his shyness and developing an aggressive style. He conducted himself in this manner until he reached his mid-thirties when he began to feel that his credentials spoke for themselves.

The passage of the middle years of his fourth decade became a time of great transition for Paul, as they are for many other people in our society. He was going through a divorce and did not feel as omniscient as he described himself during his adolescence. He also began to realize that his previous desire to be strong, powerful, distant, helpful, and capable at all times did not reflect his true personality.

The process of divorce stimulated Paul to analyze anew his lifetime of relationships. He discerned that disability issues were crucial to each association.

While these thoughts and feelings were whirling around in his consciousness, Paul also began affiliations with other disabled people. He found himself on the Board of Directors of a Polio Survivors Group and while attending a media conference for the group he met June Kailes, Barbara Faye Waxman, and Tari Susan Hartman. These contacts turned out to be a critical turning point in his life.

Paul knew he wanted professional assistance to sort through the vagaries of his life and emotions. But he was unwilling to see a counselor who did not understand disability issues. Although he had just met June, Barbara Faye, and Tari Susan, he asked if there was a local psychologist who fathomed disability issues.

They referred him to Carol Gill.

When Carol asked Paul his purpose in coming to see her he exclaimed that people discriminated against him because he had a disability. She agreed. It was the first time since his revelation of prejudice in his teens that someone had affirmed his belief. For more than twenty years he had harbored this feeling without any kind of confirmation.

But he was not ecstatic in her support, for the very next utterance from Paul to Carol was "I don't know if I can endure it." How can anyone deal with all of society

stacked against you? She responded that "you may not be able to."

Another first, another affirmation. Paul realized at that moment that emotional reactions to the waves of discrimination sweeping over him were acceptable. From that time forward he believed he could manage.

Paul's personal recognition and confirmation of the status of being disabled in this society coincided with greater involvement in the Los Angeles disability community. He began to speak publicly about disability prejudice.

Paul encountered distinct reactions to his presentations. Nondisabled people were nonplussed. A minority of disabled people expressed fear. A majority of people with disabilities came up to him after his remarks and informed Paul either that he said exactly what they were thinking or they had never thought about it in the way he expressed his perceptions, but that's the way it is.

One reason people study history is to place where they exist in the present day in the context of past events and trends. I asked him if his disability had any influence on his desire to become a historian. He said he hadn't really thought about that, but that he had been fascinated by history since he was nine.

He was most interested, then and now, in the American Revolution, where a large number of people underwent a transformation of values and identity. He thought that interest stemmed from the evangelical Christianity with which he was raised. He had never considered if his disability might play a role.

He did realize that in his study of George Washington he discerned particulars that others did not because of his own personal experience in being someone whose public personality was defined by society and by his culture and how he redefined himself and his culture and society. About the time his book on Washington appeared, Paul lectured about disability on the University of California at Berkeley campus. His copy editor, who was from Berkeley, attended the speech and commented that both the book and the speech were about the same issues. So his disability may indeed have had an impact on his study of history and certainly on his approach to it.

Paul describes himself as interested in identity, cultural values, and how people try to define or redefine themselves or their culture. When we started to explore the

idea of a disability identity, Paul flashed back to several memories of his years in high school and college in the late 1960s when he underwent other significant transformations.

He had followed and identified with the civil rights movement since he was eleven. In 1964, the year he graduated from high school, Paul heard about H. Rap Brown and Stokely Carmichael taking over a march led by James Meredith and talking militantly about Black Power. He began to integrate this idea into his disability experience.

Several years later, as a junior in college, he began to understand his identification with the civil rights movement on a more personal level and began to talk to friends and colleagues half-jokingly, half-seriously, about prejudice. He talked to people about what it meant to be disabled.

Paul's listeners tended to assume that the condition of disability was such a negative one that he would trade places with them if he could. But this was neither Paul's message nor his desire. He was acutely aware of both the positive and negative baggage of everyone he knew and he had yet to meet someone with whom he would willingly exchange places. He also realized that both the positive and negative aspects of his own life and disability experience were inseparable. He was not as interested in jettisoning the bigotry he felt all around him as in awakening other people to its existence.

The following year he saw an article by Leonard Kriegel entitled "Uncle Tom and Tiny Tim." It was the first commentary Paul encountered which addressed disability as a social bias. The next year he read Erving Goffman's Stigma, which extensively discussed people with disabilities. While we talked Paul put his readings and reactions to those early works together with contemporary activities and mused that disability has gone from a category to a community to a culture.

First at Stanford and now at San Francisco State University, Paul has taught a class called "Disabilities Minorities." He believes that because of the historical medicalization of people with disabilities that we have to be looked at within separate diagnostic categories. As a result of this segregation and institutionalization, it is a

historical challenge to reconstruct both the singular history of specific groups and to place them within a broader context.

As just one example of this historical patchwork, Paul cites people who are deaf, who until the preceding generation did not see themselves as a linguistic minority, but as a disability group. Today, identification as a distinct culture, fortified by a separate language, is a common claim among deaf people.

The idea of disability culture is one that Paul is not willing to proclaim as an accomplished fact. The concept rumbles around in his thinking without a clear or precise conclusion. The following paragraphs attempt to capture his somewhat stream-of-consciousness approach to the subject.

Until recently the Disability Rights Movement has labored in its first phase, the fight against discrimination. The nondisabled world has often mistaken our struggles simply to survive and go about our routine existence as bravery. What has really been courageous about being disabled during this time is enduring an oppressive society.

We are now moving into a second phase, no longer seeking acceptance and legitimization from larger society. We are, indeed, redefining both our own way of being and offering a radical critique of the majority culture, which the majority culture needs to listen to for its own sake.

All life involves an inextricable weaving of good and bad. People with disabilities constantly betray the primary myth of American culture that people can be perfect or flawless. The lesson that nondisabled people ought to learn from us is that life is not perfect. Disability experiences teaches the value of interdependence. It is a message that if paid attention to would help our culture to mature.

As a historian Paul has questions about use of the term disability culture--culture is a term with lots of definitions and is controversial. He expressed a need to read and think more about the concept. He maintains that the idea of disability culture has had self-conscious, political purposes, similar to the movements of women and gays and lesbians.

In an analysis of disability culture, he perceives a need to study more thoroughly the history of institutions because their existence has in some way affected all of the

people that were involved with them. At the very least, communities of people with disabilities in institutional settings, such as Warm Springs, were a shared community, but was it cultural? Does there need to be continuity and transference of values over time to make a culture?

Paul recognizes a stronger interest in disability culture among the group he calls the second generation of people with disabilities, those who are now in universities. Classes and departments that were once categorized as ethnic and gender studies have now been redefined as cultural issues and many groups are exploring their role within them.

Paul participated in the panel on History and Culture at the "Independent Living: Preparing for the Twenty-first Century" Conference. He discussed the League of the Physically Handicapped, a group of New Yorkers with disabilities who rebelled during the 1930s against New Deal policies that prohibited disabled people from working.

League protests took the form of picketing and sit-ins in New York and in Washington, D.C. Paul has interviewed some of the survivors and acquired some of the pictures of the protests. One sign read, "We Want Jobs, Not Tin Cups."

We were both surprised at the extent of the hunger expressed in the audience to know our history. His forty-five minute presentation was followed by a lively forty-five minute question and answer period. An evident yearning to know historical roots surfaced.

Paul now expects people to be fascinated whenever he talks about the League. He describes it as a typical American tale of people seizing control of their own destiny.

A large part of the social construction of disability is defining people as passive. The League was a politicized group of people with disabilities acting on their own behalf to challenge larger society. Their story overturns what we've been led to expect about disabled people.

The story of the League counters dominant ideology. Part of knowing you who are is knowing your history. It is easy to isolate people if they don't know their background. Looking at political activism may be a way to uncover values across time and across groups.

Although the League certainly serves as a predecessor to the kind of culture we now perceive extant among disabled people, it was an isolated bastion of activity for its time. It became lost to history for many years because its participants it did not believe that its actions were important enough to pass on to future generations. For many League members, the most significant result of the group was meeting future spouses. (Goldberger, 1991)

Paul's uncovering of the League's existence is consequential for knowing our own history. And the more we know about our past the more accurately will we be able to depict our present. With what we know we will endure.

MOVING OVER THE EDGE

My first major task after becoming Training Director for the Research and Training Center on Public Policy in Independent Living at WID was the coordination of a symposium, "Empowerment Strategies for Development of a Personal Assistance Service System." While planning for that event I received a call from Bruce Curtis, someone I had neither met nor heard about. He requested, and received, some time and space during one Symposium evening to feature some of the Bay Area's disability artists.

Presenters included Bruce himself, as part of the Earth-to-Gravity project, a contact improvisation dance group; Cheryl Marie Wade, who delivered some of her poetry; Hephaestus, a trio comprised of Dave De Weerd, Pamela Walker, and Jay Yarnell, who had named themselves after the lame Greek god known both as a blacksmith and the lucky one who married Aphrodite, and who performed a multi-media presentation of poetry, music, and video; and, Afi-Tiombe A. Kambon, who read "Black Diamond," a tale of slavery and disability.

The lesson I retained from that night was always to include examples of disability art when discussing the idea of disability culture. This is frequently the most enjoyable,

and persuasive, aspect of any presentation.

After that evening I heard about Bruce once in a while, but didn't connect with him. Toward the end of my tenure at WID, he began working there in a different department. We would pass in the halls and chat briefly, recognizing some mutual interests. But it never went beyond that office camaraderie.

When I began to explore disability culture in earnest, reading as much as I could find and talking to lots of people, Bruce's name kept recurring. It slowly dawned on me that he played a role in the development of the culture that I did not comprehend. I asked to interview him and he consented.

I tracked him down at WID during a day when he was partially responsible for supervising some international visitors. He did not have a lot of time, but he rewarded my persistence with a thoughtful, and mostly uninterrupted, monologue that explained his role and impact as a leader of the culture.

At the time of our interview Bruce was forty-three years old and had been a quadriplegic for twenty-six years. He holds a Master's degree in Sociology.

Bruce's involvement with the arts directly coincides with his stint as director of Pasadena's independent living center beginning in 1977. Located in the Los Angeles metropolitan area, the Pasadena center acquired space in a rent-free facility which also housed a local arts consortium. Bruce described the art director as a progressive who became his mentor in accessing city services. He wanted to know from Bruce how to integrate people with disabilities in the arts.

Bruce didn't really know. He had no arts background, education, or access. They learned together. In affiliation with the arts consortium, the independent living center offered classes in sculpture, painting, dance, and theater. At that time, eight independent living centers existed in California. None of the others were interested in developing art programs.

In the period around 1977 or 1978 a number of people with disabilities and their allies in the greater Los Angeles area convened and began to raise issues of media portrayal of people with disabilities, employment of disabled actors and actresses, and use of disabled people in the behind-the-scenes activities of Hollywood. They formed a

committee which eventually developed into the Media Access Office, which has become a fairly well-known media watchdog and promoter of disability issues.

Bruce himself left Pasadena about this time to move north to Berkeley where he worked as a volunteer at CIL developing materials to assist in establishing new independent living centers. After a year, he moved west to Houston to become the first director of the Houston Center for Independent Living.

The job did not work out and deteriorating health complicated the problems. After a stay in a Texas hospital, he left the Lone Star State to live in Washington, D.C. There he became involved in international activities, particularly with the escalating numbers of people disabled from war in Nicaragua.

While residing in Washington in the mid-1980s, he became curious about learning to dance. He saw no examples of what it might look like for a quad to be a dancer. He scrunched up his courage and approached a friend, a nondisabled woman, who was a dancer and an artist, about his desire. They began to explore dance together.

They developed a dance, showed it to people, received much positive feedback, and videotaped it at Gallaudet. They received many kudos for their efforts. But Bruce remained unconvinced that what they were doing was truly dance reflecting the condition of disability because their production continued to be evaluated compared to the dancing efforts of nondisabled people.

While pondering these developments he learned about a form of dance called contact improvisation. He thought that the kind of movement expressed in this art form might relate to the experiences of disabled people. He indicated that his perception of utilizing art continued to be spurred on from his political principles. He grasped his interest in dance first as an endeavor to find an avenue of true equality, then secondarily as an art form.

As he became more attuned to, and excited by, contact improvisation he needed to bring this art form to workshops that included disabled people to see if his enthusiasm was typical or an isolated discovery. People responded to the dance form in a big way. Participation changed disabled people's attitudes in a positive way about

their bodies and the ways in which they related to nondisabled people. Nondisabled people who became involved or witnessed this form of dancing began to change the manner in which they related to disabled people.

The conclusion at which Bruce arrived from this pattern was that he had, after more than fifteen years of searching, finally found a method of non-verbal consciousness change. A conscious agenda, Bruce expressed his frustration with the uncreative way in which disability activists in this country routinely seek change through informational dialogues and education.

Bruce perceives the dominant paradigm of activist change in this society as focusing on education followed by legislation. What we mean by education is that we tell people about our lives by sharing information about ourselves. If someone refuses to pay attention to the lessons of our educational endeavors, then we solicit change by force of law through progressive, or reformist, legislation. The Americans with Disabilities Act and the activities that led to its passage are perfect examples of this tendency.

According to Bruce's estimation, the past twenty years of this method of activism has caused some change, but it has been primarily external, such as legal protections from various kinds of discrimination. But the majority of people harbor the same attitudes of paternalism, negative stereotyping, and snap judgments about disability and disabling conditions.

The traditional paradigm should be accurate but people have become immune to the information virus. People today have barriers to learning from information largely because there is such a prolific and competitive advertising and media structure. People screen out information they don't want to listen to and since people with disabilities have less money and access to media time, we are easier to screen out.

Bruce maintains that non-verbal communication changes attitudes in a less direct, but more fundamental, way. It is also a way to counter the media frenzy with which we are unable to compete.

After the idea of non-verbal communication and dance became entrenched in his own activist and artistic psyche he met with other disabled artists. They were acutely

aware of their lack of apprenticeship opportunities to develop and refine their own art. Experimenting with new strategies and diverse media for effecting information distribution and consciousness change, they began to feel constricted by an inability to perform publicly.

The small, but determined, group began conducting evening events to promote their work. They were pulled together on shoestring budgets with volunteers hustling both for space and money. CIL in Berkeley donated major financial support several times. The group sponsored about four evenings, which they dubbed "Moving Over the Edge."

Although one of those evenings was held in conjunction with WID's Personal Assistance Services symposium, this juxtaposition is rare. Art and activism tend to remain separate in the minds of most activists. Bruce laments that disabled leaders in the United States tend to give lip service to art, but in general hold it as a low priority as evidenced when failing to include artistic activities as key, or most often, even minor, aspects of meetings or conferences, and tend to remain oblivious to the role art plays in enhancing our basic humanity and serving as a vehicle for transforming society.

HOMEcoming QUEEN

Lights dimmed, percussions boomed, and images appeared on a screen above the stage. Two of the three performers wore masks. Hephaestus had arrived.

Pamela Walker, one of the trio of disabled performers who comprised Hephaestus, was born in 1949 in a small town in southwest Nebraska. She acquired polio while a one-and-a-half year old infant. She attended school with her nondisabled peers. A popular student, she believes that when she became homecoming queen in 1967 it was the first time a significantly disabled person in this country did so.

After her high school graduation she attended community college, then moved to Denver to complete her education, married, and relocated to Corvallis, Oregon. Her

marriage ended in 1975, and, for the first time in her life, she lived alone. She recalls this solitude as an awakening to realizing her disability posed a problem. She was without any means of transportation. Pamela heard about an organization called the Oregon Architectural Barriers Council and began a hometown chapter. It was the first time she associated with other disabled people and she remembers feeling "scared shitless."

About a year after her initial involvement in attempts to eliminate architectural barriers, she watched on television the takeover of the San Francisco Federal Building during the 504 demonstrations in 1977. She remembers this event as a revelation. She realized at that time that the personal became political. Pamela believes that the 504 demonstrations inspired many people to make a commitment to becoming involved in the Disability Rights Movement. Witnessing the Disability Rights Movement before her eyes on the television screen, she began to believe in disability rights and in her own right to change society, not just cope with it.

Being so influenced by a television news event fit into Pamela's interests and leanings. Her earliest attention to disability occurred in the way in which disabled people were portrayed on television and film. She realized that during her childhood years role models with disabilities were nonexistent.

She combined her interest in the media and rights with discussions and presentations about images of people with disabilities. She had also moved, as so many disabled people do, from a voluntary effort to a paid position as Coordinator of Disabled Student Services at Oregon State University. She remained at this job for six years. During this time, she realized that if she wanted to compete and be promoted in the university setting that she would need an advanced degree. She enrolled in a Master's degree program in Mass Communications and began radio/TV and journalism classes.

About this time DREDF and Ann Cupolo visited Oregon with their "No More Stares" Conference. Pamela attended and wondered why with this hip group of disabled women in Berkeley she remained in Oregon? She successfully applied for a job at Berkeley's CIL, where she worked from about 1983 to 1989.

She almost immediately hooked up with Judy Heumann who had just started her "Disability Rap" radio show. It was a half-hour interview program that was aired primarily in the San Francisco Bay area with some national exposure on Pacifica Radio. The first time Pamela thought about disability culture was while doing the radio show with Judy.

The idea of disability culture for Pamela, as for all of those who contemplate it, revolves around her experiences and training. During her college education in the field of sociology she learned that culture was something that you were born into.

In pondering the existence of a disability culture, Pamela muses about language, art, and culture. She perceives both the words, "disability" and "culture" as ones that are tinged with ambiguity. The word "disability" she argues is less important than the "culture." Disability is almost synonymous with difference. What gives birth to culture is integrating into the arts themes of difference, living with stereotypes, having to develop positive self-images, and disputing negative messages.

Artists with disabilities have always existed, but they have not always focused or imbued their art from their perspectives as disabled people. An ambiguity appears when attempting to determine if artists who have disabilities emerge from a disability culture.

If a person mingles and interacts with other disabled people, then their art is bound to be influenced. Pamela cites blind musician Stevie Wonder as someone who is probably not a part of a Disability Culture Movement because he does not appear to have sought the company of any disability community. Although Wonder does sometimes serve as a spokesperson for issues that are disability related, it is those groups who have likely found him, rather than the reverse. Classical musician Itzhak Perlman, on the other hand, who had polio as a child and uses crutches, does seem to fit into a Disability Culture Movement. Although his art is not disability related, his life is. He works to enhance architectural accessibility and is involved at his own behest with disability groups.

Pamela also describes one of her own pieces as an example of disability's influence, despite its content which does not focus on disability. This particular work is

only fifteen minutes long and portrays growing up as an incest survivor. Only three lines in the piece are actually about disability, but her life experiences as a disabled person influence her writing and performing.

When attempting to integrate disability into art, it is easier to perceive the more obvious disabilities as part of disability culture. Pamela describes her vision of this process in the form of a circle. Radiating outward from the center of the circle is the group of people whose disabilities are obvious and visible and whose disability message is just as apparent. From the core, artists move toward the outer reaches of the circle in subtle gradations eventually attaining the outermost areas where an artist with a disability identifies neither their art nor their personal life with disability.

Returning to her traditional, sociology training, Pamela depicts culture as defined through such things as language, food, and decor. Most cultures have garments that are developed along with beliefs and experiences. The disability community has experienced an opposite development. Disability culture is more in the mind than in surroundings. We are now in the process of creating the garments of culture. We are creating our own languages, including a visual language.

All people with disabilities do not have the same belief systems, history, or values. But if being a part of a culture is recognized as being a member of a group that has a commonality of experiences that no one else has, then we're a culture. The closest contemporary analogy is the gay/lesbian/bisexual culture. We are a "culture in the making."

Pamela believes that a disability culture has emerged in the past ten years. If an anthropologist or sociologist were to sit down with a disabled person and discuss the concept of culture for a couple of weeks they would probably conclude that there is indeed an emerging culture.

As a matter of identity and being willing to include oneself as a member of a Disability Culture Movement as opposed to, for example, being American, Pamela thinks that people with disabilities are trying so hard to prove that we're like everybody else that many of us are unwilling to expose the importance of our disability heritage. This reluctance explains why artists until very recently have not been doing disability art

with a disability flavor.

Pamela postulates that the ongoing Disability Rights Movement will inspire us to share our stories and with that sharing we will create a culture. She indicates her own life story has been an evolution from the political to the cultural. She moved from being a spokesperson about the media to being involved in it.

After moving to Berkeley, Pamela became a member of the "Wry Crips" Disabled Women's Reader's Theater and performed in their first show. She then participated in the Moving Over the Edge evenings. During the initial Moving Over the Edge production she sat in the audience. At the next program she both hosted and began videotaping the presentations. Then she participated with a poetry reading. After that she joined Jay Yarnell and Dave De Weerd as Hephaestus. In addition to the obvious symbolism of Hephaestus as a god with a disability, he was also one of only two Greek gods who were artists. He was a blacksmith who made tools for the gods.

Hephaestus is an appropriate symbol for the manner in which Pamela describes her activities as an individual artist and as a change agent. She is both a performer and video producer/editor. As a writer and actress, she has performed her own pieces as well as acted in films directed by others. As a producer, she is sought after by area artists and has contributed to a number of videos featuring disabled artists.

Our discussion concerned more of her activities as someone who pushes the boundaries of media and art access for people with disabilities. She works with individuals who are interested in working as producers, writers, or performers. Her focus is less on their disability status than whether they are people who are contributing in the arena of difference.

When she observes a need she attempts to fulfill it. For that reason, she started to work with the Public Broadcasting System to air stories about and produced by people with disabilities. She clarifies some reasons she thinks that the media has been so tentative about approaching disability subjects in a manner that many disability advocates would appreciate.

She describes the general public as being fearful of becoming disabled, which comes as no surprise to anyone with a disability. Media decision-makers are a part of

that general public. Their fear about disability is the guiding force in what reaches the air. Simply put, unless a story tugs at someone's heartstrings, it does not get on.

This attitude of the media and the public toward disability puts journalistic coverage of disability issues in a difficult situation. If the press favorably covers an ADAPT demonstration where people are militant, participating in civil disobedience and potentially being jailed, then they are vulnerable to being accused of encouraging such actions. If the reporting about an ADAPT demonstration is negative, it is likely to be discerned as picking on "poor cripples." In either case, the media is not filling the accepted, and expected, role of portraying the fear or pity typically associated with disability. "And, though the media is supposed to be objective in covering issues, it seems to lose that perspective on disability-related stories."

Pamela speculates that when disabled individuals share our inner stories as an expression of art, then we will have arrived as a cultural movement. As yet, there is no cohesive network of disabled artists or performers. Like Bruce, she does not see the larger disability community placing a premium on the work of artists. But she believes a political movement needs the arts alongside it.

The lack of interplay between politics and art and the isolation of disabled people combined to prevent Pamela from realizing that she had a right to be an artist until she was thirty. Her late start as an artist means that she now has less stamina and a shorter time to develop than she might have if she had been encouraged from an early age. This is intensified by the lack of funding opportunities for artists with disabilities.

Pamela also resents the way the American work ethic has caused disabled people to abuse themselves. She thinks that it's ludicrous that some people with disabilities are not on benefits, but are expending their energy on a routine eight-hour day. Having once been a part of the average work world, Pamela argues that she is now filling a much more productive and important role. If she had continued to follow the established order and worked a forty-hour week she would be less productive.

She is currently filling a niche no one else is. There is no job description for what she does, but her efforts have been rewarded with a number of proteges.

Pamela is aware, and not always comfortable, that her actions place her on the

forefront of disability art activities. She makes many decisions that affect a lot of people, but her views are the ones that are being represented.

In addition to feeling like a lone spokeswoman at times, Pamela is also concerned that efforts to open up the media to disabled artists and the sophistication of the artists themselves may not be equal. What if doors are open and people with disabilities are not ready to go through them?

We will go through them anyway, because one of the attributes of disability culture is that we are a group of fakers. The reason for this is that we have not had equivalent opportunities and experiences. People with disabilities have learned to adapt to whatever situation they happen to be in because that has been a survival skill. That is also one of the characteristics that our culture could share with the rest of the world.

If you are a person with a disability, then there has been internal work you have had to do to survive. Everybody has this need, but people with disabilities are forced at some point to confront looking inside to find out what is really valuable in life. Some societies call people with disabilities "wounded healers" because of that.

Pamela concludes that what is weird for her about disability culture is that although it exists and it is important for the future of disabled people, she hopes it ceases to be. She yearns for a time in society when external images are unimportant. If disability culture can move us toward that time, then disability culture itself will become more invisible and eventually disappear. She thinks about this for a moment and then says, maybe disability culture will not vanish, but when people are comfortable telling cripple jokes in any situation, then we'll have accomplished assimilation.

CHANGING THE FACTS TO TELL THE TRUTH

Cheryl Marie Wade also performed in the "Moving Over the Edge" show that occurred during the Personal Assistance Services symposium. I remember being impressed with her reading. But it was when I attended her initial presentation of the

"Disability Culture Rap," that I realized she was putting in performance many of the ideas that I was endeavoring to approach in a scholarly manner. I looked forward to interviewing her and trying to match what I perceived as her vision from the heart with my dreams from the head.

Cheryl remembered watching Judy Heumann on television during the 504 demonstrations and learning about the independent living movement. She also recalls seeing Judy as the first time she witnessed a media event with a disabled person who did who did not simply look like a nondisabled individual sitting in a wheelchair.

As a student, Cheryl studied psychology and as part of her curriculum conducted interviews. She always interviewed disabled people and women about their lives. She loved hearing the stories, enjoyed the narrative form. She was interested in the details of personal stories: the teeny details of our lives.

People with disabilities have unusual details. There is a unique pattern, texture of disability. We see and experience the world differently. It's a culture of disability, odd, little experiences. The more detailed and minute you get the more universal the tales become.

As a young woman, Cheryl was not encouraged to be an artist, even a writer, a traditional bastion of women looking for something to do with their time. She did not see anyone else who was disabled in the arts.

After she moved to Berkeley, she became friends with one of the original members of "Wry Crips" who kept insisting Cheryl should become a member. Aware that she loved the art of writing, but did not know what to do with it, she finally joined in 1985. In March of 1986, shortly after her thirty-eighth birthday she did her first gig.

At that time, there were twelve people in the Wry Crips troupe. Cheryl and one other member were the only heterosexuals.

The troupe began with three disabled lesbians who were athletes together and who wanted a safe environment to write about their experiences. One motivation for their activity was to deal with sexual oppression from heterosexuals. They patterned themselves after Feminist Reader's Theater, especially "Fat Women."

Wry Crips did performances for women only and for general audiences. At

Cheryl's initial show, there were two hundred women in the audience. Cheryl dealt with esteeming the body in dealing with sexuality. Being in such a group seems appropriate in retrospect because the first support for Cheryl's work came not from people with disabilities, but from women, particularly lesbians. Cheryl acknowledges the existence of a lot of homophobia in the disability community.

The only example of disability art Cheryl knew about before Wry Crips was "Tell Them I'm a Mermaid." Conceived by actress and writer Victoria Ann-Lewis, "Tell Them I'm a Mermaid" demonstrated the grace and style of a group of about a half-dozen women with disabilities. For many years, it has been one of the most admired works about disability and disabled women.

Wry Crips was both an exhilarating and frustrating experience for Cheryl. The troupe welcomed beginners and people who were interested in amateur performances. The only criteria to participate was being female and being able to get to a show. Where else, Cheryl mused, could someone with, for example, a speech impairment be ensured that they would be able to deliver their own work? But this total inclusiveness harbored certain limitations. People were constantly working out horrendous experiences, and exacerbating sexual tensions. For someone who wanted to become a professional performer, the amateur status of the group was limiting. Cheryl was always quitting the group.

In October of 1990, Cheryl co-produced a Moving Over the Edge show with Bruce. It was the first time she performed memorizing her material. Her reader's theater background stood her in good stead for this experience because she had learned how to tell a story.

Cheryl still serves as an artistic consultant from time to time with "Wry Crips" and she is quick to point out its role in the development of a disability culture. The troupe is about having a voice, which is also what culture is all about.

Everything Cheryl writes about is disability infused. Life moves through her current filter of experiencing the world as a middle-aged, cripple women. Her performances, though, are always for the same person--the fifteen year old girl that she was.

For Cheryl, culture is represented in the way a cripple in a chair moves her body. Culture is using her wheelchair as a percussion instrument in her performances. That one action causes people to think about her chair differently. Finding and refining little bits of life that communicate is culture.

Disability culture issues are just emerging and are not fully formed. Cheryl does not believe they will necessarily be liked or embraced. But she is intent on portraying the "horrifying and magnificent experience of cripple."

No one outside of the culture thinks of Cheryl as a voice of her culture. She resents that it's not looked at as true art.

Culture is making your experience valid, valuable, and not reflective of the dominant culture. Not many people historically have assembled in community to tell our story and say that it has been interesting and to say that it is worth passing on. It has been difficult to locate what we've done. We've been so isolated.

FDR was a great hero to Cheryl's parents and they knew about the press assisting the President in hiding his disability. The message to Cheryl was that hiding was appropriate. She used to carry a shawl to cover her hands withered from arthritis.

Looking at FDR is irrelevant in some ways because he's not identified as a person with a disability. It's negative to the culture. In her piece, "Naming and Claiming Our Heroes," FDR is a "hero" who hid his wheelchair.

The other historical character with a disability Cheryl knew about growing up was Helen Keller. But her accomplishments were so formidable and portrayed with so little true life that she seemed like a fictional character.

The first historical figure with a disability Cheryl appreciated was the Mexican artist, Frida Kahlo. Her work is so intimate, it doesn't try to tell you about society, but it does tell you about society. The immediacy of her work is transcendent. She was the first disability artist, Cheryl recognized even though Kahlo probably did not recognize herself as a disability artist.

If anyone with a disability today is known to the general public, Cheryl believes it would be Judy Heumann or Ed Roberts, not any of the thousands of other everyday heroes with disabilities. Events like ADAPT actions or the 504 demonstrations are

probably more recognized than any individual activists. In fact, Cheryl speculates that the most well-known person involved in disability in the U.S. is probably Jerry Lewis. This directly contradicts the hopes of disability rights proponents to place equality and integration at the forefront of the American public's concern with disability issues.

If there is ever going to be change that really matters with people with disabilities being included and integrated, Cheryl does not believe it will be through politics or laws, although they're good vehicles, but art, media, and culture. That's where people get what they think and feel—through images, art, music, viewable culture. Until we have a philosophy, theory, art, language for our stories, it will be a struggle for most people with disabilities to say I'm okay. The need for a disability culture exists not only for nondisabled people, but also for people with disabilities to know that their culture is distinct from the dominant culture.

Cheryl writes for the oral, spoken voice. In academic, intellectual works you cannot change facts to tell the truth, but in art you can. Language is as important as feeling, then comes intellect. She works hard to make her poetry vibrant, accessible. The point is to get the image across, then stop; don't explain. Her goal is to get an image, an idea, a great sentence into people's heads.

"Cripple" or "gimp" are resonant words. Sharp, not apologetic. In no way do they soften the experience of disability. Cheryl has never understood "handicapped" as much better than "disabled" or "people with disabilities." To her way of thinking, it's all generic, non-offensive language—it does not set her heart afire; it does not make her cringe either.

Disability culture and disability art explores the terrain from abuse to healing and from being represented and presented as damaged goods to recognizing the power of who we have become as disabled people. Cheryl believes that all it will take to bring the message of culture from the isolation of the disability community to the general public is one breakthrough artist. It could be any of the artists portrayed in this work or it could be someone none of us have ever heard about. Someone who has the humor, the absurdist vision, and the persistence to emulate a star like Roseanne, who took a conventional form in a traditional forum and turned it to her own use. An engaging

character with a disability telling the truth about disability in a situation comedy.

CRIPPLE LULLABY

I'm trickster coyote in a gnarly-bone suit
I'm a fate worse than death in shit-kickin' boots

I'm the nightmare booga you flirt with in dreams
'Cause I emphatically demonstrate: It ain't what it seems

I'm a whisper, I'm a heartbeat, I'm "that accident," and good-bye
One thing I am not is a reason to die.

I'm homeless in the driveway of your manicured street
I'm Evening Magazine's Super-Crip-of-the-week

I'm the girl in the doorway with no illusions to spare
I'm a kid dosed on chemo, so who said life is fair

I'm a whisper, I'm a heartbeat, I'm "let's call it suicide," and a sigh
One thing I am not is a reason to die.

I'm the poster child with doom-dipped eyes
I'm the ancient remnant set adrift on ice

I'm that Valley girl, you know, dying of thin
I'm all that is left of the Cheshire Cat's grin

I'm the wheelchair Athlete; I'm every dead Baby Doe

I'm Earth's last volcano, and I am ready to blow

I'm a whisper, I'm a heartbeat, I'm a genocide survivor, and Why?
One thing I am not is a reason to die.

I am not a reason to die.

(Cheryl Marie Wade, 1993, 178)

CHAPTER SIX:

"OUT OF ISOLATION"

INTRODUCTION: ART, ARTISTS, AND CULTURE, OR, INTEGRATION AND POWER

Here is my prediction about the millions yet to be disabled, the millions yet to be born with disabilities, the millions more who are their families and friends: All will be deceived, all will take the rocky road of getting wise the hard way. Many will lose their lives in the process. They will blame themselves when real life falls short of the myth. They will take their trouble personally, not politically. They will not recognize their solidarity with people with all disabilities. They will not organize into a fighting force to expose the myth and make the world safe for people yet to be disabled. And how do I know they won't? Because they haven't.

(Lucy Gwin, 1994, 5)

Martin Luther King had a dream. We have a destiny, not a dream, a destiny, to realize. We shall have the right to choose how we live, and where we live.

(Mike Auberger, 1993, 6)

The emergence of disability culture is most clearly reflected in the arts. Artists frequently symbolize cultural movements because they become the most visible, and accessible, representations of changing perceptions.

When speaking about the idea and the reality of disability culture to groups around the country I am always certain to include many references to what might be

called the "cultural artifacts" of disability culture. Movies like "We Won't Go Away..." about disability rights as it accelerated in the 1970s, with an emphasis on the 504 demonstrations of 1977, or recent feature films, such as 1992's "The Waterdance," and "Lorenzo's Oil" are based on the actual experiences of disabled people. They are all informed by and infused with the exigencies of disabling conditions.

Music has played an extremely significant role in American popular culture for decades as well as in social movements for as long as they have existed. Music also reflects the oral tradition of storytelling and of passing from one generation to the next information that might otherwise be lost. Musicians with disabilities who soak their art with the effects of disability from their lives include Jeff Moyer, the troubadour of the 504 demonstrations, and Elaine Kolb, who penned "We Will Ride," the theme song of ADAPT during the heights of its protests against inaccessible transportation. Diane Coleman, a current ADAPT activist, sings a song written by Wynelle Carson and Dwight Liles titled, "Free Our People," about the fight to liberate disabled people from nursing home incarceration.

As has been the case with many oppressed minorities, people with disabilities have sought solace, voice, and freedom through the written word. Organs of disability life, like Accent on Living, Disability Rag, Mainstream, and Mouth have not lacked contributors. As disability rights is becoming recognized and entrenched greater numbers of authors are finding a modicum of success in traditional publishing venues.

Lorenzo Milam is one of the finest of today's authors writing about disabling conditions, not only from his own life, but also from his vantage as a literary critic. In his most recent work, CripZen: A Manual for Survival, (1993) Milam discusses many of his contemporaries in the field of writing about disability.

Milam's interest in publishing about disability and his brutally honest, undiplomatic style seems to have prevented his primary works about disability from being sought-after by mainstream presses, even though some of his other writing has attracted acclaim from traditional critics. Like many disabled people, Milam's solution to his desire to publish about disability and the lack of interest displayed by mainstream publishers was to take matters into his own hands. The result is Mho & Mho Works, a

publishing company.

Visual arts are being explored by numerous individual artists and being displayed by several organizations that host ongoing art shows. The World Institute on Disability sponsors a quarterly art show. Several independent living centers maintain continuous art shows and one independent living center, in New York City, holds an annual juried art show by disabled artists.

The best example of disability humor continues to be cartoonist John Callahan, who is syndicated throughout the country and is soon to be portrayed in a major motion picture by Robin Williams. Callahan's autobiography, Don't Worry, He Won't Get Far on Foot: The Autobiography of a Dangerous Man (1989) is simply required reading for anyone who wants to understand the joys and frustrations of disabled people, living with a disability, and the nurturing potential of disability culture in the latter part of the twentieth century.

American Sign Language is the undisputed linguistic contribution of deaf Americans and an unquestioned (now, after many years of debate) example of deaf culture. Yet many people feel that all disabled people have a way of describing ourselves which is unique to our peers. This includes not only the desire to use or prohibit certain words, as described in June Kailes' "Language is More Than a Trivial Concern," (1992) but also in the use of terminology that has a significance to disabled people that nondisabled people would not recognize. (D. Pfeiffer, personal communication, Sept. 19, 1994)

Perhaps, the most significant current example of this language emphasis occurs with the word "crip." A commonly-used appellation among sets of disabled people, "crip" becomes an insult when employed by someone outside the group. An analogy might be with "nigger" which is only appropriate when used by someone who is clearly not in a position to offend someone else with what is generally perceived as abusive terminology. At a disability rights action, I might comment that a lot of "crips" showed up. But, if I were addressing the media I would be certain to change my language for the consumption of "outsiders."

A couple of years ago, a friend of mine with a disability who works in the

corporate world, and who knew of my fascination with disability culture, but did not really comprehend it, said he wanted to talk with me about his feeling that there was a frustrating lack of disability culture. I welcomed the opportunity and wondered what he meant when he referred to culture. In response, he inquired of me whether there was literature with a disability theme. I answered in the affirmative and offered some examples. He then asked about humor, movies, music, and other cultural categories. In each instance, I answered with examples of the kind of art or activity he wondered about.

By the conclusion of the conversation he was very excited. He learned about all kinds of ventures and artists that were new to him. He speculated that perhaps indeed there was a culture. And, finally, he felt that if disabled people sustained this cultural pilgrimage that there was hope that his young son--with a disability--would grow up into a world that had created a niche for him that it had not held for those of us who were older.

For me, the initial and the final component of all discussions of disability culture revolve around the experience of oppression. About three or four years ago, I made a decision to begin almost all of my speeches about disability rights with a discussion of oppression. The one commonality shared by all people with disabilities throughout the world, and throughout time, is oppression.

This history of oppression has as a matter of course affected the Disability Culture Movement. Carol Gill stated: "the struggle shouldn't be for integration, but for power. Once we have power, we can integrate whenever we want." (1994, 7) Gill's perception of the world is almost identical to a statement made by one of the world's leading disability artists: "We're looking for interdependence, not independence. We're looking for power, not integration. If we have power, we can integrate with who we want. (Johnny Crescendo in Lathrop, 1993, 18)

With Gill's and Crescendo's creed in mind, let's explore the world of disability culture through some of the art and artists who are such a significant component of its development.

DISABILITY AND THE ARTS

One of the first visible signs of disability pride occurred in 1972, when the National Theater of the Deaf decided to use American Sign Language in their presentations. (Shapiro, 1993, 103) During the same decade, the husband-wife team of Florence Ludins-Katz and Elias Katz were turning their vision of combining art and disability into reality.

The Katz's conceptualized the idea of an art center for people with disabilities in the early 1970s. Florence Ludins-Katz, who is now deceased, had been an artist and a teacher. Elias Katz was a psychologist. They combined their interests and in 1974 founded their first art center, Creative Growth, in Oakland. This was followed by Creativity Explored in 1980 in San Francisco, Creativity Unlimited in 1982 in San Jose, and the National Institute of Art and Disabilities (NIAD) in Richmond, north of Berkeley, in 1984. By 1994, there were sixteen art centers in California, with two new ones planned, and at least twelve others elsewhere, including New Mexico, Washington, Wisconsin, and Toronto that had all adopted or adapted the Katz's model. (Connor, 3; Katz, 1993, 11-12; 1994, 138; personal communication, July 6, 1994)

NIAD is in many ways the culmination of the Katz's dream of an art center and it will be discussed here. When they began their efforts to create an art center the Katz's focused on visual arts, because it was their own area of expertise, and on serving developmentally disabled individuals because there was an accessible funding base. Katz described the venture as a pragmatic approach to providing needed services. (personal communication, July 6, 1994)

NIAD provides prevocational and vocational training in art and art-related fields. There is no age limit at the art centers so each one includes people ranging in age from twenty-two to their eighties. Those who enroll in the program attend a full-time, five-day work week. The environment tries to be supportive, without pressures, threats, or an emphasis on competition. Students can work with paintings, sculpture, printmaking, creative crafts, and other media in a studio setting.

Artists display their work in an on-site gallery, managed by a professional curator

who is a practicing artist, and in an on-site gift shop. NIAD regularly schedules shows by its own and other artists at its building and in other galleries, museums, government buildings, colleges, businesses, and gift shops. In February, 1993, NIAD established the Creative Spirit Art Gallery in San Francisco's Ghiradelli Square near the popular tourist area of Fisherman's Wharf.

The founders' dream is that art centers for people with disabilities will eventually not be necessary and that all people will work together. The basic commonalities of developing and structuring an art center for disabled people are a focus on creativity, a belief that all individuals can grow in many dimensions and enjoy themselves while producing work of high artistic quality. To promote this philosophy NIAD not only constantly exhibits its work, but also conducts workshops, conferences, classes, and prepares and circulates publications and videotapes. (Katz, 1994, 137-40)

A personal word seems appropriate. A couple of years ago I had a chance to visit NIAD. I walked into a building that in many ways reminded me of sheltered workshops. There were several rooms, a lot of tables spread around, people who observed me with great curiosity and several who stopped to ask me who I was and what I was doing there. I saw a lot of people engaged in what might be considered menial artistic tasks and several facilitators interacting with clients.

There were two differences, though, between NIAD and sheltered workshop settings I had seen. First, there was lots of art all over the walls and everywhere else one cared to look. But most importantly, everyone I watched seemed happy to be there. I had never seen that emotion in a sheltered workshop setting and it was enough to convince me that the idea has merit. I continue to see NIAD's efforts as innovative.

Toward the end of the 1970s, during the same decade that the Katz's were conceptualizing and implementing an arts center, a small disability arts show occurred across the San Francisco Bay in Sonoma, California. Anthony Tusler, who earned a living as a photographer, before becoming paralyzed describes how these two shows, both called *Disability and the Arts* came about:

It was about seven years ago that I was trying to find

ways of combining my photography and my identity as someone with a disability. Two students at Sonoma State University helped me combine the two. I had seen Martin Lesinski's piece, *Disability*, (included in both of the shows), and I knew that Erby George, co-curator of *D & A²* along with Donna Lee Phillips, was doing work that included disability issues. Martin's piece was done for a class he took with Donna Lee, probably the person most influential in the birth of *Disability and the Arts*¹. It was her influence on Erby, Martin Lesinski, and myself that brought about so much work and thought related to disability and art. Martin had a show that included *Disability* and invited me to see it so that I could give him my opinion. It stunned me. It was a documentation of the injuries he had received in Viet Nam, interspersed with documents relating to his disabilities. These ranged from childhood reminiscences of wanting to be a soldier to his discharge papers. I had never seen anything so immediate and vulnerable. It fulfilled my need to address my own disability. (1985, 6)

This show was one of the first examples of disability culture in the sense that it combined art about disability experiences by artists with disabilities who wanted to portray just what it meant to be a person with a disability in this culture. It heralded what has been called "A New Renaissance" of disability art and culture. (Brown, 1993)

ART, CULTURE, AND PHILOSOPHY

When discussing art, disability pride, and disability culture, it is often much easier

to focus on the production of the artists than on their thinking about the subject. In the last chapter, individuals like Neil Marcus, Bruce Curtis, Pamela Walker, and Cheryl Marie Wade were described for both their artistic endeavors and the way that they think about their art and their role in the existing disability culture.. But none of them have described in a sustained way the process of creation and its impact on disabled people and the general social structure. The only people I know of who have essayed that task have been the English photographer David Hevey and the American shaman, Frank Moore. This section will be devoted to their ideas.

Two years ago I became immersed in Hevey's The Creatures Time Forgot. No one had approached disability, disability art, and disability rights in a like manner. Although the book is intense in traditional European intellectual style, expensive, and not particularly well-known, it is a pivotal work about disability and disability rights in its current incarnation. Its influence is likely to extend far beyond the actual numbers of its readers.

Hevey tentatively explored some of the themes that occur in The Creatures Time Forgot in a 1991 presentation entitled, "From Self-Love to the Picket Line: Strategies for Change in Disability Representation." In it he offered one of his most enduring contentions--that the disability arts movement is the first sign of a post-tragedy disability culture. (4)

A year later, in the first chapter of his momentous book, 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)

One of the most portentous of his messages is that in order for disability rights to succeed the task of observation must be reversed. 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 argues that one of the tasks of outsider photography is to locate the

person in the image and text. Writing in the language of dialectical theory, he maintains that the free-floating meaning in an image is anchored by the identification of the consumer (reader) and producer (writer) of signs which mark similar journeys, experiences, and memory. It is the artist's/photographer's/propagandist's job to name these journeys, experiences, and memories in terms of symbols which the consumer/reader can experience themselves in viewing the image. Because the purpose of political disability imagery is to mobilize disabled people into self-love and action the dual process of subjective and objective identification becomes vital. (99-100)

If disabled people are to change oppressive photographic imagery it must be as makers of the processes linked to the product. Disabled people must be changing imagery, not merely interpreting it. (110-11)

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.

The indivisibility between process and product must continually be reiterated. The ability of an image to impart the reality of a political struggle is within the image's ability to force a collision between the old consciousness and the new. Although we have to pressure all aspects of oppressive image-makers to get their "act" sorted out, the core site of change is within ourselves and our own processes. (117-19)

Unlike the abstract thought of David Hevey, Frank Moore's art and life are downright earthy. In the 1970s he created a cabaret show called "the outrageous beauty revue." In a 1989 letter to the Disability Rag, Anthony Tusler described the revue as a hard core punk troupe of disabled men and women who satirized disability issues with a vengeance, rarely letting good taste get in the way. (2)

Joseph Shapiro's rendering of Moore in No Pity is quite different than Tusler's description. The journalist described Frank's Church as a Berkeley-based, avant-garde,

performance group that used nudity and sexual themes to discuss nondisabled people's fear of disability. (1993, 103) Others describe him as someone who fuses art, ritual, and religion, or as a performance artist with Cerebral Palsy who uses a power wheelchair, head wand and who does "eroplay," with his partner Linda Mac and the audience. (Carr, 1990, 102; Sparks, 1987)

Moore describes himself as someone who does painting, performance art, video, writing, and music. Two years prior to the publication of The Creatures Time Forgot, Moore published a description of his ideas from a lecture that he gave at New York University, in a monograph entitled, "The Art of a Shaman:"

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. Primitive tribes believed that if a cripple could survive childhood, he was blessed by the gods. He was special. He was not really from this physical world. He belonged to the spiritual world, with an inside channel to the gods. He was not suited for the normal activities of living such as hunting and fighting, but everything he did or said were omens from gods. He was taken care of by the tribe and lived in freedom. The court jesters in the Middle Ages came from this tradition. They were given an easy life and freedoms such as the ability to tell the king off because their babbling just might have been divine in origin... (1990, 6)

The thought is continued in another article about Moore: "As a symbol of the deformed medicine man, I am a medium to other dimensions. My body and attitudes toward life break taboos and change things. (Snider, 1993, 40)

Moore is an active, creative artist who always seems to be in the process of some new endeavor. In the mid-1980s, he established the University of Possibilities, a

shamanistic, performance school. In this decade, he has published an underground magazine, The Cheriotic Revolutionary and a book, Cheriotic Magic. In 1992, the San Francisco Bay Guardian, a weekly newspaper, voted him the area's best performance artist. And in the 1990s he also became notorious as one of the subjects of Senator Jesse Helms' hit list of artists who should not be funded by the National Endowment for the Arts. (Moore, 1990, 43; Snider, 1993, 40-41)

One of Moore's core beliefs is that the suspension of time creates an avenue toward new experiences. (Moore, 1990, 37) His public performances contain a lengthy period of planned inactivity, a quality that repels many potential participants. He believes that a quality of timelessness is requisite to achieving his goals.

Breaking out of isolation is the root of his life and work. (*Ibid.*, 4) This theme is clearly identified in an essay and video both called "Out of Isolation."

A seemingly stream-of-consciousness work, the essay pulls the average reader into an unrecognizable, but very real, world. A lengthy excerpt follows:

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, mindless 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 invade 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. They 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'm not a Mister, a Mrs.,

Miss, a nurse, a doctor. I understand I am not a bony finger. 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 makes me feel. But I know 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 that makes me feel 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. (1993, 145)

Out of isolation, away from the numbing silence of oppression, and into the light of shimmering imagery materializes a new kind of art--disability art. The remainder of this chapter will be devoted to a sampling of the many artists who have made their mark in the recent past and continue to do so now.

BREAKING THROUGH

Perhaps the most well known of the current crop of disability artists who are representative of a Disability Culture Movement is Johnny Crescendo. A rock'n'roll musician from England, Johnny has released several tapes of his music, all of which have a disability focus or infusion. He has crossed the Atlantic numerous times to perform his songs before American audiences and he is a staple figure at ADAPT's annual Washington, D.C. demonstrations and actions.

As a member of an English troupe that goes by the name, "Tragic But Brave," a satirical commentary on the plight of individuals with disabilities in the last half of the twentieth century, Johnny was a key figure in England's successful anti-telethon campaign. (Crescendo and Barbara, 1994, 4-5) A charismatic figure, Johnny has been the subject of several articles. One, in particular, is noteworthy both for its discussion of Johnny and his career and for the author's juxtaposition of biography and personal analysis of the idea of disability culture: "This dialogue [over the existence of disability culture]--or warfare, often enough--takes place most loudly within the arts, for without art, culture would have no voice." (Lathrop, 1993, 15)

Crescendo himself believes that: "Disability arts is very powerful. If done right it is a very powerful force--primarily for the disabled but also for nondisabled people. Disabled people have got a lot to teach the world." (in *ibid.*, 18)

In the liner notes to his 1993 "Pride" tape, performed with the P.O.P. (Piss on Pity) Squad, Crescendo writes:

This album is about PRIDE. It's about being comfortable in who you are as a disabled person, It's about having the self-respect & self confidence to challenge the system that screws me & you, It's about disabled people as lovers, as parents, as sexual beings, There's a war goin' on for our right to be included in the human race. Stay Strong, Stay

Proud, Stay Angry...GET INVOLVED!

But, it is in his songs, that Crescendo is most eloquent. One example is his 1993 composition, the "Ballad of Josie Evans:"

Josie was a wheelchair user
She spent eleven years inside
A short stay institution
Where she was banged up without trial
Eleven years the white coats met
And talked & analysed
Dispensed the drugs politely
Until one day Josie died

Not me said the social worker
I was Josie's friend
I was with her till the end
Our boss said no resources
Were available at the time
I'm just an employee
Can't put my job on the line

Not me said the director
I can't be held to blame
It's the politicians who make decisions
I'm just a pawn in their game
I agree most strongly
That Miss Evans was done wrong
But the Council wanted cuts
& I had to sing their song

And the finger of guilt
Draws a circle in the sand
And who'll take the blame
For the desperate and the damned?
And which people vote?
For injustice in the land?
Is it you or your mother?
Is it you? Is it you?

The leader of the council
Wrung his hand & shook his fists
You gotta blame the government
For a scandal such as this
Blame Thatcher, Blame John Major
Blame the ones that put them in
Then he went to wash his hands
Declaring he was clean of sin

I give to charity everyday
Said John Major at the table
It's the very least I can do
To help the poor disabled
Efficiency is what we need
Poor management's to blame
Would you like a small donation
To the memory of what's her name?

And the finger of guilt
Draws a circle in the sand
And who'll take the blame

For the desperate and the damned?
And which people vote?
For injustice in the land?
Is it you or your mother?
Is it you? Is it you?

Josie left a letter
Which I found amongst her things
It said I am and I survive
& my heart still has wings
They can take away my freedom
They can drug me with their lies
But they don't have my permission
& I hang on to my pride

Other noteworthy members of the Tragic But Brave troupe include Ian Stanton, author of the song, "Tragic But Brave;" Mike Higgins, whose tape's title song, "Thanks for Your Application," is about the universally deplorable condition of unemployment of disabled people; and comedian Wanda Barbara.

The Tragic But Brave troupe are the most well-known figures in the United States of an English disability culture that is apparently older and more sophisticated than our own. But, in 1980, thirteen years prior to Crescendo's "Pride" tape, two years before my own involvement in the Disability Rights Movement, and one year ahead of the release of "We Won't Go Away...", Oklahoma's Helen Kutz produced and distributed "Breaking Through: A Documentary on Disability."

Kutz has been a consistent pioneer in the field of disability rights. Before the existence of even one independent living center in Oklahoma, Kutz documented the status of the Oklahoma Disability Rights Movement in her twenty-eight minute film. Seen throughout Oklahoma, "Breaking Through," received a first-place award from the Oklahoma Film Maker's Association.

Shortly after my introduction to the Oklahoma Disability Rights Movement I had an opportunity to interact with a local reader's theater group. JustUs may have been my first introduction to disability culture. In the mid-1980's, JustUs, a revolving trio of Maureen Butler Stephens, Larry Bishop, and Bill Bullock, performed several skits throughout the state. My personal favorite was entitled the "KRIP News," which included savage commentary on the status of contemporary disability politics in Oklahoma and across the nation.

JustUs consistently received praise for its performances within Oklahoma and received offers to take their act on the road. Although JustUs managed to perform before larger groups on occasion, an unfortunate combination of personal problems and other interests prevented it from taking full advantage of these opportunities.

More successful than JustUs and less militantly political has been Kalamazoo, Michigan's "Mad Hatters: Educational Theatre for the Understanding of People with Special Needs or Disabilities." The group began in 1979 following results of a County Board of Mental Health survey revealing how uncomfortable area residents felt about de-institutionalization of a large regional psychiatric hospital.

Mad Hatters describe themselves as a theater of encounter between fears, misconceptions, and illusions about people with disabilities and people with special needs. Their goal is to gently, gradually ask people to examine their feelings and attitudes and, if necessary, to change them.

They have been extremely successful in their pursuits. Mad Hatters has grown from a small group of volunteers to a fully staffed professional theater, some of whom have disabilities, featuring over 100 performances each year to more than 15,000 people. In 1990, they began training their first pilot troupe in Bermuda. (Brochure, 1,5)

JustUs and Mad Hatters were early examples, along with Wry Crips, of how important theater could be to disabled people. This pattern has intensified in recent years.

About a year before I left WID a newcomer would roll in about once a week. An Asian woman with extremely fine features, she moved in her power wheelchair with an artistic grace that most people lack. Soon she was coordinating WID's quarterly art

shows. Then she brought her sculpture and other art to a WID show. Although she routinely dismissed compliments, her art captured our attention.

At the WID 10th Anniversary program in May of 1992, she performed a dance with the Augustino Dance Company. Then in August of 1994 Mainstream featured an article about her by Eric Backman called "Amazing Grace." Both the article and Grace Lin, the subject of the story seem to sail smoothly through the sometimes contentious world of disability culture.

The Augustino Dance Company, which was created to provide a forum for new and original pieces from diverse cultural roots and uprootedness in American cultural life, recognizes the disability experience as its own distinct cultural voice. (Backman, 41; WID 10th Anniversary Program, 1993, [5])

Backman describes Lin's work with Augustino, which she joined in 1992, in this context:

That Lin has a disability means her art inherently gives voice to the experience of disability as it is actually lived....In articulating this experience, Lin is helping to forge a distinctive culture and revolutionize the way society, disabled and non-disabled alike, relates to disability. In this way, Lin's work is playing an influential role in the larger arena of social and cultural politics....This is exactly what Lin and company are trying to forge: a vision that espouses the unique and powerful voice of disability as its own culture, deserving of inclusion, equality and celebration. (41, 43)

Other artists of all kinds abound in San Francisco's Bay Area, including dance troupes, visual artists, writers, and comedians. The Northern California Bay Area may be the most active current repository of disability culture, but it is not unique. Several

hundred miles south in Hollywood, there are also significant disability arts activities.

Perhaps the most influential, and well-known, disability artist in Hollywood is Victoria Ann-Lewis. Co-author of No More Stares, creator of "Tell Them I'm a Mermaid," and actress for many years in "Knot's Landing," Vicki Ann-Lewis moves with greater ease than most from the world of established Hollywood productions to being a pioneer in the creation and promotion of an alternative culture.

As founder and director since 1981 of "Other Voices," at Los Angeles' Mark Taper Forum, Ann-Lewis has produced two videos, "Tell Them I'm a Mermaid," one of the first looks at disabled women, "Who Parks in Those Spaces?" and a recent play, P.H.reaks: The Hidden History of People with Disabilities." Most recently, she coordinated "A Contemporary Chautauqua: Performance and Disability," which harkened back to the nineteenth century lecture circuit to produce a weekend of art and thought about art by those involved in the production of disability culture. (personal communications, 1994)

Across the continent another sign of disability culture is signaling for attention. Much of American culture is wrapped up in sports and it is no different for people with disabilities. In addition to wheelchair basketball and quad rugby, disabled people participate in just about any other sport one can imagine. This has been recognized during several of the past Olympics, which have been followed by a Paralympics.

Atlanta will host the summer Olympics and Paralympics in August of 1996. Organizers anticipate 4,000 athletes from 110 countries to take part in the Paralympics.

In a true recognition of the nature of disability culture, the Paralympics will be combined with a Cultural Olympiad. Paralympiad offices have already received interest from dancers in Sri Lanka, musicians from Europe, comedians from California, and theater groups from across the world. The Cultural Olympiad will use as its spokesperson, popular writer and recording artist, Curtis Mayfield, who was paralyzed in a stage accident in 1990. The cultural arts program intends to promote messages about inclusion of people with disabilities. (Henry, 1994, D9, personal communication, 1994)

In sports, in cultural activities, and in politics, people with disabilities are

constantly in the process of forging ahead into new territories. The Disability Culture Movement is at the forefront of this emergence from a history of institutionalization and oppression.

Disability art and disability culture is about breaking out of isolation into a new world that not only accepts people with disabilities, but recognizes that this distinct group of individuals just might have something to offer to rest of the world that is worthy of attention.

One day our Movement will create such a brilliant world for every one to live in, a world of equal access and opportunity and a world where people give and take with respect and dignity. We will create a New World of openness without fear and without oppression. These are the lessons that we, as Disabled People will teach the world. (Crescendo, 1990, Liner notes)

A typical, traditional work of scholarship would conclude here. But this is not a traditional study. This is a study that belongs to the culture of which analysis has been attempted. The only appropriate way to end such a work is with examples of the culture itself.

I offer two pieces. Each explores the culture from the vantage of loss and memory; discovery and identity.

I AM

ancient ways
two silver rods
my father's son
short-sleeved shirt
a video monitor
physical sensations
bisexual
many faces
robin red breast
my mother's burden
my father's plaything
a crooked olive branch
apathy
atrophy
invisible
an empty well
an empty nest
a blue shadow
an artist
a creator
able to laugh
able to cry
able to play once

I WAS

alone
different
sick and tired
unfeeling
High School Drum Major
denial
homecoming queen
gypsy moon
rock'n'roller
hippie
nervous breakdown
reincarnation of Cleopatra
iron legs
disabled
handicapped
unimportant
invalid
invisible
cripple
switch hitter
cat lover
Lego maniac
an aging child

With a backdrop of rock 'n' roll
And a '50's way of knowing
Miss America was my dream
And the fantasy started growing

The crown would rest upon my head
Of this I had no doubt
Until a newspaper clipping]
Turned my reality all about

"Miss Handicap America"
Is what the heading said
And all my dreams and hopes and joys
Were smashed and left for dead

And the wheels of alcehmy started turning...turning...turning...
Wheels started turning...turning...turning...

Ten years later I took a toke
And watched as two streams of smoke
Rose to the sky, made me aware
Of how my life was in the air

One stream showed the truth of me
The other how I was expected to be
As I took my last hit...Only one stream rose
I asked myself which...But who really knows

And the wheels kept turning...turning...turning...

Now, having a disability
is part of my reality
But lovers, friend, and family
Closed their eyes and wouldn't see

Yet to all the strangers on the street
All of me was in my feet
And everything that I would do, think or say
Was seen as being
The crippled way

Well...what is having a disability really about?
Being disabled is being unable
Unable to what?
Unable to hang onto the myth of the indestructible human
It is to know that no matter
What cure,
What adaptive aid,
What cosmetic surgery,
What bottle of peroxide,
What brand of toothpaste,
No matter what wrinkle remover or vitamin,
What cosmetic surgery or cellulite plan...
...I still have a body
That will age
That will die...

But...Meanwhile...I'm a gypsy moon
I'm a golden tear
I am alive!
And I am here.

(Pamela Walker, 1993, 5-7)

MARTYRS

I.

The following have drawn their last breath,
They've been courted by death
Many gave their lives to the cause
Their passing should give us pause
Many gave all their hearts had to give
So the rest of us might live

II.

Sandra Beasley...
Wade Blank...
Sheldon Berrol...
Roger Chambers...
Tim Cook...
Gerald Davis...
Dave De Weerd...
Phil Draper...
Cheryl Elliott...
Milton Erikson...
Lockhart Follin-Mace...
Gerald Garner...
Lynn Hart...
John Hessler...
Cristina Hopkins...
Gini Laurie...
Kirk MacGugan...
Sharon Nelson...

Lonnie Nungesser...

Randy Shilts...

John Simpson...

Benjamin Stuart...

Bill Tainter...

Diana Viets...

III.

The list is not complete

There will never be such a feat;

The deeds are not done

Many more tales have yet to be sung:

My list, my friends, my foes, the lines grow longer every day,

Leaving me breathless, with much too little to say,

Tribute to those whose voices we no longer hear,

Tribute to those whose vision we still are privileged to see,

Tribute to those whose dreams are yet to be;

Death be not too loud,

Life's accomplishments demand be proud:

Remember, we remember, tears and laughter,

Friends and foes

Hugs in victory, surrender from those we oppose,

Remember, we remember, laughter and tears,

Cries and fears;

Remember, we remember, heroes and martyrs,

Deals and barter,

Remember, we remember, those who have gone before,

Remember, we remember, those who paved the way,

Remember, we remember, for those of us who stay,
Remember, we remember, for all our descendants who will be here one day.

Remember, we remember...
Remember, we remember...
We remember...we remember...
Remember...we remember...
Memories will stay,
It's up to all of us,
To make sure and say,
Memories will remain to energize each day,
Memories will keep the wolves at bay,
Memories will sustain our way.

No list will ever be complete
There will never be such a feat;
The deeds are not done
Many more tales have yet to be sung:

These tales we tell have begun,
Songs and poems and stories in all their glories
These tales we tell have begun,
I don't believe an ending will ever come.

(Steven E. Brown, 1994)

APPENDIX A:

Disability Culture Letter and Survey

DISABILITY CULTURE SURVEY

TO: Survey Participants
FROM: Steve Brown
DATE: June 14, 1994
SUBJECT: Filling out enclosed survey form

As many of you know, I received a one-year fellowship to "Investigate a Culture of Disability," from the National Institute on Disability Rehabilitation and Research (NIDRR) of the U.S. Department of Education. This fellowship began on October 1, 1993.

During the past nine months, I have talked with a great many people about disability culture; taped eight interviews with scholars, artists, and advocates; been a participant in several presentations about disability culture; and done much reading, listening, and watching about various aspects of disability culture.

One of my concerns about the short time remaining in the fellowship year is an inability to interview all of the people on my wish list. In fact, as the year has progressed the list itself has gotten longer and longer as I've met and heard about more people.

I'm hoping that you will be as excited as I am about the opportunity to participate in this study of disability culture and that the enclosed survey form will facilitate broader input in the eventual product of this fellowship year--probably a monograph.

Any format you prefer would be welcome--print, tape, disc, etc. A self-addressed stamped envelope is included for your convenience.

A return date of August 15, 1994 would be extremely helpful.

THANK YOU FOR YOUR TIME AND KNOWLEDGE!

DISABILITY CULTURE SURVEY
INTERVIEW QUESTIONS

1. What's your name? _____

2. What is your address? _____

3. What are your organizational affiliations, if any? _____

4. How old are you? _____

5. What's your disability? _____

6. What kind of education do you have? _____

7. In what ways has your disability impacted your life? _____

8. How did you get interested in disability issues?_____

9. What does disability culture mean to you?_____

10. Do you know of any examples of disability culture?_____

11. Do you believe disability culture will have a positive impact on people with disabilities? Why, or why not?_____

12. Please feel free to send a resume, items of disability culture which you know about, or to write anything else you would like about the idea of disability culture.

THANKS VERY MUCH!

APPENDIX B:

Survey Responses

1. Name--Number of Respondents: 20

2. Address: Confidential except by state:

California: 8

Colorado: 1

Georgia: 1

Kansas: 1

Maryland: 1

Massachusetts: 2

New Mexico: 1

New York: 1

Ohio: 1

Oklahoma: 1

Ontario, Canada 1

Texas: 1

3. What are your organizational affiliations, if any?

University of Southern California

California Association of the Physically Handicapped

Actors Equity Association

AFTRA

Screen Actors Guild
 Interguild of Performers with Disabilities
 National Organization of Women
 American Civil Liberties Union
 Mark Taper Forum Theatre
 State University of New York--Plattsburgh
 North County Center for Independent Living
 Mho & Mho Works
 RA Fessenden Fund Inc.
 Public Communicators
New Mobility
One Step Ahead
 ADAPT
 Let's Get Together
 Concrete Change
 Disability Action Center of Georgia
 Fulton County Commission on Disability Affairs
 Society for Disability Studies
 numerous professional organizations in aviation, business, journalism, and
 writing ADAPT
 Central Texas Legal Aid
 Coalition of Texans with Disabilities
 Society for Disability Studies
 Colorado Cross Disability Coalition
 Region VIII Cross Disability Network
 Community Resource Conference
 Independent Living Resources
 Center for Accessible Housing
 Adaptive Environments Center
 Boston Globe Foundation

Rehabilitation Advisory Council
Oklahoma Office of Handicapped Concerns
Total Independent Living Today
Institute on Disability Culture
Berkeley Planning Associates
Pacific Research & Training Alliance
Cosmos Club
Democratic Party
Episcopal Church
Pacific Disability and Business Accommodations Center
National Telecommunications Blue Ribbon Panel
Research and Training Center on Public Policy in Independent Living
California Commission on Aging
Research and Training Center on Aging
California Department of Aging
National Institute on Disability Rehabilitation and Research
National Council on Disability
Public Interest Center on Long Term Care
National Council on Independent Living
California Coalition for Independent Living
Media Access Office
Ohio State University Dept. of Social Psychology
Chicago Institute of Disability Research
Westside Center for Independent Living
Media Access Office
Society for Disability Studies
Association of Higher Education and Disability (AHEAD)
Massachusetts Coalition of Citizens with Disabilities
American Political Science Association
American Society for Public Administration

Association of Public Policy Management
 National Wheelchair Athletic Association
 National Organization of Women
 Metro Opera Guild
 University of Texas Alumni Association
 University of Rochester Alumni Association
 World Institute on Disability
 University of California at Los Angeles
 University of Southern California University Affiliated Programs
 McMaster University

4. How old are you?

55	47	39	60	43	57	36	44	34	47
47	31	61	45	24	55	60	28	81	48

5. What's your disability?

Post-polio
 Post-polio
 Fibromyalgia
 Polio
 C5-6 quadriplegic
 Artificial hip/part of femur, part of pelvis, diminished use of one wrist/hand/fingers
 SCI para t-12
 SCI (T-10)
 Blindness
 Peripatetic Quadraparetic (Spinal Cord) with aspirations to several others
 Wheelchair user

Lemzo-neuro Muscular Neuropathy (falls under Muscular Dystrophy Category)

Polio quadriplegic

CP

Arthrogryposis Multiplex congenita

MS

Post-polio paralysis--residual paralysis from polio

Dissociative Identity (Dis)order (aka Multiple Personality (dis)order)

6. What kind of education do you have?

B.A. Ph.D. B.A. M.A. Ph.D. B.A. M.Ed.

Ph.D. Ph.D. M.A. Basic (60s) Liberal Arts Psychology (with student of

Tim Leary's) & Religion with Director Southern Christian Leadership Conference, 2

unfinished Master's in American history, Education M.HR. Some college, no

formal degree MA MA (so-so) BA, in Ph.D. program

B.S. Ph.D. B.A. Ph.D. Ph.D.

7. In what ways has your disability impacted your life?

In every way

Jobs, art, sex

I hurt to some extent all the time--and I get extremely tired--this affects what I do when, how, and for how long (work, fun, cleaning, etc.)

Disability made it impossible to escape from both reality and fantasy provided opportunities/impetus for learning about what's important, diversity and inclusion

Mostly minor inconvenience--can't do many things I used to do using legs for heavy physical activities such as long distance running, mountain climbing, parachute jumping, etc, but maybe at mid-50s I should be slowing down

Every way, it is integral to who I am and how the world sees me

It has changed the way I think about things. It changed my career direction (I probably would have been a blue collar worker. I discovered that physically I couldn't do the things I wanted to do, so I decided to go on to further education. I am the first from my family to graduate from college.

Created opportunities & provided excuse for social engineering (?)

Gave me a sense of mission and a sore butt

It has changed the course of my life. I was raised in a small rural community in southern Missouri and planned to stay, but becoming disabled facilitated my leaving that community

Restricted my options; wanted to be a truck driver, clown in a circus as a child

Every conceivable way. It is an integral part--but just a part of who I am

Thousands of way in terms of activity level or various kinds of sports or recreational activities, writing, balance, walking, value systems, all kinds of values, in thousands of ways

Loaded question, of which I can't answer. I can say that finding the disability community has given me a place to belong and find who I am. My disability has caused me to search desperately for this community to belong, but afraid of being rejected for my other difference (race & gender)

After being diagnosed with multiple sclerosis in 1974, it took me several years to accept and understand the ramifications of being disabled. The world I grew up in had excluded and devalued disabled people. They were objects of pity and charity needing to be cured. In the years that followed my diagnosis, I was divorced and in search of a new career. I became aware that, though I was still the same person, people treated me differently. I also came up against social and employment barriers. When I began to learn about the stereotypes and stigma historically attached to disability, I got involved in what is being called the last civil rights movement. It became apparent that media coverage largely ignores our real issues.

Every way, in virtually every way, polio at 9, good and bad, improved my life; can't envision what life would have been like without disability.

Besides coloring all my thoughts, words, and actions for as long as I can remember? Hmmmmm... I have difficulty in varying degrees and at various times with the following: eating, sleeping, thinking, breathing, working, walking, talking, hearing, taking care of my personal needs, etc. My disability has made me more compassionate, more aware of the struggles other people face, and angry about injustice. (Have I answered your question?)

NA

Have been concerned since late 1960s about inequities in life circumstances for individuals with disabilities

8. How did you get interested in disability issues?

I've lived them

I worked at CIL Berkeley as editor of quarterly, The Independent

First as a medical sociologist, then personally--or, in a way all at the same time
I had no choice

Initially I became aware personally, was reminded during counseling sessions I facilitated but most importantly through an experience with public transit in 81-82;

I became disabled and was doing research on new ADA for a book I was writing

Trying to make my college (Harvard) accessible under 504, grew from there
through wheelchair sports & work

I received a scholarship from the local National Paraplegia Foundation (as it was called then). After graduating from junior college I became the president of the Hiawatha Valley Chapter of the NPF. At first, it was more of a social club--as many were back then (early 70's) We were not so politically active and astute (at least in the Midwest) then. It was a time of finding ourselves and bonding with others who could give support...perhaps an early peer support and we didn't even know we were doing it.

No longer a choice to ignore them

Life, as the man said, is what happens to you when you're busy making other plans

At the University of Oklahoma, in 1970, it was inaccessible, so I became

involved in organizing a student organization.

Moved to Berkeley, met other active crips

I was refused a Rhodes scholarship in '56 because of my disability

Living with it and meeting other people who are living with disability and seeing pluses and minuses, strengths and weaknesses, and the struggles and the barriers, the inequality

Through internship at Dole Foundation and direct mentoring from Paul Hearne, Jeanne Argoff, and Diedra (sic) Davis and Corbitt (sic) O'Toole

When moved to Boston, interested in American politics, campaigns, elections, tired of reading numerous indirect accounts--changed from policy process to output--others doing same, calling themselves policy analysts in transportation, politics, employment, disability was not mentioned--interested in people with disabilities individually and collectively--by 1978 focusing almost completely on disability issues; saw need of people with disabilities to organize, in 1976 became State Director for White House Conference on the Handicapped.

I'm not sure, really. I've always been interested in issues of difference. I think that once I found out about the disability movement and disability consciousness, it was natural for me to feel drawn to the issues. Once I came to terms with the idea of myself as a disabled person, my interest naturally became more personal and more intense.

I was commissioned as a clinical psychologist in World War II. Worked with people with developmental disabilities since 1951, as well as cerebral palsied, mentally ill, in hospitals, clinics, private practice.

Worked in a variety of communities with individuals with disabilities as a therapist, trying to support inclusion--often wasn't successful

9. What does disability culture mean to you?

A legacy of customs and value that represent the common experiences of disabled people

Creation of words controlled by disabled person--creation of work and voices that responds specifically to the psycho-social environment of the disability experience
an "ideal"--unless you live in a place like Berkeley, Boston, etc, I find it hard to imagine a disability culture--I define culture in a very "anthropological" way,

Pride, a feeling and beliefs not typical behavior

Not too much--perhaps a subculture/society of people who have disabilities

Has two related meanings: First it is the filter through which we people with disabilities experience the world (shared experiences, & thoughtfully developed concepts). 2nd our expression of ourselves in writing, words, art, etc. as well as organizations, etc.

D.C. means a sense of camaraderie, of knowing what it is like by my peers to be discriminated against, to share the sense of empowerment that my peers are also sharing. DC is also the movement and the leaders and the persona they radiate....leaders like Justin Dart, Ed Roberts, Judy Heumann, Lex Frieden, Marca Bristo, and Max Starkloff, plus many more.

Separation by choice, inclusion by choice, not by ?, unique experience

Disability culture to me is a movement culture, see Populist Movement

(Goodwyn)

Currently experiencing anger of culture--people are mean to each other--typical of people who have been oppressed and gained a little power--typical of IL movement now, ILs going through Directors quickly--part of people winning their rights and punishing people who have wronged you--disability culture is part of anger turned inward toward each other

Artists (visual and other) who have disabilities, knowing the history of various disabled folks, knowing how disabled people impacted on general history and specific movements, going to events that are attended by mostly disabled people, that are disability, positive, publications

By any definition of "culture" that I am aware of, the disabled are not a culture. A community of shared interests, perhaps. A minority in the civil rights sense, certainly. We have no common traditions, ceremonies, shared history, etc.

A different heritage, history, different kind of value system at times, attention to language attention to identity, valuing of peer support, valuing of diversity and difference and all kinds of things that I wrote about in that publication that you already got from ILRU

I must admit that because my experiences with disability crosses ethnic & gender and my mentor[s] are diverse, I'm so confused about how I feel about a "disability culture." When I think of culture, I can't help but to only think of my ethnic culture

To me disability culture is about elucidating, accepting, and celebrating that which makes us different: our different ways of coping, eating, shitting, making love, laughing, etc. It is what we share, and what we have to teach the rest of the world.

Creative expressions of people with disabilities. Raising public awareness of the contributions of creative arts to improving the quality of life of all people regardless of the type or severity of their disabilities.

For me culture and history are tied together

10. Do you know of any examples of disability culture?

Fast food--because it's difficult for many disabled people to get in and out of car or into restaurant or supermarket

maybe in some cities, but that's disability communities I think, not necessarily culture

difficult for me to separate pride and culture, culture implies a civilization, but environment (institutions, segregated schools and sheltered workshops) were created by nondisabled folks--pride is changing our view of ourselves and nondisabled people's response

I don't know

In England I understand the arts angle is more developed (Johnny Crescendo, Wanda Barbara--2 people (music, comedy). Anthropology-wise Zola (Irving from Brandeis is a good source. FDR & Nazi books by Hugh Gallagher good, Vicki Lewis's works, Paul Longmore)

There are numerous examples. There are even sub-disability cultures...the culture of the Deaf community is well known. I believe that wheelchair athletes are another sub culture...as are adapt members who exercise their civil rights rather than their muscles. Then there are the functionaries who basically meet and carry out business of relevance to veterans. There are those who are in the intelligentsia or are

interested in higher education issues and how we can bring people with disabilities into active involvement with the university community...Certainly the SDS folks have an impact of the latter sub culture. DC is kind of squishy...there are so many aspects to it (at least for me that is hard to get a hold of it)

Probably, one of the things I'm noticing is becoming a popularization of disability culture. We need always to be stretching the definition because it's in some ways self-defining. Many people seem to defining disability culture as art or artistic definition, but that's only a part of it. It's what a group of people have in common—traits or behavior that people have in common that's particular properties of being disabled. Could be artistic expression, but it's more intangible than that; in crip culture things start late, which is directly related to people's lifestyle eg having to use attendant care, public transportation, higher odds that something goes wrong in course of getting up and getting somewhere. This office opens at 10:00, not at 8:00 or 9:00 til 6:00 or 7:00. If someone says meeting is accessible and it starts at 7:30 am, it's not accessible. People with disabilities are expert problem-solvers. We're used to finding alternative ways of doing tasks, which transfers into issues that are not disability related. People can be very creative about getting a job done. That's a positive cultural aspect. How people communicate in a group of people with disabilities, group will stop if someone does not have access, if group is functioning well. Another one I notice in groups of blind people, especially, because communication is all verbal. Whole culture around public transportation and rejecting medical definitions. I think there's beginning to be one around civil rights, but most people with disabilities still define themselves medically. Culture around institutions and institutionalization; still good amount of institutionalize culture among people with disabilities that can be transferred to solidarity experience.

Tension between groups who want to assimilate and those who want to create something different. Art is easiest way for people to understand culture, but it's very limiting, but it creates excuses or reasons for people not to participate.

Roberta Flack did a song, "Go Down Moses," says something like "Black people, let Pharaoh go--all you got to do to let Pharaoh go is let Pharaoh go---say byyyyy--Pharaoh---

Yes, I do--individuals who are blind in this state have a culture that is pretty exclusive--because they spend a lot of time with each other and wield a lot of political control which is good and bad; IL culture in state being very angry with each other, but there is a culture; some endearing experiences like positive cross-disability training with storytelling, funny disability stories, bonded and had a good time as group of people; shared culture was not a goal, but shared because they were there together

Frida, Disability Rag, Cheryl Wade, ADAPT, SDS, Max Dashu, Bill Bruckner, my sister and I both in the same family

Class reunion is tons of examples of disability history and culture; commonality of experience in history, identity, and coping and on and on and on

Definitely our language and how we transform once negative terms into our own

Examples--canes, braces, wheelchairs; language, distinct terminology that we use and others don't know--deaf would be subculture--what we call ourselves; information and knowledge we share that gives different meaning than nondisabled have; amount of planning lives necessary is a cultural distinction

Sure, Neil Marcus, Axis Dis/Abled dance troupe, Artists for Recovery, wry crips, Cheryl Wade, Altered States of the Arts, the occasional WID brown bag lunch

Yes

Currently working in 3 areas, Canadian World War II veterans with disabilities,

Aging and Disability, Adults life experiences living in Ontario with intellectual disability

11. Do you believe disability culture will have a positive impact on people with disabilities? Why, or why not?

Yes, it will help to [develop] positive sense of identity based on disability, yes, reaffirms negated areas, creating energy

hmm--hard to say since I do not think a common culture exists yet--there are elements of one--"pockets"

I don't know

Some yes. We are in infancy of disability. Most folks don't buy into pride, etc. We will all need to grow long time to really reap benefits but w/o culture shift we become isolated and in-valid

Certainly. For the most part these sub cultures are reinforcing for PWD (people with disabilities) and allow for increased self-esteem and actualization. There are probably some sub cultures that are not positive (e.g. those with disabilities who are perpetual whiners). The National Federation of the Blind probably fits into this category.

Yes

Yes, once people affirm themselves as a group, we will also be affirmed as individuals

Sure, because it normalizes our existence, makes us less "other" & gives us

pride

I believe strongly we need much more study in history of disability, our role in society in different cultures, different times, etc.

Yes, I do feel it can, does, and will have a positive impact, but only if ILCs and other consumer groups live it and teach it and promote it and talk about it and explain what it is and explain why identity with the culture is important and explain how it helps people to function and survive, and cope well, and understand disability from a different perspective from the majority culture

Mixed--it will be negative if nonwhite pwd do not be well represented in the defining of disability culture--we run the risk of it being white disability culture

Yes, if we can get the word out.

Absolutely, consciousness-raising; everyone needs consciousness-raising; more that disability culture is discussed, studied, better for whole community, be more legitimate, could have negative impact--backlash

Oh of course! Because it's one of the best ways for us to get through our internalized hatred and learn to be accepting of ourselves and one another as we really are.

Yes, I have seen great positive changes in productivity, self-esteem, quality of expression in settings where the person's creativity is supported and promoted

Yes, using a historical framework it can provide a foundation for understanding and provide voices and stories where there has often been silence

12. Please feel free to send a resume, items of disability culture which you know about

or to write anything else you would like about the idea of disability culture.

A lot of BS is palmed off as disability culture. We need at once to be more inclusive and more selective. Some of the crap I read & hear...well, it's degrading to disability that this is considered worth notice. Yet too many of us are unaware of the concept of disability community/culture.

Tell Switzer to renew your fellowship & study it some more. It's too important.

I'd like to know if you've included any of the Psych Survivors/Ex-patients/Consumers art folks in any of this. They haven't really been thinking of themselves in terms of Disability Culture, but I think that [they] belong in there. Let me know if you want contact info for some of the groups, OK?

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