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Review of Disability Studies, Volume I, Issue 1, 2004

Preface

Tribute to David Pfeiffer
1934 – 2003

Professor David Pfeiffer passed away unexpectedly on December 17, 2003. An internationally recognized scholar in the field of disability studies, Pfeiffer, who used a wheelchair as a result of childhood polio, received a Ph.D. in Political Science from the University of Rochester in 1975. Pfeiffer retired in 1997 from Suffolk University in Boston, where he served as Chair of the Department of Public Management. He also initiated Suffolk's Disability Studies concentration in the MPA program.

In Hawai`i, Pfeiffer became Resident Scholar at the Center on Disability Studies, Visiting Scholar in the Department of Political Science, and affiliated with the School of Medicine. Pfeiffer published over 200 articles about disability studies, primarily in refereed journals. He also was a well-known advocate who spent the years from 1977 to 1980 as the Massachusetts State Director for the White House Conference on Handicapped Individuals. He was instrumental in the creation of the Massachusetts Office on Disability, organizing the Massachusetts Coalition of Citizens with Disabilities, and amending the state constitution to prohibit discrimination based on disability. Among his numerous other accomplishments, awards, and activities, he was a Past-President of the Society for Disability Studies and editor of Disability Studies Quarterly. In recognition of his combined excellence in the areas of research, teaching, and advocacy in disabilities, the American Public Health Association DisAbility Special Interest Group awarded Pfeiffer the Alan Meyers Award during its annual meeting in San Francisco in November 2003.

He also served as a mentor to many disability studies scholars and writers, as demonstrated in the many tributes that arrived after he passed on.

At the time of Pfeiffer's death, he was completing a book about disability theories and leading the effort to develop the *Review of Disability Studies (RDS)*. In recognition of his many contributions *RDS* will perpetually recognize him as Founding Editor.

He is survived by his wife, Barbara, of Hawaii, son Clifford, of Massachusetts and daughters Katherine Pfeiffer and Carol Messmore, her husband Peter, and their son, Peter, all residing in Florida.

Consistent with Dr. Pfeiffer's wishes and with the support of his family, anyone wishing to acknowledge his life-long accomplishments, may make a contribution to the Dr. David Pfeiffer Memorial Fund being established with the University of Hawai'i Foundation, Account #120-3263-4 (UAP) at the following address: University of Hawai'i Foundation, PO Box 11270, Honolulu, HI 96822-0270.

A Selection of Tributes to David Pfeiffer

"I and fellow Australians who knew David were saddened to learn of his recent passing. He was a giant among us in terms of his wisdom, energy, advocacy and plain common sense. Like many great people before him, his legacy will live on in our hearts and minds." Trevor Parmenter

"I first met David in 1982 when he and Irv Zola participated in an Office of Technology conference on mental health adaptation to physical disability. That year, I sat at the feet of these two plus Hugh Gallagher as they opened my eyes and heart with their powerful stories to the world of physical disability that I, as a mental health clinician, had never

known…Ten years ago, when David was Chair of the Public Management Department oat Suffolk…he was a leader in research, teaching and advocacy and developed a devoted group of students and associates…All of the above, though, misses the real David…He was such a warm, kind person. He was a lover of fine aged port and stimulating conversation. He was a mentor, a father to many, and a role model for us all. We missed him when he decided to go surfing in Hawaii. I miss him now that he is gone." Richard Beinecke

"[David] was a person who made a difference…I am thankful that the DisAbility Special Interest Group of APHA honored him with the Alan Meyers Memorial Award in November of this year for his scholarship, advocacy and teaching." Gloria Krahn

"I came to know David first and foremost through the eyes of his daughter, Carol, some 25 years ago when we lived in the same freshman dorm at George Washington University and became fast friends. I will never forget the love and pride she had for him or how she stared people down when he fell coming into the dorm rather than have them gush all over him. Somehow this thing they call disability pride never seemed as palpable as it did after seeing him through her eyes." Bob Williams

We at NIDRR were very sad to hear of the death of Dr. David Pfeiffer. Please accept our deepest sympathies. As a fellow Bostonian, I remember David from his days at Suffolk in Boson. He was a tireless worker to maximize the full inclusion, social integration, employment and independent living of individuals with disabilities of all ages." Richard Melia

"…I could tell [David] was a man of integrity. I would watch him at SDS conferences, intrigued by his big and strong presence and his confidence. I thought: here is a man who likes who he is…" Laureen Summers

"…Often I feel as if I am a voice in the wilderness. [David's] support meant a great deal to me…" Jim Overboe

"…[David] was kind and supportive. He encouraged me to join the field. He sent me articles on 5.25 floppy inch disks. We laughed at the time that perhaps we were the last ones using these disks and WordPerfect 5.0…I will miss him and his leadership. I regret that there will be no more lunch discussions with him. I mourn his passing and I salute him as a brother. Hail and farewell." Jim Ferris

"A smile and a hug and a raised fist for David, to all his friends, and to his wife Barbara. I'm sitting here in sad shock, full of memories of David and glad to have a place where they might land. We met in 1977 when he chaired the Massachusetts component of the White House Conference on handicap…He was the first chair of the Adaptive Environments board of directors in 1978. Many stories to tell from those early days…." Elaine Ostroff

"…David was a wonderful mentor to me in graduate school in Boston back in the 1990's, and for a couple of years I was privileged to assist him in teaching his Disability Studies courses at Suffolk University. I will never forget when David asked me in our first conversations if I would stutter, as I usually do, when I addressed his class at Suffolk. Braced to weather another job lost (ADA or no ADA), I answered in the affirmative. I was surprised and gladdened when David replied that it would be good for the students to hear me stutter. It would be important for them to realize that an individual with a speech impairment can communicate and explore complex thoughts and feelings in the classroom. I do quite a bit of teaching now, and occasionally I still look for support to the strength of David's firm conviction that people who stutter can successfully teach. Thank you David, for your splendid contribution to my life and to the lives of so many and for your great dedication to the field of Disability Studies. I hope that have been able to return your [dedication]." Miriam Hertz

"Sorry we did not get your message until Sunday [that the celebration of David's life had been postponed]. However, the gift given to us was

spectacular! Thank you, David. The weather was gorgeous. My daughter was delighted to play along the beach. We made birds from palm leaves as we chatted with a group of tourists from England. It has been years since I had watched a sunset. It did my soul wonders. I will always remember David this way." Richard Radtke

"David worked behind the scenes many times and I think many of us on the 'in' crowd don't appreciate his many accomplishments…I knew David because of his work here in Boston, where he spent most of his life. David, from Suffolk University, and Irv Zola , from Brandeis University, were two of the great disability philosophers here…In 1979 RSA $2,000 in end-of-year money…During those days consumer involvement was a radical concept…David was one of a dozen cross-disability leaders who planned a conference, funded by the $2,000, that founded the Massachusetts Coalition of Citizens with Disabilities. Dave continued to advice the organization for many years, in addition to his work with the Boston Self-Help Center (one of the first and best self-help organizations for people with disabilities)…He worked hard to create effective advocates to interface with government at all levels…

"David is best known for his work as the Chairperson of the Suffolk University Master's in Public Administration Program. He saw the valuable role that educated people can make on the inside, as well as the outside of government. He taught skills to people, with and without disabilities, that would make them better bureaucrats…I'm afraid that we've lost another vital philosopher and touchstone…The World War II generation is touted as 'America's greatest generation.' I think that to people with disabilities, the post-polio survivors of the 1940's and 1950's will be known as our greatest generation." John Nelson

A New Journal Is Born

David Pfeiffer, Ph.D.
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The need for a new journal for the field of disability studies has been declared for some time and from various perspectives. Without naming them there are only four journals which characterize themselves as being in the field of disability studies. There is one journal published in the United Kingdom which was very international, but over the last several years it has almost exclusively published articles written from the viewpoint of the social model, used qualitative methodology, and had a sociological orientation. There is a second journal published in the United Kingdom which was very international, but it was written from the viewpoint of medical rehabilitation, used narrow quantitative methodology, and had a medical orientation. It often publishes articles which downplay the role of people with disabilities. There is nothing wrong with these orientations (except for discounting the views of people with disabilities), but they are not the only ones.

Crossing the Atlantic there is a third journal published in the United States which was not very international, was written from the viewpoints of vocational rehabilitation and special education, and used various methodologies and orientations. It was short on articles using the disability paradigm. There is a fourth journal published in the United States which was moderately international and was open to various viewpoints and methodologies. It strongly endorsed the disability paradigm, welcomed younger scholars and non-academics, and attempted to be a forum for essays and poetry as well as research articles. It is presently undergoing a reorganization and it is too early to tell what its future may bring. Members of the governing board of the association which owns it often were dismayed at what they saw as a social science orientation of its articles. They called for articles to be published which showed a post-modern, humanist

orientation. There is nothing wrong with these orientations, but again they are not the only ones.

There are some journals which focus only on one disability or experience. They are narrow and usually are concerned with "best practices" and similar things. There also were a number of special symposiums concerned with disability studies published in journals which are identified with the traditional academic disciplines. Although these symposiums and forums were worthwhile, they were only occasional outbursts of disability studies scholarship and writing. In other words, the outlets for disability studies scholars is limited outside of the four journals just described.

Disability studies is a growing field. There are a number of approaches and orientations in the field. The existing journals do not provide enough opportunity for the established and the emergent scholars in the field. In addition they all fail in their intent to be international. In part it is because of the language of publication and in part it is because of problems of outreach. There is a need for a journal which attempts to be very international, welcomes all orientations, publishes anonymously refereed research, and is an outlet for writers who do not wish to take the time nor do they need anonymous refereeds endorsements.

The Center on Disability Studies, University of Hawaii at Manoa, is attempting to meet these needs by starting the publication of a new journal, *The Review of Disability Studies: An International Journal.* The new journal will contain peer reviewed research articles, essays, and bibliographies relating to the culture of disability and the experience of people with disabilities. It will also publish forums on disability topics brought together by forum editors of international stature. Poetry, short stories, creative essays, photographs, and artwork related to disability are also invited. Reviews of books, films, videos, art, music, and photographs relating to disability will be included.

These items will be reviewed to ensure a high standard of professional quality by an in-house and external editorial staff with the highest qualifica-

tions and reputation. If appropriate and specifically requested, a manuscript will be anonymously reviewed by two outside peer reviewers and this fact will be noted when it is published. There are many scholars who are in a tenure track position or who are applying for promotion who must have anonymously peer-reviewed publications. While we neither condone nor agree with the power struggles which this requirement represents and we do not concede that anonymous peer reviews guarantee quality, we do understand that many academics and non-academics as well exist in such a milieu. In any event, *The Review* will represent quality in all of its published writings.

The Review will be published on the Web and will be produced in a print version. The first two issues will be freely available on the Web, but a subscription is necessary to obtain printed copies. The charter subscription price is $50 US for individuals, $25 for students, and $100 US for libraries and institutions with a $15 US fee for postage outside of the US and Canada because it will be sent via air mail in order for it to arrive within a reasonable time. Student-subscription rates are available.

The Review is open to all perspectives, approaches, views, and paradigms relevant to the study and experience of disability. There will be no one view represented with one caveat. Any submission based on the functional, deficit view of disability will be questioned. The editors can conceive of an article written from this viewpoint which can make a contribution, but since the deficit view of disability causes prejudicial behavior and pejorative attitudes toward people with disabilities it will be carefully evaluated. Generally, such a perspective is not considered to be within the purvey of disability studies. In fact, it is considered to be the antithesis of the study of disability and people with disabilities. In addition, any inspirational story or writing will be considered outside of the field of disability studies because the deficit view is implicit in it.

There are a few journals which are read by persons working in the field of developmental disabilities, in the field of disability studies, and in the

field of gerontology. They each appear to have their own sphere of research and publication with many persons in gerontology even refusing to consider disability to be a legitimate concern beyond being a deficit which has to be dealt with. *The Review* will attempt to bridge this gap. The editors of *The Review* consider this gap to be an artificial and a non-productive one.

In addition there are few journals which are truly international in authorship, readership, and concerns. *The Review* will attempt to remedy this unfortunate situation.

There are few journals which publish material from authors who describe themselves as humanists with a post-modern perspective using a qualitative methodology and at the same time from authors who describe themselves as social scientists using a quantitative methodology. There are a number of scholars who bridge both these descriptions and they have a hard time finding an outlet. *The Review* welcomes both perspectives as well as humanists who use quantitative methods and social scientists who use qualitative methods. It is not the methodology used, but whether the appropriate methodology was used to draw conclusions.

The extensive experience, training, and publication record of the editors will guarantee that we will live up to these expectations. Our independence shields us from undue influence from any one perspective. Our integrity and professional dedication motivates us to accomplish our goal. We will be guided and counseled by our evaluators and referees and other staff. We extend a welcome to all of our readers and ask you to join us in achieving the goals of *The Review*. Feel free to contact us at <rds@cds.hawaii.edu> and to send manuscripts and other material to <submissions_rds@cds.hawaii.edu>. The guidelines for contributions as well as a submission form and a subscription form can be downloaded from <www.rds.hawaii.edu>.

Upcoming Forums

Editors Note: To inquire about submitting to the forums below, please contact the Guest Editors for each Forum individually. If you are interested in being a Guest Editor and have ideas for a Forum Topic, please contact the RDS Editors at submissions_rds@cds.hawaii.edu or Tel. 808-956-6166. General guidelines for Forum Editors are on the back cover of the Journal.

Spring, 2004: "Research on Postsecondary Education and Individuals with Disabilities"
Editor: Robert Stodden, stodden@hawaii.edu,
Tel. 808-956-9199

Summer, 2004: "On the Cutting Edge – Conference Papers"
Editor: Steve Brown, SBrown8912@aol.com,
Tel. 808-956-6166

Fall, 2004: "Infusing Disability Culture into Education"
Editor: Megan Conway, mconway@hawaii.edu,
Tel. 808-956-6166

Forum: Disability Culture – A Decade Of Change

Disability Culture: A Decade of Change

Steven E. Brown, Ph.D.
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Abstract: A reflection on the life of David Pfeiffer, why the Center on Disability Studies decided to begin this journal, and what we hope to achieve with it, leading into a forum about disability culture.

Key Words: David Pfeiffer, disability culture, *Review of Disability Studies*

This is a bittersweet forum for me. When a group of us at the Center on Disability Studies at the University of Hawaii at Manoa sat down together to plan this journal and this issue, David Pfeiffer led us.

We planned to follow David's leadership for a long time. Alas, that was not to be. David passed away suddenly in December 2003. We lost our leader.

Each of us feels David's loss in different ways. I'm still discovering ways I miss him. In the first days after his passing, I missed my friend. Someone who lived only a few miles from us and was easy to see whenever we could arrange it. I also missed my colleague. Someone who attended meetings sporadically in the past couple of years, and who credited our being here with permitting him to do that. And, we in turn, thanked David for bringing us to Hawaii. He invited us to present at a symposium in early 2002. We loved Hawaii and the people we met, and with encouragement, we moved here a few months later.

When David did attend meetings, he was zealous about it, bringing with him not only his passion, but a full agenda. I always wondered how our one or two hour meetings could be completed when I read what David had in mind for us to do—and knowing how talkative (and argumentative) we all could be. To my amazement, we somehow did it.

I'm not of David's generation. He was about twenty years older than I. He is the first person I heard talk about Franklin D. Roosevelt being a role model for him as a child who survived polio.

David, in turn, became a role model for many others. This became crystal clear in the days after his passing, when dozens of people shared memories and discussed how much they would miss him.

I recalled the first disability rights meeting I attended in the early 1980s when someone turned to me and talked about the need for "new blood" in the state's disability rights movement. I looked at him in astonishment and wondered what was I?

I'm no longer "new blood" or anything close to that. With David's passing it dawned on me that I have a responsibility to carry on his legacy of mentoring. I'd like to think I've done my share of guiding over the years, but as I age my thinking about mentoring has changed—and David has a lot to do with that.

While I prepared myself to write this introduction I realized something about my relationship with David. He was always enthusiastic about everything I ever wrote. I know from long conversations with him that he didn't always agree with me. Indeed, it's probably fair to say that we had some basic philosophical differences about life itself.

But we also shared a fundamental agreement about life as a person with a disability. We both knew that disability was a socially constructed identity. We also both knew that disability was not only external—we shared some internal physical manifestations of our different disabilities. We also both believed with a passion in the existence and efficacy of disability culture.

David, at least in his final couple of years, liked to think of himself as curmudgeonly. He called himself "mean" and a few other things that were

less than flattering. But the David I knew was one of the nicest, gentlest, and yet most passionate people I have ever met.

He was also one of the most honest. If you said something he disagreed with, he let you know. He didn't hesitate to speak up at meetings to confront someone. But he was also quite conscious of whom he challenged. If it was an older and respected scholar, he'd take you on vehemently. If you were a young student or emerging scholar, he'd try to be gentle, get his point across, and encourage you to continue your work.

It's a little less than a week, as I write, that David passed on. I've grieved each day. I thought about him most days as I went to sleep and as I woke. I turned on my computer and read email messages about David every day for a week. I'm fighting back tears as I write, not because I don't want to cry, but because I want to see the computer screen.

And yet… I don't wish only to mourn for the work my colleague had not completed. I don't want only to grieve for the friend I will no longer see. I desire also to celebrate.

I want to celebrate a life that made a difference to a lot of people all around the globe. I want to celebrate a life full of love and friendships. I want to celebrate a life lived with zest. I want to celebrate my friend. Which leads me back to the subject of this forum.

David was one of the first people to write about disability culture. When in the mid- to late-1980s this idea of disability culture began to jell with me, I started reading whatever I could that might relate to it.

I found two articles from the 1984 Conference of the Association on Handicapped Student Service Programs in Post-Secondary Education (AHSSPPE, now the Association on Higher Education and Disability, or AHEAD). The presenters were David Pfeiffer, then at Suffolk University and Andrea Schein, then of the University of Massa-

chusetts-Boston. Each asked, "Is There a Culture of Disability?" Their affirmative responses were published in the Association's *Proceedings*.

Years later I also read an article by Vic Finkelstein, of England after having fled South Africa, published about the same time as the AHSSPPE articles. Like David and Schein, Finkelstein argued for the existence of disability culture.

In the late 1980s, when I first approached my friends and colleagues about the concept of disability culture, I had yet to read any of these articles. I still don't know exactly where I formulated my initial ideas about disability culture, but as best I could reconstruct them while I wrote *Investigating a Culture of Disability*, I combined my background as a historian interested in reform movements with my reading of grassroots magazines like the *Disability Rag* (now the *Ragged Edge*). And as the three articles by Pfeiffer, Schein, and Finkelstein demonstrate the idea was in the air.

I tentatively approached a couple of meetings in the late 1980s and early 1990s to explore my ideas about disability culture. I received mixed, but always passionate, reactions. I knew I had touched some kind of core about what people believed and I plowed on.

During the 1990s I talked, wrote, and promoted disability culture in any way I could. I wanted to be clear about my own biases and always tried to be honest about them. In my 1997 review of the literature, "'Oh, don't you envy us our privileged lives?' a review of the disability culture movement," I wrote:

1) When discussing disability culture I focus on cross-disability culture, meaning a movement that crosses all disabilities and all cultural groups. I do not do this because I believe the meaning of disability culture is the same for everyone, but because I (and the discussion) have to start somewhere;

2) I write about disability culture primarily in the United States, because, once again, one has to start somewhere. There is a thriving, energetic, intellectual discussion of disability culture in England. One of these days I hope to experience it firsthand and write about it. The concept of disability culture has also excited people of every nationality that has encountered and discussed it;

3) I examine primarily a British—influenced middle class history and culture. The reason for this is endemic to American history. This background has permeated our national history, politics, culture, and most importantly, the people who have recorded it. It is in part a reaction to this characteristic of our academic settings that disciplines such as social and cultural history, ethnic studies, and women's studies developed. It is also one of the primary motivations for the development of disability studies. Discussions of disability culture from a non-British-based, non-middle class perspective are as needed as they are for other topics;

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

5) I am a white, middle class male and am writing from that perspective.

When we planned this journal, and this forum, we endeavored to address some of these biases. Perhaps the most important tendency we tried to avoid was being Anglocentric. We were not as successful as we would have liked. The primary reason for that was the deadline created for this issue. We worked with people from Japan, Korea, Spain, Malaysia, and the Micronesian island of Chuuk. None were able to contribute in the timeline discussed. We hope to hear from each of these countries in the future. We also welcome reader input and suggestions for writers, especially those with an international background.

We did have some success in broadening this forum. We include contributors from Canada and Germany. While most articles remain cross-disability ones, there is some emphasis on specific cultures, especially Deaf culture.

The articles in this forum reflect thriving disability cultures. We are lucky to have David Pfeiffer's final words about disability culture guiding us as we move into the future. *RDS* is also privileged to include Tony-award winning playwright, Mark Medoff, in our inaugural issue. His reflections about Hollywood and deafness will ring true to many of us who have not experienced the dizzying heights of fame he's achieved.

Perhaps the youngest of the contributors is Jillian Weise, a multi-talented artist, who's appeared in the pages of the *Atlantic*, as well as now gracing us with her observations about disability culture.

Ottmar Miles-Paul is recognized as one of the premier leaders of the German disability rights movement. We are fortunate he took time off from his busy advocacy and journalism schedule to introduce us to a German disability culture festival.

Academic scholars, Stephen Gilson and Elizabeth Depoy, explored the concept of disability culture from the vantage of people with disabilities who do not necessarily identify with a disability rights movement. Their conclusions will challenge us all.

Tanis Doe, like David Pfeiffer, is a thinker who possesses the rare ability to critique where she finds herself academically, movement wise, and culture wise. She has taken on the daunting task of trying to link Deaf and Disability cultures.

Last, I've tried to tie together some of my experiences as a proponent, writer and talker about disability culture for the past decade or so.

We hope that this forum will engage you, challenge you, and motivate you. Just like our friend and colleague, David Pfeiffer, always did.

Steven E. Brown, co-founder, Institute on Disability Culture, and Resident Scholar at the Center on Disability Studies at the University of Hawaii at Manoa earned a doctorate in history in 1981 at the University of Oklahoma. Brown's most recent publication, *Movie Stars and Sensuous Scars: Essays on the Journey from Disability Shame to Disability Pride* (People with Disabilities Press, 2003), joins dozens of articles and five previous monographs about disability, including *Independent Living: Theory and Practice* and *Freedom of Movement: Independent Living History and Philosophy*. Also an award-winning poet, Brown has published six books of poetry, including *Dragonflies In Paradise: An Activist's Partial Poetic Autobiography*; and *Pain, Plain--And Fancy Rappings: Poetry from the Disability Culture*.

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An Essay on the Beginnings of Disability Culture and Its Study

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Abstract: The formal study of disability culture began around 1985. Steven Brown, the editor of this Forum, was the pioneer. Of the many indicators of the existence of a culture the first article in the field emphasized artifacts and language. Out of sometimes heated discussions of disability culture emerged disability pride. The concept of disability culture is a vital and important one today for the disability movement.

Key Words: disability culture, disability pride, disability movement

Since before people with disabilities were recognized as something different there existed disability culture. There are many ways in which it could have started. Before speech was recognized and used for communication people used gesture and body language to communicate. People with hearing problems probably originated the first sign language even though today many persons who are deaf consider themselves to be part of the Deaf Community, that is, a linguistic minority who are not disabled. People with mobility problems developed means to get around. People with other disabilities developed what we would call assisted technology today, although it was not highly sophisticated at all.

The self-conscious study of disability culture, according to Steven E. Brown, the editor of this Forum on disability culture, began with an article published by the author of this essay, Pfeiffer (1985). It was a paper delivered at the 1984 conference of the Association on Handicapped Student Service Programs in Post Secondary Education, now known as the Association on Higher Education and Disability (AHEAD). Andrea Schein (1985) and I delivered identically titled papers raising the question of whether a culture of disability existed. The answer was affirmative.

In researching and writing that paper I discovered that there were many different definitions of the term culture, especially in the discipline of anthropology. The definitions ranged from identifiable music and literature to the existence of artifacts to behaviors which were supportive and related to the behaviors of others. There is no single definition of disability culture, but rather there are definitions. These definitions, while being distinct, have overlapping concepts.

In my original paper I emphasized artifacts and language. The artifacts consisted of things such as wheelchairs, crutches, brailed documents, hearing aids, stair lifts, and other things. Language consisted of sign language (although today I would respect the position of the Deaf Community that those of us not conversant with sign language are the ones with a disability), large sized print, signs like those indicating an accessible bathroom, slang and insider terms like survivor, and some professional jargon. There are publications, such as magazines, which are directed toward the disability community. There is music and there is poetry written by people with disabilities and for people with disabilities. There are performing arts groups composed entirely or almost entirely of people with disabilities.

There are pieces of written literature which are part of disability culture. While many persons in the Deaf Community would not agree that they belong here, there is sign language literature available on video. There are terms like crip, blinkie, and deafie which only persons with certain disabilities can use with legitimacy. There is also disability humor, but do not ask for examples right now.

The most influential work which not only discussed and analyzed disability culture, but also is a representation of it along with many pieces of literature it contains, is Steven E. Brown's final report as a Mary E. Switzer Distinguished Fellow of the National Institute on Disability and Rehabilitation Research for the academic year 1993-1994. (Brown, 1994) It is titled *Investigating a Culture of Disability* and is the place to start in order to

understand disability culture. Brown and his wife Lillian Gonzales Brown are the founders of the Institute on Disability Culture which was located in Las Cruces, New Mexico. They are both now associated (in various capacities) with the Center on Disability Studies, University of Hawaii at Manoa.

In his work *Investigating a Culture of Disability*, Brown presents a history of people with disabilities and their developing culture. He pays attention to the social situation of people with disabilities and other people's reactions. These reactions included oppression, institutionalism, paternalism, and asylums which gave way to ideas of rehabilitation, independence, rights, and the personal experiences of people with disabilities. He documents the fierce struggle within and outside of the Society for Disability Studies over the question of where or whether a culture of disability existed. Out of this milieu emerged disability pride and survival scenarios. He surveys disability culture as it existed in the 1990s.

Out of the sometimes heated discussion over disability culture there emerged three primary understandings of it. First, there are many people who equate disability culture with the arts which are by, for, and about disability. There is also, second, the contention by Jessica Scheer and others that no separate disability culture can exist because disability is vastly different from linguistic and ethnic identities. Instead, they argue, there is a shared consciousness by most people with disabilities which is a strong bond between them. And third there is the equating of disability culture with participation in the disability community. These three understandings dominate the discussion of disability culture at the start of the twenty first century.

No matter how it is approached and defined, disability culture is an extremely important concept for the disability community, the disability movement. It is that one thing which binds together many people with disabilities. It is that which sets us off from non-disabled people. It is at the core of our being. That is why *The Review of Disability Studies* chose to have a Forum on disability culture in its first issue.

David Pfeiffer was a Resident Scholar at the Center on Disability Studies at the University of Hawaii at Manoa. He had numerous publications in the field of disability studies and other policy areas. His received his Ph.D. from the University of Rochester and he was a wheelchair user. He was a past president of the Society for Disability Studies and long-time editor of the *Disability Studies Quarterly*. He was a founder of *The Review of Disability Studies*.

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Disability, Identity, and Cultural Diversity

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Abstract: Eighteen disabled individuals, nine with disabilities present at birth and nine with acquired disabilities participated in tape recorded interviews lasting between 60 and 90 minutes. For this study, disabilities present at birth were defined as those disabilities identified or diagnosed by the age 5 years; acquired disabilities were those disabilities that occur after an individual's 5th birthday. Life stages were identified as: Middle Childhood/Adolescence (ages 8 years through 17 years); Beginning Adulthood/Young Adulthood (age 18 years through 34 years); and, Middle Adulthood/Later Adulthood (age 35 years and older). The mixed method design relying on semi-structured interview and inductive analysis was used to answer the following research questions: (a) what are the nature and scope of disability cultural identity articulated by informants; (b) and what differences in disability cultural identity are related to informant age, condition and onset? Five themes emerged from the transcripts: fitting in; disability wisdom; it's just what you do; I can do it despite what you say; and disability talk as shared interest versus talk as boring. None of these themes revealed cross disability identity. Despite being unable to answer the initial research questions in the manner anticipated, the data analysis provided important and challenging knowledge and implications for further inquiry and practice.

Key Words: culture, identity, qualitative inquiry, disability theory

Introduction:

Until the disability movement was initiated in the early 1970s, individuals with disabilities were seen as medically or functionally disadvantaged. And for the most part, health and human service professionals were educated to understand disability as a long term to permanent result of pathology or injury. Consistent with the view of disability as pathology or anomaly, services for disabled adults typically focused on individual rehabilitation or adaptation of the environment to accommodate the disabling intrinsic condition. Since the 1970s however, alternative conceptualizations of disability have been advanced in the scholarly literature with legislation, policy, and habilitative and rehabilitative practices rhetorically reflecting these theoretical changes. The shift from disability as internal condition to human condition in which the disabling factor is a hostile social context has evolved and currently dominates much of the academic discourse within disability studies. Central to the social view of disability are the notions of disability culture and cultural identity, both which position disability within the political and discursive agendas of cultural diversity. Given the multiple definitions and perspectives on the meaning of disability, how disability is explained by those who are disabled, by providers, and by policy makers is critical in determining the nature of community supports, services, policy, legislation, and overall quality of life for individuals with disabilities. This study was initiated to examine the primacy and nature of disability cultural identity in a set of diverse informants with disabilities. The study was intended to position the discussion of disability within health and social service professional practice, education, and research not only as a medical condition or explanation but, as a social and cultural phenomenon positioned within diversity, civil rights, and marginalization discourses.

Literature Review

Historically, disability has been conceptualized, explained, and treated in numerous ways. There is no agreement in the literature regarding a clear definition or even taxonomic organization of disability theories. However, a synthesis of the literature on disability definition reveals commonalities that fall into four categories: disability as medical, social, political, and cultural. While these categories are not mutually exclusive, they each have an

important focus which influences how disabled individuals are perceived and responded to in their social contexts (Gilson & DePoy, 2002).

Disability as Medical

A medical approach to disability defines disability as a long term to permanent impediment and positions individuals with disabilities as less able than those who can recover from illness or who are non-disabled (Gilson &DePoy, 2002). As a form of biological determinism, the focus of disability in this definition is on physical, behavioral, psychological, cognitive, and sensory inadequacy and thus the problem to be addressed by disability services is situated within the disabled individual (Shakespeare, 1996). Interventions are designed to be curative, restorative, or adaptive. That is to say, services are aimed at curing the condition if possible, and if not, restoring function to the extent possible, and then adapting the environment to diminish the limitations imposed by the individual condition (Finkelstein, 1991; Gilson & DePoy; Quinn, 1998).

Disability as Social

In this broad perspective disability is viewed as a hostile environment in which social barriers limit community participation and civil rights of individuals with selected impairments (Hahn, 1993; Ravaud & Stiker, 2001; Swain, Finkelstein, French, & Oliver, 1993). Negative attitudes, limited physical access, limited access to communication and/or economic, political, or social resources and to the rights and privileges of a social group are considered as just some of the barriers that interfere with the impaired individual's potential to actualize his/her desired roles (Barnes & Mercer as cited in Barnes & Mercer, 1997). Thus impairment is seen as diversity of the human condition and disability is the imposition of purposive restrictions on those with impairments (Swain *et al.*). The focus of intervention from the social perspective shifts from

the individual to the social systems that create disabling circumstances.

Political Model of Disability

Closely aligned with the social model of disability but moving the focal emphasis into the domain of power and resources is the political model (Stone, 1986; 2002). In this view, the disabling factor is curtailment or withholding of the opportunity to earn or possess economic resources in part or in total from impaired individuals. The disability from the political vantage point therefore refers to the absence or limitation of resources to be exchanged for privilege in a global economic environment (Gilson & DePoy, 2002; Oliver, 1992; Scotch & Schriner, 1997).

Cultural Definition of Disability

Defining disability as culture transcends internal determinants of disability, subsumes social and political definitions, and creates a cultural discourse that characterizes the collective of disabled persons. Cultural views of disability suggest that all individuals who define themselves as disabled belong to a unique group that shares experiences, tacit rules, language, and discourse. In this view, the notion of disability is one of group belongingness and distinction from other groups who do not share the disability identity (Hahn, 1993). Within this definition, issues of race, class, gender, and power differential are important determinants of the shared experiences that bind disabled people together in a single, identifiable community of concern (Charlton, 1998; Linton, 1998). Furthermore, positioning disability within current multicultural discourse provides the disabled individual with a precedent and social action model enacted by other minority groups to counter discrimination. It is therefore not surprising that disabled activists are asserting disability identity as a construct that is or should be central to the lived experience of disabled individuals. While disability identity

has been examined, characterized, and described (Gill, 1997; Linton, 1998), the complexity of age, condition, and circumstances of onset have not been studied. Research building on current knowledge, and further informing theory, policy, professional education and practice is therefore needed to elucidate disability identity as it occurs in diverse individuals.

Method

A mixed method design relying on semi-structured interview and inductive analysis was used to answer the following research questions:

1. What are the nature and scope of disability cultural identity articulated by informants?

2. What differences in disability cultural identity are related to informant age, condition and onset?

Eighteen informants, ranging in age from 5 through 65, with diverse birth-based and acquired disabilities at corresponding life stages participated. Disabilities present at birth, for this study, were defined as those disabilities that are identified or diagnosed by the age 5. Acquired disabilities are those disabilities that occur after an individual's 5th birthday. Life stages were categorized as Middle Childhood/Adolescence (ages 8 years through 17 years); Beginning Adulthood/Young Adulthood (age 18 years through 34 years); and, Middle Adulthood/Later Adulthood (age 35 years and older). Table 1 presents the demographic and personal characteristics of the informants.

Announcements in multiple, accessible formats were distributed to community agencies serving children and adults with diverse disabilities. Informants and/or their families were asked to contact the interviewer to discuss the study. Informants were selected purposively to represent a range of ages and conditions, as well as gender and ethnic diversity. Following informed consent

from adults and assent from children, interviews were scheduled and conducted. Each interview lasted between one and two hours. Broad, open-ended questions were posed at the beginning of the interview and followed by semi-structured probe questions if the necessary data were not offered in open-ended responses. All interviews were audio-taped and transcribed verbatim with each line of text numbered. Thematic analysis was conducted with the intended purpose of providing categories for content analysis to examine differences in identity related to age and disability. However, content analysis was not performed because the data analysis did not yield clear categories relevant to these queries. To assure rigor, authenticity and trustworthiness, the analysis was completed independently by two investigators and then negotiated for meaning.

Findings

Five themes emerged from the transcripts. However, none revealed cross disability identity as discussed in the literature and thus we were unable to answer the initial research questions. Despite the lack of answers to the initial questions, the data analysis provided important and challenging knowledge and implications for further inquiry and practice. We present each of the themes below with exemplars from the transcripts.

Theme #1- Fitting In

Contrary to the construct of disability as separate from mainstream culture, informants discussed their desire for acceptance in non-disabled groups to a greater or lesser degree. Youth were particularly vocal about wanting to be "just like everyone else." For example, one informant stated, "I mean most people even like my self are just like normal, so everybody that are my friends are like just normal people because, I mean, I usually have friends that are normal people that don't have any disability at all."

Only two of the youth articulated their differences from non-disabled peers, and their affinity to others with disabilities. As one youth lamented, "My girlfriend told me that she thinks like when girls see me they don't really think of me as like a regular guy."

Another youth stated, "My disabled friends have more of an idea of where I am coming from when I talk about…"

In both adulthood groups, informants saw their disabilities as personal characteristics among many others. Three were active in disability organizations. Yet, none, regardless of their involvement with disability efforts and organizations articulated belongingness to a separate and distinct disability culture. To the contrary, one informant who used a wheelchair stated, "I mean people; people don't look at me like I have a disability."

Of particular note within this theme was the interaction between limitation and disability identity. Although not initially or necessarily desired, the strongest expression of disability identification among the informants emerged from unwanted negative experiences of isolation, discrimination, and exclusion.

The informant who stated, "So I have been just thumping along kind of glued, imprisoned in this room" strongly identified as a disabled man.

It is curious to note that with one exception, even those who perceived disability as primary to their lives and personal identities did not discuss disability identity as cultural pride. The exception was the informant who at the time of the interview was a professional studies graduate student who was reading scholarly works in disability studies, advocacy, and social justice.

"I think that I'm at a different place in identifying, I mean I've had more years in having identified, and very proudly so. But it certainly took me a long time to get to that point."

Common to all informants, regardless of age or disability pride, was the experience that acceptance of disabled individuals within non-disabled groups is a function of time and exposure necessary for comfort of all involved.

Theme #2-Disability Wisdom

The second theme that was commonly expressed by informants was the unique knowledge that comes from living with a disabling condition. While informants did not see disability as a distinct culture, many spoke about how living with non-typical conditions provoked unique learning. They believed that this learning would not have occurred without the disability. Not all saw this wisdom as desirable but many did. For example, one informant stated, "I am happy that this happened to me because it has made me a better person, and has made me a different person than I was. I don't know how long it would have taken me to get where I am today, and I don't consider myself financially successful. I haven't really achieved anything of great momentum to the public or to anybody but I feel that I have gained a lot inside and have become a better person and a greater person because of it. And I don't know if that ever would have happened if I hadn't been faced with the challenges that I have been faced with."

Theme #3-It's Just What You Do

This theme refers to the continuum of approaches that respondents discussed regarding the primacy of disability in their lives. On one extreme, the disability shaped the daily life and personal identity of the respondent. "Having friends is pretty much non-existent because I'm pretty much off the beaten path, all the friends I had were all back in [name of town], pre-injury. When we moved out here, my brother and his wife developed friends, but I didn't because there are no people around here like me so it is pretty difficult. These problems keep me around and confined to the house."

On the other extreme, tasks related to the disabling condition were simply seen as part of living and something that regardless of the nature of the challenge, all people face. For example, one informant stated, "What ever is gonna happen is gonna happen, I can't change that." Another said, "I deal with my disability when it is shoved in my face like when I have to do something in a practical way or I have to fill out some papers and then I get on with being just a human being."

No pattern related to age or nature of disability was found.

Theme #4-I Can Do It Despite What You Say

A strong theme, particularly in individuals who were not embittered by disability, was the notion that the disabling condition posed a challenge for "normalcy" of activity. Some informants were even motivated to perform highly competitive sports, work and so forth as a means to debunk the myth that disability is equivalent to inability. As one informant commented, "I have been determined for a long time to become a nurse and it is going to be a sight to be seen when I walk across the stage and get my diploma because I had to go through so much and I was determined to graduate."

In large part as a response to "a psychologist who said he was going to suggest to my parents that they put me into a nursing home or institution or something, which I would never do anything," one informant has set a career goal of public speaking and counseling disabled people.

Theme #5-Disability Talk As Shared Interest
Versus Talk As Boring

This theme refers to how informants perceived the topic of disability when it arose in conversation. Respondents described a continuum of responses to conversations about their conditions and disability in general. Some experienced discussions of conditions and resources as an opportunity to share feelings and information with other disabled

individuals or those concerned with disability issues while others felt that any reference to disability in conversation was a burdensome and boring topic. One informant expressed both perspectives. "But I don't talk to them [non-disabled individuals] as much about disability issues as I do with my disabled friends. Because I also don't want to make it the focus of my life and at times it has been the focus of my life, more so than I would care for it to be."

Illustrating the burden of disability conversations, one informant asserted, "you didn't want to hurt them, but what you really wanted to do was to kick their butt out the door."

Others described their conversation as non-disability focused, "we talk about girls and what the other guys are doing."

One informant noted that, "When I am around students with other disabilities, its student related, problems, questions, support. As a matter of fact I don't really know that any of us get that personal when we get together, at least not that I've seen. We may know basic things that we are married or not, age, what the disabilities are, but most of the time its student related issues."

On the other end of the continuum, is the phenomenon of disability conversation as special sharing as exemplified by the following quote, "You know I feel like I have more of a bond with people with disabilities or people with spinal cord injuries, there are just some things that are a part of me that I don't even share with [my husband], he wasn't there he doesn't even know what I went through. It's just like my own private little pocket of all kinds of stuff."

Sharing resources was also a component of disability conversation, as noted by one informant.

"With the disabled friends I can discuss things about my disability. Say, because the disabled friends and I have the exact same disability, we exchange things like how you deal with this thing

and how you handle that problem and that kind of thing. It is back and forth information."

In summary, the five themes that emerged from the data set depicted disability identity as a personal, individual characteristic that varied in its primacy, importance, and meaning to each informant. With the exception of one informant who was studying disability and social justice scholarship, none of the informants expressed an awareness of disability culture as described in the literature.

Conclusions

The initial questions that framed this study were founded on theory advanced in the disability studies literature regarding the existence and desirability of a culture of disability that included membership from individuals with diverse conditions and experiences. Theoretically, members of the disability culture are posited to be bound by the experience of oppression and marginalization and to share a common language, values, and political powerlessness. Moreover, membership, while restrictive in some sense, is asserted by some disability studies and health and social service professional scholars to be an important prerequisite for personal esteem, sense of community, and assertion of civil rights on the part of all individuals who identify as disabled regardless of medical condition. Therefore, we believed that it was important to uncover the interaction between personal characteristics, onset and nature of disability, and disability cultural identity as a means to promote what the disability literature deemed as positive and essential group belongingness. However, this data set revealed that disability identity is distinct from cultural identity. Informants illustrated significant diversity in their responses to their disabling conditions. Some saw the disability as an important personal characteristic that defined their lives, social interactions, daily activities, and future dreams while others did not. Some saw disability as creating wisdom, while others saw it as a negative, restrictive, and limiting learning experience. This study did not support the construct of a distinct culture of disability and thus questions regarding how disability identity is related to developmental phase, onset, and nature of disability could not be answered. The findings, while unexpected, raise important questions about the fit of the construct of culture with disability identity. The notion of disability as culture emerged from academic discourse and is discussed primarily among academics and students. It is interesting to note that the only informant who was conversant in the cultural discourse was a graduate student who was exposed to this body of literature. Thus, the cultural perspective of disability seems to be a public yet elite discussion among scholars, and carries with it the political aim of joining disability with other social movements in which power has been garnered through cultural distinction and positioning. Thus, the application of the construct of culture to disability identity may be a useful and purposive academic aim to replicate and exploit the success of ethnic cultures in obtaining civil rights and political recognition. The question of disability culture as transductive thinking is also raised by this set of transcripts. Transduction is the attribution of a label or category to a phenomenon based on only one or a few of many characteristics. For example, using transductive thinking, we might assert that people are dogs because both people and dogs have noses, eyes and ears and so forth. In transductive thinking, the commonalities are used to make comparisons but differences are not included in the reasoning. Applied to the disability literature, transductive thinking would suggest that the experiences of disabled individuals who as a result of their condition experience discrimination and exclusion are the characteristics that have been held in common with other minority groups. Therefore, the cultural paradigm which has been successfully applied to these ethnic and other marginalized minorities is assumed to fit disabled individuals based on this one essential characteristic. However, the findings of this study challenge that assumption. Because only one of the informants talked about a common identity with other disabled individuals, the degree to which the presence of a disabling condition is the criterion for membership in a cultural

group is open for challenge and future inquiry. Further, the diversity of conditions and contexts in which these conditions are experienced seemed to obfuscate a group identity or even a unique language among the informants in this study.

Implications

The findings of this study have important implications for disability theory, as well as professional practice, research, and education as well as for disability studies in general. Regarding disability theory, the findings of this study raise questions regarding the distinction between cultural and individual disability identity. Individual comfort with one's disabling condition and thus one's disability identity seem to be idiosyncratic, personal, and individual in nature in this informant group. One's level of acceptance of a disabling condition and the degree to which the condition is experienced as positive further seemed to provide a lens through which the fit between the disabled individual and other disabled as well as non-disabled groups was perceived. The cultural paradigm, while critical to policy, academic theorizing, and social justice concerns seemed not to be useful or even relevant to the identity of individuals in this study who have disabling conditions. Positioning disability identity as a part of human diversity may be a more accurate context in which to begin to understand how a disabling condition affects the individual in his/her view of self, life goals, and daily activity. Aligning disability with other oppressed cultures seems to provide a purposive and powerful model for the assertion of previously denied civil rights, but not to explain individual disability identity. A second and important implication of this study for research and practice is the recognition that the debate about defining disability as culture, social, political, or medical circumstance merges from the lack of distinction in the literature between description and explanation. Informants described their disabilities in terms of their activity and their limitations and some offered explanations for what they were able to do or not do. Analysis of the data suggests that disability can be best understood at

several levels and those descriptors of disability seem to lie in human activity. Medical, social, political, and cultural definitions lie in the domain of explanation and therefore are not necessarily competing. Rather, explanatory analysis provides analytic depth to descriptions of human activity. The need to advance theory and further investigation are therefore suggested by this study. For professional practice, research, and education, two important confounding positions that have characterized these domains provide the backdrop for the implications of the study. Many health and social service professions have a history of viewing individuals as unique while simultaneously legitimizing categories or groupings of specific disenfranchised and marginalized communities. How then do health and social service professionals make a determination of how to respond to disability? The study seems to support recent movement by some professions to replace identity politics with broad categories of diversity that apply to all individuals (Council on Social Work Education, 2001). Descriptive understandings of disability as another element of the diversity of human activity fit well with the contemporary views of some progressive professional thinking. Adding the explanatory dimension guides the direction for thinking and action about health and social service interventions. For example, disability as medical phenomena may provide the basis for clinical intervention with disabled individuals, while viewing disability through a cultural lens forms the foundation rationale for policy and environmental change strategies. This study, while unsuccessful in answering initial questions about disability identity and culture has advanced important knowledge that has the potential to advance conceptual clarity and inform professional practice and disability studies discourse. Further inquiry and theory building regarding the nature of disability as human activity are warranted in order for much of professional practice to approach disability from an informed, clear, and purposive perspective.

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On Deaf Ears: Disabled in Hollywood

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Abstract: A playwright/screenwriter reflects on two decades of pitching American Sign Language inflected stories at deaf Hollywood ears.

Key Words: Hollywood, Deaf, Solipsism

In *The Hands of Its Enemy*, the second bilingual (English and American Sign Language) play I wrote, there was a line I've used almost as a mantra: "The thing I love about the theater is the collaboration of separate spirits who share the responsibility of a play's fate."

Making theater bears the same power in my experience as playing sports and living within a family. As a model for the notion of the sum being greater than its constituent parts, making theater has been as illuminating to me about how to live in the world as playing on dozens of sports teams from the sixth grade into my fifties; as complex and ultimately satisfying as being part of families I was born to, married into, procreated and adopted.

In 1979, I met Phyllis Frelich, an actor who happens to be deaf and doesn't speak out loud. Since that year, she and her husband Bob Steinberg have been part of a team on which I play, a family in which I live.

I've written five plays now for Phyllis that incorporate English and American Sign Language. The first, *Children of a Lesser God*, changed our lives.

I know I could get the bright idea to adapt the nearest phone book into a stage piece for deaf and hearing actors and some theater somewhere would welcome me and my deaf and hearing buddies and we would have the joy and challenge of trying make that phone book live for an audience.

Film, though, is a different kettle of ears where my work with Phyllis, with the deaf, with American Sign Language is concerned.

In March 1988, for one week, there was an event at predominantly deaf Gallaudet University in Washington, DC, that came to be known as the Deaf Revolution, driven by a cry, signed, written, and spoken of "Deaf President Now!" In the year following that "revolution," Tony Award winner, Emmy nominee Phyllis, her designer-actor husband Bob, and I tried to sell an idea for a fiction set against the events at Gallaudet. A single sentence at one of our pitch meetings was indicative of a familiar way of thinking about "diversity" in America: We pitched our story concerning a deaf mother and daughter at cultural and generational odds; at the end of our carefully orchestrated narration, one of those ubiquitous children in Armani who have no discernable job in Hollywood studios but to over-populate meetings in studio chambers, said in his youthful wisdom, "But there's already been a deaf movie."

That sentence struck me, sadly, as both epigrammatic and epitaphic.

This was not the first time I had "pitched" a movie idea in Hollywood that involved Phyllis at the center. Our favorite encounter involved a pitch at Warner Bros. back in the early 80s. We were running on the notoriety of the success of *Children of a Lesser God* in New York, a Tony for Phyllis, a Tony for me.

The idea we presented went like this: Phyllis's character has been in a mental institution since she was very young. She has no history and no language other than the combination of incomprehensible speech and gesture that she's invented for herself. A lawyer is in trouble with some of the nasty people he's been keeping out of jail and has himself committed to the same facility to hide out. Phyllis immediately attaches herself to the most interesting new person in her world. She plays cards with him. She has an amazing visual memory and always wins. The mob finds the lawyer and he is able to escape but only with Phyllis's help (she knows where the Thorazine is kept and disables his pursuers) and they end up on the run together, the definitive innocent with a reluctant teacher who in turn is taught. We sketched a lot of fun doing all her "firsts": first restaurant, first motel, first airplane, first love, first kiss…We find out that Phyllis' father is a major mobster who had her put away because of something she witnessed. Phyllis and her lawyer companion wind up in Vegas; using her visual memory and card playing skills, she and her lawyer partner/love interest break the bank at her father's casino.

The standard "pitch meeting" in Hollywood has the writer narrating and/or acting out the story in a very compressed 10-15 minute stand-up (or leaning-forward) routine. Our plan was that I would pitch the basic three act structure of the movie with Bob interpreting for Phyllis; then Phyllis would take over with Bob interpreting for the listeners while she signed. At a pre-planned point, Bob would stop interpreting and Phyllis would go it alone, in silence, using ASL, so that the studio folks would get an idea of what a brilliant mimic and comedienne she is, with or without the standard compensation for her deafness in a hearing world.

When the moment came for Phyllis to go solo, she rose, she moved, she signed, she used conceptual gesture and the sort of inarticulate but comprehensible (we thought) noises indigenous to her character.

Phyllis, Bob, nor I will ever forget the looks of abject confusion on the faces of the president of Warner Bros. and his Armani Army as Phyllis played out some of the scenes for them. They shriveled in discomfort and were mightily relieved when we finished. And left.

If the story we pitched seems reminiscent of a movie called *Rain Man*, we have, for years, thought so too. Plagiarism, though, can only exist if its opposite exists, and in Hollywood there is no such thing as plagiarism because there is no such thing as originality; everything is in the air for any-

one to breath and exhale back into the atmosphere, naming carbon monoxide fresh air.

In the most basic way, those "normal" executives, those arbiters of cultural taste, were discomfited by the alien, "disabled" person in the room. And though it may be only me, that discomfort seemed but a step away from contempt.

In the mid-90s sometime, Disney wanted to talk to me about doing the story of the Gallaudet revolution, a more or less historical two-hour movie. I didn't want to do that. I had learned the hard way that dealing with living subjects was a nightmare. Though I knew I was supposed to create an "artistic distance" between me and them, that I would need to embellish, abridge, even alter their stories for dramatic purposes, I inevitably felt responsible for the basic verity of their lives, the sanctity of their secrets, and grew to hate the inevitable disparate needs between the producing organization and the subject. An example: I was signed to write about a famous football coach once. When I turned in the first draft, a TV executive noted that the subject seemed awfully pristine, even noble. I was asked, "Didn't he ever cheat on his wife?" I said I certainly had no evidence of that. The TV executive suggested I *invent* an affair for the coach. I noted that we were dealing with a *real person*, still alive, not a creation of my imagination, and that to make up a hurtful event like the executive was suggesting was perfidious and egregious.

At that point in my TV/movie life, I was stunned by the suggestion. Though I think I wrote a good script about that football coach, the script is moldering on a network shelf somewhere. I had a similar experience with a script about a famous Russian dissident whose wife spent over a decade trying to get him released from a Soviet prison. The wife really didn't want a movie made about her and her husband's experiences. She wanted to live her life with her husband and her children quietly, even anonymously. Whereas he was very forthcoming, she was not. The head of a major Hollywood studio asked me if I thought she'd had any affairs during that decade-plus. I replied that

I had only heard rumors I could not substantiate. In truth, it wasn't that I couldn't substantiate the rumors, but that I wasn't going to try. Another moldering script.

As a screenwriter, I became pretty unshockable by the shifting moral ground in Hollywood. I knew that in the inner sanctum of film and TV "creative development," there was not only a modicum of creativity but there was a profound dearth of moral conviction – *unless a particular moral stance was pragmatic,* pragmatic being synonymous with: 1) Does it work for the story? 2) Will it sell tickets? I was ever reminded of the old saw that goes: "It's not called Show Art, it's called Show Business."

I should not have been surprised, really, to learn that Hollywood has some highly refined and peculiar views of the disabled, as well as foreign languages.

My memory of films made in Hollywood during my childhood is that all Germans had one clichéd Germanic accent, regardless of class or region; same with the Russians; and everyone else from Europe had a British accent. Asians were modeled on the now infamous Charlie Chan accent. No one, to my memory, was ever from a Scandinavian country. All Native Americans sounded like Tonto. Everyone from Latin America, Central America, Cuba, and Mexico sounded like Eli Wallach who, I think, played every person of Spanish descent with some hybridized Spanish-New York accent from around 1950 to the recent present when, amazingly enough, many Latin roles began to be played by people of Latin heritage (though we haven't reached the point where any distinction is made among those of Brazilian extraction, who speak Portuguese, Castilians, Basques, or Argentines who emigrated from Nazi Germany. The etymology of the name holds force, however; if it sounds Latin, it's good.

Phyllis, Bob, and I had another story we wanted to tell, one about a group from a deaf school in New Mexico trying to *get to* the revolution of 1988 at Gallaudet in a stolen school van. Lo and behold, Disney bought the pitch and moved ahead with us

until somebody realized The Mouse was developing a movie intended to have *real deaf people in it* and that sub-titles were integral to what I was planning to write and shoot. Two common errors hearing people make about the deaf are 1) all deaf people are fabulous lip readers (when in fact the best lip readers only get a modest percentage of what people say) and 2) most deaf people can learn to speak so that hearing people can understand them (a large percentage of deaf people do not speak, period, and many *choose* not to speak).

We were informed that Disney didn't want sub-titles. We explained there was no way, given the proximity of the camera to the actors that we could do a viable story with a cast that was at least half deaf without asking the audience to read sub-titles at least some of the time. Disney was adamant; they could – or would – not do a Sunday night movie that required children to read or that their parents would have to read to them.

It didn't take Phyllis, Bob, and me long to conclude that what Disney wanted was a deaf story *without deaf people in it.*

The project died at Disney but became a play called ROAD TO A REVOLUTION, commissioned by Deaf West Theater. As with the phone book reference earlier, we had the joy and challenge of working on the idea and putting it in front of an audience.

I did a movie called *Clara's Heart* back in the late 80s, starring Whoopi Goldberg, an extremely nice lady and a terrific comedienne though not a trained dramatic actor. The producer, director and I very much wanted Alfre Woodard for the role. The studio involved made it clear though that the movie would only get made if Whoopi would do it. The inference was that, in studio-think, there was only one African American actress in the world and, in order to do movies with African Americans at the center, she would have to do all of them. Sidney Poitier had earlier born the mantle of *The* African American Actor. Eddie Murphy got it for a while. Denzel Washington and Halle Berry share it now.

For several years, Marlee Matlin, currently *The* Deaf Actor for Hollywood, and I tried to sell a remake of *Johnny Belinda*, a story about a deaf woman which has been twice made with hearing actors. Those were funny movies, largely because the hearing actors playing the deaf character had *no clue* how to convincingly pretend to be someone and something they weren't.

For all of Marlee's popularity, we weren't able to set that project up. On the face of the rejection was reasoning that had to do with lack of interest in redoing something that had already been done, however ineptly.

I did win one notable battle in Hollywood with one of my plays that involved a deaf character. When I sold the film rights to *Children of a Lesser God*, I asked for assurances that the central deaf character, Sarah Norman, would be played by a deaf actor. I was assured the actor would be deaf. Within a matter of days after signing away the rights, I was asked whether I preferred Goldie Hawn or Meryl Streep for the role.

The only real power a writer has in film is that which he can exert through the people who have the power – studios heads, producers, directors. Over the course of several years, I was finally able to exact a promise from the people with the power that using a hearing actor in a role made notable by a deaf actor would not only be unfair, but would cause a backlash of considerable size from the millions of deaf and hard of hearing people around the world the powers that be would like to come see their movie.

There have been several movies that have dealt powerfully with motor disabilities: *Born on the Fourth of July, Coming Home, The Waterdance.*

Mostly, though, Hollywood salves its conscience where the disabled are concerned by periodically making TV or feature films about what can be called "The Hollywood Retarded Person," whether the person -- usually male -- is technically retarded or not. Nice mentally defective people, entertaining, and ultimately, grandly sentimental-

ized. And in some amazing synchronicity, along with their looks of Edenic innocence, each Hollywood Retarded Person always wear pants that are just *slightly too short*. This is a signal that none of them has bought a pair of pants since he was 12, right before the final growth spurt, and that more importantly, no one has thought to update his wardrobe since. In recent years, Dustin Hoffman, Tom Hanks, Kevin Bacon, William H. Macy, Billy Bob Thornton, and most recently, Cuba Gooding, Jr., fine actors all, have stooped to a variation of the short pant retarded guy, reaping accolades as each salved our guilt with the balm of righteousness in this time of under-representation of any real variety of stories of persons with disabilities.

Giving Oscars to people who play Hollywood Retarded Persons – Hoffman, Hanks – makes me wonder at the legitimacy of Marlee Matlin's Oscar for *Children of a Lesser God*. Was it compulsory that she win to ease consciences in a flick that would soon be described to me as "But there's already been a deaf movie"? Did the mass of Academy voters pretend Marlee was a real and valid actor because most of the voters knew in their cool business hearts there would only be another analogous opportunity for a deaf actor over their dead bodies?

I can't say I ever forget that my friend Phyllis is deaf. Neither do I ever forget that she's the best actor I've ever been privileged to work with.

After the success of *Children of a Lesser God*, it seems I was *always* called to gauge my interest in writing the plethora of so-called "Disease of the Week Movies" in the 80s. I worked on one feature about a blind woman (who would no doubt have been played by a sighted actor) and another about a young man with cerebral palsy who, with his father, started and finished the Ironman in Hawaii (same as above). I turn those offers down now, as much because the view of those with the money to make the movies is hackneyed as because I no longer hope that any great effort will be made to populate the movies with disabled actors.

It's good to see Marlee on *West Wing* with some regularity; it's terrific that Deanne Bray has her own show on *Sue Thomas, Private Eye*.

It would be great to see a new version of *Ironside* with a disabled actor in that wheelchair. But show business is largely not disability-accessible. Unless you're wearing an iron lung, don't hold your breath.

Mark Medoff won a Tony Award for *Children of a Lesser God*. He is currently Reynolds Eminent Scholar at Florida State University and recently directed the feature film *Children On Their Birthdays*.

"I'll Pick You Up By Your Back Brace and Throw You Like a Suitcase": On Naming Discrimination Against Disability

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Abstract: What word is there for discrimination practiced against disability? In the following essay, I will explore—through personal narrative—incidents of discrimination in the academic, non-academic, and reader-text environments. Then I will discuss the various meanings of the word *ableist* and the importance of placing a name for discrimination against disability in the public domain.

Key Words: Disability, Discrimination, Ableist/Ableism

"What is politically correct these days?" a visiting poet said during a workshop class at the University of North Carolina at Greensboro. We were discussing a poem in which a deaf and physically challenged boy enlightens the speaker during church. "Is it disabled? Malformed?" he asked the class.

No one answered.

I bent my head down and pretended to focus on the language of the poem. I bent my head down because I have bangs for hiding my eyes. I wanted the bangs to hide my eyes because his words named me—the disabled, the malformed. Me, with prosthetic leg and metal rods along my spine. Had he not read my own poem included in the workshop packet? Had he not even read the title, "Crip Language"? The title alone should have informed him of his audience. Did he not notice that I carried a blue and pink plastic seat into class? Did he not notice that I used this child's device to sit on so I would be tall enough to see over the table? And even if he didn't read or notice any of these things, was he really going to critique the poem using discriminatory, offensive language?

"Is it deficient? Incapacitated?" he said.

"I think the boy's deficiency..." another student adopted his language to continue discussing the poem.

"There's a Professor at Princeton University, many people think this is very controversial, even fascist," he said. "Professor Singer says that if we kill defective animals, why don't we kill defective babies?"

I did not cry. I did not cry. A list of options ran through my head. I could stand up and walk out. But if I walked out, how would I explain myself? What word could I use to describe the visiting Professor's choices during class? Was there a word for discrimination against disability? What was the word? I could raise my hand and ask him to refrain from making discriminatory remarks. But he was the visiting poet. What did I know? I couldn't even find the word to describe his language. I felt voiceless and trapped.

When it was time to discuss my poem, I said, "I'd rather not."

"But I didn't have a chance to write much on your poem, so I'd really like to talk about it," he said.

"No thanks," I said.

His comments continued to reverberate in my head as class ended, as I drove home, as I type this sentence. If his comments had been aimed at African Americans, and if I were a member of that minority group, then I would have redress through the NAACP. For the sake of conjecture and analogy, let us consider the same conversation using racist language. The only word I will change in this analogy is the second use of "defective." What if the visiting Professor had said, "If we kill defective animals, why don't we kill black babies?" Or what if he had said, "If we kill defective animals, why don't we kill female babies?" If he had made either of these remarks without placing Professor Singer's comment in context, we would label him as racist or sexist.

Let us also consider his question of "What is politically correct these days?" If he had been discussing the politically correct word for African Americans, he may have said, "Is it African Americans? Blacks? Niggers?" We would call him racist. We may even write the NAACP and ask for a public apology, a withdrawal of his tenure. After all, we do not want racism infiltrating the minds of our youth through a reputable Professor, do we? However, if the Professor is discriminating against disability, then his comments are validated because none of us can name what offense, if any, he has committed. If he had made offensive comments toward African Americans or women, then at least a word exists for describing his language and therefore, his offense. We would at least have the power of words like *racist*, *sexist*. Without a word for discrimination against disability, we are powerless.

Here is another incident that illustrates how discrimination against disability occurs outside the academic setting and how this discrimination receives the support of the public.

The public, in this case, was an audience of approximately one hundred people attending a singer-songwriter event at Ace's Basement in Greensboro, North Carolina. The audience consisted of teenagers, college students, and a few business professionals. The venue smelled of cigarette smoke and cheap beer. The main act began setting up their equipment. During sound check, the guitarist spoke into a microphone, yelling this remark to someone in the audience.

"I will pick you up by your back brace and throw you like a suitcase. I'm going to do you like Christopher Reeves [sic], take that straw and blow you on out of here..." he said.

The audience cheered and clapped.

Once again, I felt suffocated by the public approval given to discriminatory declarations. The guitarist's evocative threat, "throw you like a suitcase," reminded me of how other minorities have been treated when sharing space with the public. I thought of segregation. Surely today, we would

not overhear a white person say to a black person, "I will throw you out of here like a suitcase." But, in the unfortunate situation where we would overhear this, we have in our consciousness a word: racism. We have a tool for defining and defending: language.

Even though the incident occurred in a less reputable setting, in a bar, at a concert—what does the guitarist's comment and the audience's response say about the state of discriminating against disability in today's society? I argue that the incident described says, "Vocalized prejudice against disability is okay."

So far, the incidents I address have occurred in an academic setting and in a non-academic setting. But we do not have to travel to an event to see discriminatory language in action. If we are to evaluate discrimination against disability, perhaps we should begin with the Bible's punishment of lepers or Shakespeare's treatment of *Caliban*. However, we do not need to search older texts for this treatment of disability. It is pervasive in contemporary literature. The third incident I will describe occurs between reader and text.

There are multiple challenges to taking these excerpts and showing them as examples of discrimination. The excerpts will be out of context. I will commit the same act as the visiting poet who placed Professor Singer's philosophy out of context. Since I am only offended by sentences that use discriminatory language, I will illustrate those sentences. But in doing this, I will neglect to assess the work as a whole. Also, what would happen if there were guidelines to what a person could and couldn't write? I am not advising that these words should not have been written. I am not arguing for boundaries on what a person writes. I am asking for a language, for words, to describe the characters views in these texts, the guitarist's comments to the audience, and the professor's discussion of a poem.

While reading *Open City*, a journal of literature and art funded by the National Endowment for the Arts (NEA) and New York State Council on the Arts (NYSCA), I encountered the following

passage in Saïd Sayrafiezadeh's short story, "My Mother and the Stranger." The main character in Sayrafiezadeh's story discusses their "own anti-Semitic associations" which they admit they are in "great possession of."[1]

> "I have always asserted that my mother's Jewishness is why I have found her so ugly my entire life, and why as her offspring I have often found myself to be so ugly. It is certainly helped by the fact that my mother does not have her hair done… does not date men ever, does not have sex with men ever, does not exhibit any sexuality… And the one time she wore a skirt I was confused and made vaguely uncomfortable by the sight of her calves and thighs in stockings, uncomfortable in the way one is when one watches a handicapped person attempting to dance, for instance. It is a painful attempt."[2]

I found it difficult to continue reading the short story. I flinched. I put the text down. The author writes about a character's awareness of anti-Semitic views. However, Sayrafiezadeh does not write about the character's awareness of their discrimination against disability. Yet clearly, a character who thinks "it is a painful attempt" to watch a "handicapped person" dance is discriminating.

Since I could not initially continue reading the text, I called a Jewish colleague to discover her reaction to the text. She was not offended.

"Why is it that you are more offended by disability than I am about the anti-Semitic comment?" she said.

"I don't know," I said. I knew that the text had proven unreadable for me. I knew that if the short story had come from the literary canon, it would have been easier to think of the character's views as arcane and no longer acceptable. But since the story was contemporary, and since it so blatantly ostracized the "handicapped" from the nondisabled, I was offended.

"I think it's because I've been brought up studying and talking about Judaism and anti-Semitism. But for you, it's not something that's been talked about. It's not something that people discuss."

"What do you mean?"

"Well, I can place what you read over there. I can think, 'Okay, this person is this type of person who thinks these things.' I can be more objective about it. I don't like it but it doesn't upset me to my core," she said.

After speaking with her, I returned to reading *Open City*. My experience as a reader was about to get worse.

Mark Jude Poirier's short story, "Happy Pills," is written in second person which makes the following sentences even more disturbing to read.

"You have every reason to be afraid of Thelma. She is retarded and smells like your grandmother, like cigarette smoke and cleaning fluid. Her eyes are crazy; there is nothing behind them."[3]

Since the reader does not have the mask of a character, the reader must adopt the views of the second person, or at least enter the contract of believing for as many pages as the story continues. Therefore, "you" discriminate against mental impediment. "You" reduce the "retarded" girl to a corpse: "There is nothing behind them [her eyes]."

Poirier's second person further exploits disability by describing a rumored rape scene involving Thelma in which older boys "poked her pussy with a stick."[4] At this point, I am numb. I continue reading to find out how much more offensive it can possibly be.

"You walk into Sam Goody Music and you're greeted by a robotic voice: *Welcome to Sam Goody*. The source of the welcome is a deformed woman awkwardly perched in a wheelchair…You don't look closely at her. You can't… People will assume

that Sam Goody is a charitable company for employing the handicapped."[5]

The name of the music store places the anecdote in a realistic setting. We recognize Sam Goody and since we are directly addressed—we are the "you," we are the main character—the views expressed in "Happy Pills" are projected as our views. When Poirier writes, "You don't look closely at her. You can't," it is the reader directly who observes this need to look away from disability. Also, the reader views Sam Goody as a "charitable company." This implies that employing the disabled is an act of charity rather than a person working a job like anyone else.

"In a cab ride, 'you' think of what to say to the driver.

"Tell him about the long-haired kid outside a T station in Boston, blasting White Snake on a boom box, playing air-guitar with a fucked-up arm. And speaking of fucked up arms: that beggar kid in the bus station in Quito."[6]

The excerpts from these short stories are from nondisabled perspectives. Lennard J. Davis describes the conflict that arises when a character in a work of literature is disabled. He writes, "The disabled character is never of importance to himself or herself. Rather, the character is placed in the narrative 'for' the nondisabled characters—to help them develop sympathy, empathy, or as a counterbalance to some issue in the life of the 'normal' character."[7] In "Happy Pills," the disabled characters "counterbalance" the narrator's tension with his wife who has chosen to abort a deformed fetus.

Regardless of the 'normal' narrator's life issues, the words "fucked up arms" are offensive for a disabled reader. For an amputee, these words pierce. It would not be as offensive if I had a language with which to describe this text. If I could name, discuss, and talk about the text, using words to address the discrimination, then I may even appreciate it. "The notion of giving something a name is the vastest generative idea that ever was conceived," writes Susanne K. Langer.[8] By naming, we men-

tally classify and sort or, as my Jewish colleague says, we can begin to think, "This person is this type of person who thinks these things." Whether the thoughts are racist, sexist, or discrimination against disability, by naming those thoughts we generate an idea of the person or text. Ann Berthoff describes the process of naming when she writes, "our instruments are the names by which we differentiate; with those differentiations, those sortings, we weave the fabric of discourse."[9] Without coming to a consensus that extends beyond the arena of disabled individuals and disability studies scholars, we allow for a void in public discourse of disability.

When researching the word for discrimination against disability, a colleague told me the word already exists. How did she know the word? One of her friends, a disabled female, used ableist to refer to a person who privileged the able-body over the disabled body. Paul K. Longmore uses this word and has given the acronym U.S.A. an alternative meaning—the United States of Ableists. Disability studies texts use the word ableist to mean a variety of different things from society's negative views about disability to discrimination against the disabled. Davis likens ableism to "better known terms like *racism* or *sexism*."[10] The word ableist has a substantial history in disability studies. However, one quick search via the online edition of the Oxford English Dictionary turns up zero entries for ableist. The word is not in Merriam-Webster or Cambridge's dictionary. If ableist has been adopted by the disabled, and scholars in the field of disability studies, but it has not been adopted by dictionaries, what does this say about the public consciousness of the word ableist? How are we to become empowered by a word that has no public awareness?

As cited, the word ableist is used by people encountering its implications or by people in its field of study. If ableist is not recognized by the general public, what does that say about our awareness of discrimination against disability? When I surveyed my non-disabled colleagues and friends, not only did they not know the word ableist, but when I

said the word aloud, they could not infer its meaning. What is ableist? Would it not make sense to be an ableist if the word means a person who prefers able-bodiedness over disability? No one wants to be disabled. Perhaps this is why non-disabled people become uncomfortable discussing disability. Rosemary Garland Thomson discusses how we are both "obsessed with and intensely conflicted about the disabled body. We fear, deify, disavow, avoid, abstract, revere, conceal, and reconstruct disability..."[11] There is an eerie feeling of It-Could-Happen-To-You that foreshadows a conversation on disability between an able-bodied person and a disabled person. It is easy enough for an able-bodied person to dismiss concerns about addressing the lack of language in disability discourse. Their dismissal may reflect an underlying fear of one-day joining America's largest minority.

Now is the time to look beyond our fears and embrace a discourse long overlooked. We need words for discrimination against disability. We need them yesterday, today, and tomorrow. Without a publicly acknowledged word for discrimination against disability, people will continue practicing this prejudice without being named, without consequence. The visiting professor will continue to use words such as "malformed," "deficient," and "incapacitated." The guitarist will continue to discriminate and receive public approval rather than disapproval. Characters in contemporary literature will slander disabled characters. Perhaps these incidents will continue regardless of whether or not a name for discrimination exists. At the very least, naming discrimination against the disabled and placing that name in the public consciousness will begin to hold individuals accountable for prejudiced beliefs while giving a voice to those who endure the consequence of that prejudice.

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The Difficulty with Deafness Discourse and Disability Culture*

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Abstract: This paper addresses why the Deaf Culture stance is to distance itself from disability and how this divides rather than unifies communities in common. From the perspective of a member of both the Deaf World and Disability Culture, current discourses are considered and presented for discussion.

Key Words: Deaf, Disability, Culture

My Standing (and Sitting) in the DEAF-WORLD

Writing about this topic is both personally and politically risky for me. There are some potentially negative consequences of writing about Deaf culture and its relationship, however tenuous, to disability culture. By doing this I transgress against the dogma of Deaf Culture by questioning basic tenets. If Deaf Culture is as firm as its proponents say it is, it will withstand criticism. All worthwhile concepts deserve interrogation. I want scholars of disability studies to understand the complications and the lack of resolution in the murky issues. Let me start by positioning myself. Sometimes this is called self-locating.

I am a marginal member of the Deaf community by virtue of the fact that I can speak and was not born deaf. But I am an honored member because I have a Deaf child and have raised her within Deaf schools and the Deaf community. I am also respected for my teaching and community activism having been on the Canadian Association of the Deaf Board of Directors and worked for them in various capacities. I am marginal because I sit. I use a wheelchair (Deaf people are not disabled, See Moore and Levitan, 1993). This paper will deconstruct some of the difficulties of Deaf culture from the perspective of Disability culture (with a capital D).

My obvious use of a wheelchair is a visible signifier that I cannot be Deaf (or at least should have the dignity not to claim so). I arrived (in my wheelchair) at a table where the interpreters were positioned at an international conference in Washington, D. C. once and was told that this seating (the table) was for "the Deaf." (*emphasis mine*) I signed. "Like me." I was given a look of curious doubt and suspicion and then Dr. Yerker Andersen recognized me and I was allowed to stay. He is the former president of the World Federation of the Deaf and professor at Gallaudet University. He also knows me. His acceptance of my claim to the seat, to Deafness, was sufficient. But Dr. Andersen is rarely at the events I attend and I remain generally un-accepted. From this position of marginality I have a unique position of being able to live the discrimination of being disabled (socially constructed and physically impaired) in the DEAF-WORLD as well as being a part and party to it (Lane, Hoffmeister, and Ben Bahan, 1996).

For newcomers to this DEAF-WORLD, let me explain some of the language being used. When someone cannot hear there are various terms used by the public and medical professionals to signify that state. Hard of hearing, hearing impaired, late deafened, deaf and sometimes deaf-blind (although there is a true marginality in that condition as well). Being Deaf-Blind is a state of liminality that throws one out of the DEAF living room and into the Deaf but Blind too corridor. The use of the capital "D" Deaf does not describe the condition of not being able to hear. It describes a membership in a community of choice. That is you self-identify as being Deaf by using sign language and joining with Deaf friends and sharing Deaf values. Being Deaf is far less about audiological ability to hear pure tones and more about your ability to be culturally appropriate in the presence of other Deaf people (Padden and Humphries, 1988).

Deaf culture is considered a high context culture; that is one in which communication requires a great deal of insider knowledge. The non-informed person, even with sign language skills, will have a hard time following a conversation without a sense

of the topic and the participants. Deaf Culture has been compared to Israeli Culture in how it sees time and how rules of interaction are adhered to (Mindess, 1999). Similarly, it has been contrasted against the dominant hearing (white non-disabled) American culture because Deaf culture is direct and explicit and hearing culture tends to be vague and implicit (Mindess, 1999).

The concept of a Deaf culture is essential to understand if we are to understand why Deaf people do not want to be considered disabled. And then I will try to explore some difficulties in this argument based on my own experience with Disability Culture. As Cheryl Marie Wade eloquently has written, there is a Disability Culture and it is as real and as much a minority community as Deaf culture. But for Deaf people disability is not this. They see disability, in lower case, as a deficit that nondisabled, hearing people created to oppress (Lane, 1992, 1995). In his recent book on disability history, Paul Longmore identifies the problem that Deaf history scholars have constructed. "Finally and distressingly, to counter prejudice against Deaf people, Lane stigmatizes people with other disabilities. A minority model fits Deaf people; the medical model applies to other handicapped people. In fact a minority model that defines "disability" as primarily a socially constructed and stigmatized identity and that Lane so convincingly applies to the history of Deaf people also best explains the modern experience of blind people, physically handicapped people, and even most mentally retarded people" (2003:44).

Why Deaf People Oppress and Marginalize Disabled People

I have come to believe three contributing factors about this difficulty.

One, Deaf people are raised by hearing people, put in schools run by hearing people (mostly) and live (mostly) in a society dominated by hearing values. Because of this Deaf culture has acquired, through schools and the media, most of the same negative stereotypes and understandings of what disability means. And to Deaf people, it is NOT them. They are NOT that. Not crippled, not blind, not crazy, not sick. Disability is "othered" to the extreme, at least in part because of the negative stigma it would attach to otherwise "less" oppressed Deaf people.

And this is often true. In the lower case world of impairment people who do not hear are usually not the same people who use wheelchairs or canes or who have learning disabilities. Probably at least 65% of people with disabilities are not Deaf. But there is nothing special about being deaf that prevents you from having a disability and certainly nothing magic about having a disability that prevents you from being deaf. But being deaf does not equal being Deaf.

Corker has argued that some Deaf cultural positions are devaluing disability in part because hearing values which have feared disability have been transmitted and so Deaf people do not want the label of disabled anymore than hearing people want it. I find this to be a convincing argument. Deaf people are as much a party to the social construction of what disability is as are hearing nondisabled people. I have seen it at Schools for the Deaf, at Deaf events and in relationships:

> Hearing impaired people, and particularly deafened people, are often trapped between different discourses of tragedy from which there is no escape and from which they cannot develop alternative discourses because of the marginalizing effects of negative value judgments. In a sense, then Lane selects particular discourses on deafness and disability which are not directly comparable. In doing so he successfully emphasizes his main premise that Deaf people are not disabled by drawing upon the disablist discourses; he thus justifies Deaf

people's claim to the right to coexist as a minority group (1998: 63).

Corker, by the way, was deaf, could sign, but also talked and was positioned in a marginal status to both hearing and deaf communities in Britain. She, like I, risked her social status by arguing against the dominant Deaf discourses. She was willing to name ableism (she called it disablist) when she saw it.

Secondly, to be Deaf you must sign, respect Deaf heritage, embrace Deaf values and associate primarily with Deaf people. It helps if you do not speak and when you have Deaf children and/or parents (Evans and Falk, 1986). This is important because to really understand the Deaf perspective you must be a signer, a fluent one, and you must be immersed in history and cultural knowledge. For Deaf people, this is not about disability at all, it is about language and values.

Thirdly and perhaps most importantly, Deaf people do not see being deaf or Deaf as a stigma. They are proud of their culture and do not want it to be "contaminated" by the enormous stigma associated with lower case disability and impairment. As a movement they have made some great gains and do not want to lose this precious progress. This may seem like I am simplifying but in fact I am complicating. Deafness as Culture does not carry with it the stigma that Deafness as disability does (or could). Many Deaf people, at the grassroots and at the academic levels, really believe that hearing people (the world in general) are mistaken by seeing being Deaf as a limitation (or disability).

Disturbing Differences of Discourse

There is significant difficulty with this discourse that creates a serious rift between and among communities. I am worried that my Deaf colleagues and my daughter who is also Deaf, are being misled by hearing people about the way they are perceived as a Culture and as a population with a deficit. My daughter is seen as limited when she goes to the store or even gets on the bus. Not because she CAN sign but because she does NOT speak. Deaf people, generally, do not get Disability (capitalized on purpose).

As a Deaf person with a disability (several actually) I claim my capital D Disability Culture status with equal pride and celebration as my Deaf status. However at disability events I am far more likely to have an interpreter provided, and to have my Deaf status recognized (maybe not understood) than have accessibility for my disability or Disability at a Deaf event. The Deaf community is at least partly built on an ableist foundation that says, "we are not them" and "they are not us". But this divides, unnaturally, groups of people by a status that is determined medically or legally and not culturally or individually by choice. It has caused numerous Deaf people to be marginalized from their own group- other Deaf people- on the basis of access and acceptance.

Maybe some deaf (who cannot hear but are not part of Deaf culture) people do not mind how the Deaf feel about disability because for them deafness **is** disabling and since they are not part of the Deaf culture these arguments do not affect them directly. Certainly I know hard of hearing people who cannot be bothered with arguing about or with Deaf people.

But these issues do affect me. They affect me as a person, as a mother, as an advocate and as a teacher. How can I sit in a wheelchair and teach, in sign language, Deaf students about instructing sign language to hearing people? I am out of place, I do not belong. I am mis-fit. I am mis-constructed and mistaken.

How can I as a Deaf person (with a Deaf daughter) teach a Disability Studies class when Deaf culture refuses to associate itself with the literature and discourse of disability/Disability? I sometimes wonder if the Deaf leadership and membership of Deaf Culture have taken the time to read what Disabled people have been saying about Disability. Because what we are saying about Disability Culture

fits in nicely with what many radical Deaf Culture proponents say. But the dialogue is missing.

Disability, in its lower and upper case forms, is LIKE deafness. It can exist on the biological plane and be physically a problem. It can be primarily an impairment or it can be primarily an identity. We seek human rights, sometimes called civil rights, as people who are citizens of nations. We are not willing to pretend to be non-disabled to get a job, go to school, have children or be on TV. We, d/Disabled people, want very much what people who argue for Deaf Culture want - status as a minority rather than status as sick, needy, dependent, and disordered.

Culturally Deaf people have struggled with not wanting to be categorized as disabled. Not struggled among each other, but against the huge special education and rehabilitation industry that puts them squarely in the category of disabled. Society, too, is guilty of considering deafness (not Deafness) to be an impairment. There are many people who acquire hearing problems in life after age 30 who agree that it is an impairment and seek out solutions. The Deaf community has little argument with them because they are really hearing people who cannot hear rather than Deaf people after all. There are double standards for the valued members of DEAF-WORLD and for those who just became deaf:

> An embarrassment for the medical model of cultural deafness heretoforeward that this "pathology" had no medical treatment. With cochlear implants, however, the medical specialty of otology has been expanding its traditional clientele beyond adventitiously deafened hearing people who seek treatment, for whom an infirmity model is appropriate, to include members of the Deaf community, for whom it is not (Lane, 1992: 206).

The main concern is with hearing parents, and hearing professionals (usually doctors and audiologists) who do not want deaf children to become Deaf. They want their deaf children to be as close to hearing (and Hearing) as possible. In order to approach the fixing of deaf children through current cultural and social norms it must be deemed a tragic disability and severely impairing condition. If not why would governments and medical organizations pay so much money for implants, research, interventions, treatments, and hearing aids?

Deaf people who use sign language argue for a minority status. This is in part the result of trying to distance Deaf identity from a negative deficit model. But it is also much like a white Hispanic person saying, 'I am not a person of colour' (because he is not) even if he still fits some of the roles of a person from a minority background for language reasons. Women have had to realize that they cannot always distance themselves from their biological sex because it is part of what interacts with the world and co-creates gender but also has medical implications (such as issues of cervical and breast cancer).

The linguistic minority status that Deaf people and the DEAF-WORLD (This is another way of writing what is signed in ASL) want will not come with the same benefits as the label of disability because in North America, there is not a particularly good history of how linguistic minorities are treated. There are few if any entrenched rights and the social structures in general push for unilingual assimilation (Speak English you are in the US! or Speak French you are in Quebec!). But the formation of a positive identity as Deaf – one that is free from the negative affiliation with disability, is the first step in resisting oppression (Davis, 2002: 10). The next step after having established group solidarity, is when people "are comfortable about self-examining, finding diversity within the group and struggling to redefine the identity in somewhat more nuanced and complex ways" (Davis, 2002: 11). Some Deaf academics, who study Deaf Culture, have been able to look around and recognize

that some groups were not at the table, and that some groups were dominating, and that some inequality existed in the purported Nirvana that was/is DEAF-WORLD (See for example Sheridan, 2001).

If culturally Deaf people can realize that they can be little 'd' deaf (biologically) for the purposes of educational and vocational benefits, but capital D Deaf for social purposes they can avoid the inherent conflict. Many people who are NOT disabled biologically by hearing loss want to identify as part of the Deaf community. Interpreters, hearing children of Deaf parents and people who work directly with or are partners of Deaf people. There are also some small 'd' deaf people who physically qualify as being disabled but who do not claim their cultural Deafness as an identity (Glickman, 1986).

Clearly there are both little 'd' deaf people who feel their hearing loss does need to be fixed and is "a disability" and capital 'D' Deaf people who are quite satisfied with their lives and do not want to be fixed. But it is not useful to pretend, or to argue, that BOTH do not co-exist. It is important for the Deaf academic position to be fortified by theory and epistemology that recognizes our social and our biological existence without denying the importance of political or cultural stances.

A socio-political model of disability, also seen as a civil rights approach, looks at disability as the consequence of how society is organized rather than biological experiences of difference. "This approach is based on the premise that disability is not a deviation or an anomaly, but that persons with disabilities are an inevitable part of the population" (Roeher Institute, 1996:17).

One of my favorite arguments is about the Miss Deaf Pageants. In Canada, Miss Deaf Canada was discontinued when the Canadian Cultural Society of the Deaf and other Deaf organizations agreed that it was sexist and outdated to parade Deaf women around in the name of "culture". My argument with the leaders of the pageants who claimed that this was a Deaf Cultural opportunity for leadership and recognition for Deaf women, was

that this was no more Deaf Culture than breakfast. Miss Deaf Canada is directly lifted from Miss (hearing) Canada and all other such pageants. The only thing Deaf about it were the contestants but it certainly did not support or reinforce anything Deaf. It supported a sexist image of what women (hearing or deaf) should look like, act like, walk like and sign like. Deaf people are somewhat snobbish when it comes to sign; like hearing people who value speech, Deaf people value good signing. But in the U.S. there is still an event that parades Deaf women around for the title of Miss Deaf USA. I have even seen it argued that it is MORE necessary now that a "deaf" (lowercase) woman has won Miss America. Separatism lives, but they are not supporting Deaf culture in doing this, they are supporting patriarchy and sexism. So one of my favorite arguments is an example of how the Deaf Culture has emerged as just a specific version of hearing culture and with all the faults that go along with the dominant culture and its hegemony- racism, ableism, homophobia, ethnocentrism (Anderson and Bowe, 2001). These are not Deaf attributes, but they are attributes Deaf people learned from hearing people.

What to do? (SIGNED DO-DO? WITH RAISED EYEBROWS)

Political strategies are in conflict with cultural values, and debate divides people who share linguistic needs unnecessarily. Deaf studies can learn from women's studies and cultural studies of other people's struggles. Women's groups struggled for 20 years with the idea that by bringing up the idea that "maybe" women are "different" from men that they would be erasing accomplishments towards equality. Now, they are realizing both sex and gender exist and that equality is only going to be achieved if both are addressed fully. In addition feminists have argued that patriarchal structures hurt some men too and so it would be good for everyone to implement (radical) social change.

Deaf people who are part of the "grassroots" of the Deaf Culture often are employed in jobs that might be considered menial or blue collar. Dis-

crimination against Deaf people in the mainstream is still a main barrier to success in the professional fields. Deaf people are clear that while they want minority status as a Culture they want access to the majority as well. Deaf people watch TV dominated almost exclusively by hearing issues, stories and actors. Deaf people (the majority, not the professionals) work in a primarily hearing environment.

Deaf professionals, those Deaf people who have attained university education, now teaching at colleges, Schools for the Deaf, or universities, are in unique situations where the students they work with are often deaf (and/or Deaf). Deaf community leaders who work full time as directors of Deaf organizations or who lobby full time for Deaf children's rights might be around Deaf people more regularly in their day than the average Deaf person.

But there is not enough DEAF-WORLD to go around. There are not enough Deaf spaces and Deaf jobs and Deaf cultural events to fill the needs of all Deaf people all the time. So Deaf people will join the hearing majority for part of the time. They may work at the Post Office, or at a local business, or attend a local community college instead of Gallaudet, or may even marry a hearing person instead of a Deaf person. Deaf people, despite the academic arguments of the cultural minority status, are very much a part of the mainstream of hearing/nondisabled society. And they want to be. At least they use court cases to contend that they are being discriminated against if the mainstream does not provide them with interpreters, captioning, technical aids, accommodation and access. Oh, and the discrimination is based on disability not cultural minority status.

But legal strategies are tricky. Sometimes you have to argue one way even if you do not believe it in your heart. Legal strategies around the Americans with Disabilities Act of 1990 (ADA) have included arguments that being "gender confused/dysphoric" could be a disability (a transgendered person may use this argument to defend rights that are not otherwise protected) even if being transgen-

dered is seen as a natural and not at all a deviant status by that person.

The argument can be made that deafness as a disability does not have to be denied as long as it is recognized as the basis of accommodations such as captioning, relay services or TTYs. Cultural Deafness may not bring with it the benefits of the ADA or the Charter of Rights or political sympathy based on the deficit model, but it can bring solidarity, pride and a sense of a future as a people that little 'd' deafness does not. Strategic identity politics might be a solution.

As Lane (1995) acknowledges, and Susan Foster (1996) discusses, if capital D Deafness is accepted as only a linguistic minority status by the governments, it would mean that most of the services and benefits that Deaf people are currently entitled to would be withdrawn. This is because they are based on the medical and disability models of what deafness means.

This has been a painful struggle for me because I was not born deaf and I was not born with disabilities. I was also not born literate or educated. It is only through my experiences growing up, going to school, raising my daughter, advocating for Deaf rights and later Disability rights that I learned what I know. I want more people with disabilities and more Deaf people to understand that we might not be so different in what we want or even in how we strategize to get it. I believe, that slowly, very slowly things are changing. This is in part because there are deaf people with disabilities and there are disabled people in the Deaf community. At the most recent World Federation of the Deaf a group of Deaf people with cerebral palsy and/or brain injury were highlighted in the daily newsletter as making important points about their need for full acceptance in the DEAF-WORLD. I was absent from that historic event but read about it on line.

The minorities in the world have a considerable history of being oppressed and exploited by the majority so the idealism of being a linguistic minority does not bring with it hope for a higher status. In fact, even the negative images of being

disabled are not always seen as negative as the images of being a slave, a non-English speaking citizen, or a foreign language immigrant no matter what the skin color (Ruiz, 1988). Minorities are minorities in status, power, and acceptance. More work is needed on the issues of Deaf people who are racial/ethnic minorities but more work has to also be done on Deaf Culture (Reagan, 1990).

It is my hope that the Deaf community will come to understand that the Disability community also wants to be recognized not as deviants or broken "normal" people but as people with Disabilities in our own right. We have as much Disability Pride and Culture as Deaf people have Deaf Pride and Culture.

Deafness as a Cultural phenomenon can still be promoted for the purposes of maintaining a population of Deaf people who may, as citizens, want specific policies implemented, in the same way that religious groups, political parties or trade associations are pushing for favorable policies.

It is an uneasy alliance, to be sure, but the Disability community has begun and is succeeding in turning the previous negative conceptualizations of disability into one of pride and cultural membership. The Deaf community might even take some credit for getting a head start and giving the Disability community the idea that Disability could be POSITIVE and that membership status might be useful rather than stigmatizing. Disability dance, theatre, prose, poetry and arts have flourished at least in part because Deaf arts paved some ground to support arts and culture for people with disabilities (oh I mean Deaf).

If the Deaf community continue to distance themselves and deny any connection to the Disability movement they may lose out on a potentially politically powerful movement. This is possibly the movement to acknowledge difference, to embrace diversity but to provide for support and accommodations as a human right. Support does not need to be an entitlement per se but available because it is the right of all people to participate fully in their world as they are and not as the dominant powers that be say they should be.

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* Please note that MUCH of this article appears as a chapter in Tanis Doe's self-published book *Studying Disability* (2003) It was mainly published to be used in course work at the University of Victoria- it has not been widely circulated and other than this book this chapter is brand new.

From the Cripple-Power-Festival to Independence Days:
Disability Culture in Germany

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Abstract: The German cripple-power-festival is an initiative which promotes disability culture in Germany. The fourth festival of this kind took place in September 2003 as a part of the European Year of Disabled People. Ottmar Miles-Paul, a free-lance journalist based in Kassel, Germany provides insight about this initiative and the changes disability culture is making in the area of general disability politics in Germany.

Key Words: Cripple-Power-Festival, Germany, disability culture

When Christian Judith presented his idea of a Cripple-Power-festival the first time in the mid 1990s many people didn't believe that it could ever happen. They doubted he would be able to organize and finance such an event in Germany.

Today the German disability rights movement has already seen four such events. Christian Judith, who uses a tricycle to move around because of his bodily short stature, formed the non-profit organization "roll over" which organized these festivals and promotes a new disability culture in Germany by organizing cultural events with disabled people.

The Roots of the Cripple-Power-Festivals

Christian Judith's dream of a Cripple-Power-festival has two roots. First, it is based on a phase of the history of the German disability rights movement. A part of this movement called itself in the 1980s for quite a while the cripple movement in order to provoke society with the term many people still used about disabled people and to show the real status disabled people were facing around that time in Germany. This was especially the case around the UN Year of Disabled People in 1981 when many celebrations took place in Germany. The cripple movement criticized the so-called helpers and politicians they believed used this year mainly to celebrate themselves, while nothing really changed.

Disabled people were basically the focus of pity and exclusion in special schools, institutions and sheltered workshops, which were widely seen as the best solution to "help those disabled people". In this situation the cripple movement shocked many people in Germany with demonstrations and provocative actions against the celebrations of the UN-Year. The movement made mainstream news headlines when an activist hit the German president with a cane on his leg to prove that disabled people were not taken seriously in 1980s Germany. He never faced any criminal charges.

This was a time of a new self-awareness, self-confidence and pride of disabled people and helped to create their own culture and pride. Many different cripple groups around the country were formed around that time. They provided a space where disabled people for the first time had a chance to share their experiences of being different. They discussed discrimination and developed a sense of having their own culture without non-disabled people telling them what to do or what to think. The second root of these festivals was based in the growing desire of the disability rights movement in Germany to create and support their own culture around disability with a spirit of disability pride and to showcase more disabled artists.

Even though Germany has some disabled people who made it into the mainstream of musical performance, the theatres or the movies, Germany still lacked a culture of disability pride. Therefore the cripple-power-festivals were also designed to bring not only disabled people on the stage to perform, but also to support the culture of being different and of disability pride.

The idea of these festivals was a good addition to other cultural events with disabled artists, which in Germany are traditionally organized by different disability related organizations, like exhibitions by

organizations for people with mental disabilities or performances for deaf organizations.

The cripple-power festivals provided a cross-disability approach and a main focus to bring people with different disabilities together in a common spirit of empowerment.

Get Together

The idea of the Cripple-Power-Festivals was to combine disability culture, with the inclusion of well-known non-disabled artists, to draw non-disabled people, who never would show up at a festival which included only disabled artists. Therefore discussions and panels around issues like bio-ethical questions, equal rights legislation and accessibility were also included in the festivals, as well as kids programs and basketball courts, where non-disabled people could use a wheelchair, and play together with disabled people.

This focus towards including the non-disabled public was also a question of survival. The idea of disability culture is still not grounded enough under disabled people themselves in Germany to run such a business, with the main focus on disabled participants at such festivals. Even though there was always quite a crowd of people with different disabilities, the majority were always non-disabled festival visitors who wanted to see the better-known bands. While the first festivals drew between 2,000 to 5,000 participants, the Independence Days festival from 2003 drew 10,000 people.

The Artists

Mat Fraser, from Great Britain, with his provocative lyrics and powerful beats was certainly a must during this year's Festival because he is already well known from former festivals in Germany. He symbolizes what's still missing in Germany– good songs around issues which are important to disabled people themselves. Heart 'n Soul impressed the festival visitors also with their music and performance. Klaus Kreuzeder from Germany is probably one of the most well known musicians who uses a wheelchair. He plays saxophone like hell and impresses every time with his energy and long breath. Many other disabled artists like BKey – a woman with a great voice who uses a wheelchair – or Mike Al Becker, who rocks, were present at the last festival.

Marla Glenn was probably the most well known non-disabled artist. While she did a photo-shooting for the posters before the Festival with Josef Stroebl – a leader from the German People First movement – she asked him to join her on the stage and tell people why the People First Movement is so important. As one can imagine Marla Glenn has now a growing fan club in the German People First Movement.

The European Year of Disabled People Provides New Opportunities

The first three festivals took place in Kassel, which is a city with about 200,000 inhabitants quite in the middle of Germany, and is known as a main center of the disability rights movement in Germany. The fourth festival took place from 12th-14th September 2003 in Muelheim, which is in the west of Germany.

The last festival, which was called "Independence Days 2003" was a part of the official events for the European Year of Disabled People 2003 and took place with support and close cooperation from the German Ministry for Health and Social Security.

The history of the funding of these festivals are a good mirror for the development of the German Disability rights movement as well. While the first and smallest festival was organized and funded quite independently by common sponsors, the second Cripple-Power-Festival was already supported by a main welfare organization for disabled people who started to change their image and funding strategies around that time. In March 2000 this big welfare organization, which runs a lottery, changed its name from "Action Sorrow-kids" to

"Action human" and is also funding cultural projects of disabled people because of the pressure of the disability rights movement.

The close cooperation with the federal Ministry for Health and Social Affairs during the last festival symbolizes also that the former cripple movement has moved from the opposition to the mainstream and that at least the outer face of disability politics in Germany has changed. The head of the office for the European Year of Disabled People in Germany in the Ministry for Health and Social Security for example is now Horst Frehe, a wheelchair user who was a leader of the protests against the activities of the government around the UN Year of Disabled People in 1981. He stormed and occupied the stage, for example, with others, to prevent the German President from speaking at the main event more than 20 years ago. In 2003 he put a big priority on funding the Independence Days festival and on supporting disability culture and disability studies.

Despite the criticism of the disability rights movement during the European Year of Disabled People that politically nothing really has changed, it definitely provided a good platform for a changing perspective on disability culture. Many events featured disabled artists who played a main role with performances and exhibitions that introduced new perspectives from the view of disabled people.

Summer University Disability Studies

The first summer University on Disability Studies, which was organized by the Research and Training Institute on Self-Determined Living, took place at the University of Bremen for two weeks in July 2003. It was a fantastic forum for disability culture. A wide program with workshops for creative writing, contact dancing, disability culture, theatre performances, exhibitions, presentations of movies with disabled people and big parties with disabled musicians with different disabilities impressed not only the over 10,000 participants,

but also gave the city of Bremen in general for two weeks a new spirit of disability culture.

What some people called "the main event of the last decade" gave the German disability rights movement a new push because during that event one could experience the spirit of empowerment and a culture with the right to be different very strongly. Especially a conference on the cultural perspectives of disability studies this summer showed universities how wide the field for research and expression in this area is and how neglected disabled people and their culture has been in the Germany of the past.

From a Culture of Disabled People to a Disability Culture

Even though Germany mainly still has a culture of disabled people who try to perform their art in the mainstream rather than a spirit of disability culture with all the expression of our differences and pride, the last years have shown t there is a good basis for a growing movement towards new approaches in this area.

The spirit of the events during the last years and especially during the Cripple-Power festivals and the European Year of Disabled People provide a good basis for further empowerment in this area and for a powerful disability culture in Germany.

Especially because of its history of segregation, discrimination, sterilization and the mass-killing of disabled people during the Nazi-time Germany probably needs such a culture more desperately than many other countries in order to move on towards a culture of self-determination and equal rights of disabled people.

More Information on the Internet
:
Information around the Independence Days Festival www.independence-days.de and
www.roll-over-ev.org.

Information about the summer university on disability studies www.sommeruni2003.de.

Ottmar Miles-Paul is 39 years old, visually impaired and works as a free-lance journalist in Kassel, Germany. He has a Master's in Social Work from the University of Kassel and spent 1989/90, one and a half years, in Berkeley, California for his studies, where he caught the spirit of equal rights and self-determination of disabled people. In the 1990s he served for many years as director of the German Council of Centers for Self-Determined Living and fought together with many others successfully for the first anti-discrimination law in Germany. Currently he coordinates a campaign for another equal rights law in Germany and is the president of a main online-disability magazine in the German speaking area with daily news around issues concerning disabled people under www.kobinet-nachrichten.org.

Personal Reflections on Disability Culture

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

Key Words: disability culture, disability history, disability pride

The Blossoming Culture of Disability

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

> "The existence of a disability culture is a relatively new and contested idea. Not surprising, perhaps, for a group that has long been described with terms like "in-valid," "impaired," "limited," "crippled," and so forth."[12]

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

> "Scholars would be hard-pressed to discover terms of hope, endearment, or ability associated with people with disabilities. But as rights and social standing have become more available to disabled individuals so too has the need and belief in the integrity of group, community, and cultural identity."[13]

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

> "To date, no one has written the history, of the Disability Rights movement or told the stories of the persons with disabilities who lived the movement

that forever changed the lives of persons with disabilities in America." [14]

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

> "Another respondent offered two definitions of disability culture. 'First it is the filter through which we people with disabilities experience the world (shared experiences, & thoughtfully developed concepts). 2nd our expression of ourselves in writing, words, art, etc. as well as organizations, etc.' Those two sentences concisely summarize the status of disability culture as it exists today."[15]

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

A Decade of Change

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

Looking at some of the sites returned by Google demonstrates how common the idea of disability culture has become during the last ten years. There are sites that specifically tout disability culture as the highlight of their product, for example, "The artwork of artists with disabilities is explored within the context of disability culture in the exhibit, 'Art, Disability & Expression'…"[16] Or, "The culture and media these artist/activists are producing has come to be collectively called Disability Culture…"[17] An Amazon.com customer named Carolyn, who calls herself "an enlightened PWD [person with a disability] has a Listmania! feature

called, "An Introduction to Disability Culture."[18] C. Marfisi, a student of the Temple University Disability Studies program, presented a paper entitled, "Disability Culture-What's the Purpose?" at the inaugural meeting of the Cultural Studies Association in Oakland, California, in June 2003.[19]

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

A webzine calling itself Delirium: An Interdisciplinary Webzine of Culture and Criticism (http://www.deliriumjournal.org) seeks submissions "in any genre or form, and from any disciplinary perspective, on any issue related to disability culture."[20] Another, newer journal, Breath & Shadow, intends to be a monthly journal of disability culture and literature. It is described as a journal that "will feature poetry, fiction, essays, interviews, drama, and other writing that examines the human experience of living with disability."[21]

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

And write we have. When I published Investigating a Culture of Disability, I wrote a section called, "Deviants, Invalids and Freedom Fighters: Historical Perceptions of People with Disabilities in the United States."[22] A year earlier, journalist Joseph Shapiro, published No Pity, a journalistic analysis of some aspects about U.S. disability rights history.[23] Another journalist, Sonny Kleinfield, actually wrote about us fifteen years earlier than that.[24] The primary difference between Kleinfield and Shapiro and what has followed has been that it has been us—people with disabilities ourselves—who are doing the writing.

Paul Longmore, perhaps the preeminent historian researching disability today, who himself has a disability, has become the co-editor of a New York University Press series about disability. The first volume in that series is appropriately called The New Disability History.[25] Longmore also recently published a collection of essays with the intriguing title of Why I Burned My Book.[26]

A few years ago, in 1999, I had the privilege of co-facilitating a teleconference with Longmore and others, sponsored by ILRU (Independent Living Research Utilization) called "Freedom of Movement."[27] The teleconference and the monograph that accompanied it discussed disability history as we knew it at that time. I recall a caller asking if we knew much about minority disability history, like that of Hispanics or African-Americans. I responded that no, we knew almost nothing about the disability history of any groups beyond those of white Americans.

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

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

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

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

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

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

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

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

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

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

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

Epstein, Susan, *We Can Make It: Stories of Disabled Women in Developing Countries* (Geneva, Switzerland: International Labour Organization, 1997).

Fleischer, Doris Zames and Frieda Zames, The Disability Rights Movement: From Charity to Confrontation *(Philadelphia: Temple, 2001).*

Fries, Kenny, *Body, Remember: A Memoir* (NY: Dutton, 1997).

Fries, Kenny, *Staring Back: The Disability Experience from The Inside Out* (NY: Plume, 1997).

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Hockenberry, John, *Moving Violations: War Zones, Wheelchairs, and Declarations of Independence* (New York: Hyperion, 1995).

Husson, Therese-Adele, translated and with commentary by Catherine Kudlick and Zina Weygand, *Reflections: The Life and Writings of a Young Blind Woman in Post-Revolutionary France* (New York: NYU Press, 2001).

Jacobson, Denise Sherer, *The Question of David: A Disabled Mother's Journey Through Adoption, Family, and Life* (Available from Creative Arts Book Company, 833 Bancroft Way, Berkeley, CA 94710, 1999).

Johnson, Mary, *Make Them Go Away: Clint Eastwood, Christopher Reeve and The Case Against Disability Rights* (Louisville, KY: Advocado, 2003).

Linton, Simi, *Claiming Disability: Knowledge and Identity* (NY: New York University, 1998).

Mackelprang, Romel W. and Richard O. Salsgiver, *Disability: A Diversity Model Approach in Human Service Practice* (Pacific Grove, CA: Brookes/Cole, 1999).

Mairs, Nancy, *Waist-High in The World: A Life Among the Nondisabled* (Boston: Beacon, 1996).

Pelka, Fred, *The ABC-CLIO Companion to Disability Rights* (Santa Barbara: ABC-CLIO, 1997).

Priestley, Mark, *Disability: A Life Course Approach* (Cambridge, UK: Polity, 2003).

Russell, Marta, *Beyond Ramps: Disability at the End of the Social Contract: A Warning from an Uppity Crip* (Monroe, ME: Common Courage, 1998).

Saunders, Kathy, *Happy Ever Afters: A Storybook Guide to Teaching Children about Disability* (Staffordshire, England: Trentham Books, 2000).

Shakespeare, Tom, Kath Gillespie-Sells & Dominic Davies, *The Sexual Politics of Disability: Untold Desires* (London: Cassell, 1996).

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

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

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

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

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

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

What Hasn't Changed?

I entitled a section of *Investigating a Culture of Disability*, "There Can't Be a Disability Culture, Because…" and then listed some of the reasons why people in the early 1990s balked at the idea.[28] The most intriguing argument concerned people from diverse ethnic, geographic, racial, and gender backgrounds who all claimed they would not want a disability culture to exist because they were Americans.

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

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

I think about the article in this forum written by Gilson and DePoy.[29] They argue that in a survey of people who for the most part do not fit into either the academic or the Movement world of disability studies or disability rights, the idea of disability culture is meaningless. They speculate that disability culture may have more of an impact on academia than elsewhere. My first inclination is to argue with this conclusion and cite the kinds of data I've listed previously in this article. But, perhaps that would be too hasty.

Shame and Pride

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

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

How do I know this?

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

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

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

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

Africa, has a hard time acknowledging disability beyond stories of inspiration.

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

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

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

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

I continue to believe that disability culture is important because it is one way we can convey to the world that we are proud of who we are. This does not mean that I want to separate myself from the nondisabled world because I'm proud of who I am as a person with a disability. But it does mean that I want the nondisabled world—and people with disabilities, too—to recognize that in order to benefit from what I have to offer, the world needs to change to integrate me into it, with my disabilty(ies); and not visa versa.

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

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

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

Research Articles

Exploring Disability Hate Crimes*

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Abstract: This paper identifies some of the characteristics of disability hate crimes and explains the difference between a "hate crime" and other sorts of crimes. Hate crimes are best understood as crimes with two victims (both individuals and communities) and as two crimes in one act. The high level of violence associated with hate crimes are noted, and the evidence necessary to demonstrate "hate" exists is also discussed. The differences between hate speech and hate crimes are outlined. The paper discusses the rapid growth in recent years of anti-disability websites on the Internet. It suggests that the use of the Internet to promote hatred of disabled people is a serious concern. Finally, some possible responses to disability hate crimes are identified, including legislation, improvements in reporting procedures, community interventions, and support for individual victims.

Key Words: Hate crimes, abuse and disabilities, violence and disability

* This article was anonymously peer reviewed.

What Is a Hate Crime?

The Community Relations Department of the US Department of Justice (2001:1) defines a hate crime as: "the violence of intolerance and bigotry, intended to hurt and intimidate someone because of their race, ethnicity, national origin, religious, sexual orientation, or disability. The purveyors of hate use explosives, arson, weapons, vandalism, physical violence, and verbal threats of violence to instill fear into their victims, leaving them vulnerable to more attacks and feeling alienated, helpless, suspicious, and fearful." There are two victims of hate crimes -- individuals and communities. Hate crimes not only represent an attack on the rights and freedoms of individuals, but also indicate a lack of physical safety for many people in minority communities. Hate crimes are crimes against a community because their message of intolerance can terrorize particular groups. As a result, penalty enhancement is a common response to hate crimes. Martin (1996) points to three reasons why hate crimes deserve a different response than other crimes: first, hate crimes inflict more psychological harm than other crimes; second, hate crimes have negative impact upon communities by spreading fear and anger; and third, the bias expressed when the crime is committed has its own meaning separate from the actual crime. Some of the practical consequences of hate crimes are that other members of the targeted population may move away from or avoid the area, or may significantly alter their routines to enhance their safety (Craig, 2002).

The unique aspect of hate crimes is that they involve "parallel crimes" (Jenness and Grattet, 2001: 130). That is, there are two crimes embedded in a single act - one consisting of a crime such as vandalism, theft, arson, murder, or assault, and the other being a bias crime. In order to prove that a bias crime has occurred, it is necessary to demonstrate that the offender discriminated in the selection of his or her victim. In order to prove that a disability hate crime has occurred, discrimination on the basis of real or perceived disability must be a substantial reason in the selection of the victim.

Hate crimes tend to be associated with high levels of violence, frequently involving physical threat and harm to individuals, rather than property. Hate crime victims are three times more likely to require hospitalization than victims of a non-bias assault (Bodinger DeUriate and Sancho, 1992). In one study half the victims of hate crimes were assaulted. This is a significantly higher rate than the national crime average - where only 7% of crimes involve assault (Levin and McDevitt, 2001:17). The psychological consequences of hate crimes also seem to be more significant than those for other crimes, in terms of depression, anger,

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anxiety and post-traumatic stress (Herek et al., 1997; Herek et al, 1999). Many hate crimes involve multiple perpetrators (whereas most assaults usually involve two mutual combatants) and often the victims are unarmed while the perpetrators are armed (Bodinger DeUriate and Sancho, 1992). Also, perpetrators of hate crimes often do not live in the area where they commit the crimes. They frequently spend time and money in traveling to unfamiliar areas in order to perpetrate their crimes. And in most property crimes, something of value is stolen, but hate crimes that involve property are more likely to entail the destruction rather than the theft of that property (Medoff, 1999).

Many hate crimes are committed by complete strangers -- people who do not know the victim at all. Hate crimes are also often unprovoked (McPhail, 2000). This aspect of the crime reinforces the sense that it is not something about the particular individual, but rather his or her shared identity with a collective group, which is the source of the victimization. In fact, this aspect of the crime is often seen as pivotal in establishing that the act was a hate crime, rather than another form of crime. In her study of how law enforcement officers enforce hate crime law, Jeannine Bell (2002) found that any type of pre-existing relationship between perpetrator and victim was sufficient to convince many officers that the act was not a hate crime.

Compared to other kinds of hate crimes, disability hate crimes seem more likely to depart from the expectation that the perpetrators are strangers. For instance, the literature on sexual assaults and other forms of violence against disabled people is replete with examples of perpetrators who are in some "caregiving" capacity with the victim. The reliance of the disabled person on the perpetrator may mean that they feel unable to report the crime. The difficulties disabled people may experience in reporting and leaving violence has been summarized in the phrase used by Marsha Saxton, *et al*. (2001): "Bring my scooter so I can leave you." It seems that there is a pattern of recidivism among certain care providers which entails repeated preda-

tory behavior against disabled people under their care. For instance, Dick Sobsey (1994) cites one study where ten percent of disability caregivers were known to have criminal histories for sexual assault, molestation, child abuse, and so on.

A recent case illustrates some of the problems with automatically assuming that caregivers cannot be motivated by hate. In Billings, Montana, Floyd "Todd" Tapson is currently awaiting retrial over the attempted murder of a disabled woman. He is alleged to have abducted the woman, sexually assaulted her, driven her to a remote location, and shot her in the face. The woman survived the shooting and was able to identify her alleged attacker. It was subsequently revealed that he had worked in a number of group homes in North Dakota, Minnesota, and Maryland where disabled people have vanished (TASH, 2002).

It is not necessary to enter into the details of this alleged case, but simply to remark that it is very similar to many cases examined in the literature on disability and abuse where repeat offenders situate themselves in positions of power over disabled people and exploit this dynamic in order to perpetrate criminal behavior (Sobsey, 1994). What is interesting in this regard is that this repeated victimization of disabled people is never seen as a form of hate crime. And yet such characteristics as repeat offenders against multiple victims, use of derogatory language, and a high level of violence (all commonly found in hate crimes) suggest that there may be unique dynamics which certain types of offenders exploit in committing disability hate crimes.

Signs of a hate crime can include: words or symbols associated with hate, demeaning jokes about a particular group, the destruction of group symbols, a history of crimes against a group, a history of hate crimes in the community, and the presence of hate group literature. Hate crimes often involve serial victimizations and multiple offenders.

Hate crime legislation typically outlines specific identity categories which are protected under bias legislation. This has led some critics to suggest

that there is a hierarchy of protected categories, with race, religion and ethnicity being the least controversial categories, and gender, sexual orientation and disability being the most controversial (McPhail, 2000). The high levels of hate crimes against homeless people – many of whom are disabled – has also led to advocacy for homelessness to be a separate category protected under hate crimes legislation.

There is a notoriously low rate of prosecution and conviction for hate crimes. In fact, only one disability hate crime has ever been successfully prosecuted. However, while this low rate of prosecution is appalling, it is not something which is unique to disability hate crimes. Boston has been cited as a national model for hate crime investigations, and yet a study of 452 hate crimes in Boston between 1983 and 1987 found that approximately 85% of offenders were not arrested, and charges were dropped against one third of those arrested. For a total of 452 incidents, many of which were extremely violent, only five individuals were sent to jail (Levin and McDevitt, 2002).

Only a very small minority of hate crimes involve organized hate groups. Disability hate crimes are no different in this respect. However it is important to acknowledge that some organized hate groups overtly display their hostility to disabled people. In early November 2002, the discussion forum of the white supremacist group Stormfront (www.stormfront.org) had allocated a section of their discussion forum to eugenics. Among the disablist language which appeared on the forum included the following comments: "Ever notice how visually offensive those savants tend to be??" and "Just as the Christian hates the sin not the sinner. We hate the defective genes that have crippled some of our people." Another comment stated, "We must put into place social and economic systems that encourage the best genes to dominate in numbers as well as power." A past 'Quote of the Week' was from H.G. Wells which stated:

> The ethical system that will
> dominate the world-state will
> be shaped primarily to favor the
> procreation of what is fine and
> efficient and beautiful in humanity
> - beautiful and strong bodies, clear
> and powerful minds - and to check
> the procreation of base and servile
> types.

Hate Speech and Hate Crime

Hate crime laws do not punish free speech – they simply increase penalties for acts that are already illegal. Hate crime laws emphasize that their intent is to punish conduct, not speech. The First Amendment guarantees the right to free speech; hate crime laws never can, and never intend to, override this Constitutional right. The "hate crimes- hate speech paradox", as it has been called, involves simultaneously punishing the bias criminal and protecting the right of the bigot to free speech.

Hate speech towards disabled people is widespread. Here are some recent quotes from Internet sites dedicated to expressing hate towards disabled people:

- "Retards. I hate them. I don't care how un-politically correct it is. I fucking *hate* retards. I watched something on Canadian television this weekend about a mother who had her mongoloid son chemically castrated. Thank *GOD*. He is twenty-four years old with the mind of a four year old, blind, and (obviously) not even capable of taking care of himself or others." (http://www.geocities.com/d_i_s_s_i_d_e_n_t/ ihateretards.html, retrieved 29 January 2003).

- "I hate those drooling fucking life less wall faced bastards all they do is shit themselves smell bad and try to wipe boogers and pass diseases to anyone and everyone around them. Sometimes I see them I want to take a hammer to their thick skulls. I get fed up with there [sic] stupidity and retarded

blank stairs [sic]. They always smell bad and never make any sense. They have mush for brains, and not one has ever contributed anything useful for society! They have done nothing useful ever except for being a nuisance to everyone. And with brains like a 10 month old at age 16 it gets annoying real quick. I was fortunate not to go to a high school with these drooling vegetables. Every time I see them I want to puke! They disgust me and scare me. You never know when anyone of them will try and pull your hair or hit you. They have been known to attack people for no apparent reason. I just cannot stand them." (http://www.angry.net/groups/r/retards.htm, retrieved 29 January 2003)

- A Webzine entitled "Colon D" published an article entitled "Retarded People: A Blessing Or A Crisis" which stated, "Well I will be blunt, I hate fucking retards. I dont [sic] see why they are let to live. All they are doing is continuing to supply the world with more retarded people. Im [sic] not saying they are evil or anything, Im [sic] just pointing out they are not helping the future of mankind. Now, I propose that all mentally challenged people be taken into the middle of nowhere and shot in the head and then burned in a giant hole that will be filled in with concrete." (http://www.colond.org/past/colond9.html, retrieved Wednesday, January 07, 2004)

- When a Wal-Mart advertisement for DVDs included developmentally disabled people, a discussion list contained comments such as, "I hate those fuckin' retards, too! I don't give A [sic] flying fuck about how their [sic] into DVD! I like 'em, too, but not as much as these losers! This is what happens when you move away from the film buffs, and just pander the lowest common denominator! If these losers try to pester me about their obsession with DVDs, They're

[sic] gonna get whacked upside the head with my baseball bat! Don't call us, we'll call you!" (These comments have since been removed from the site).

- Another website suggested that it was fun to administer the wrong drugs to disabled people: "If you switch the meds around on the 'tards, they all strt [sic] to dance and yodel a lot. It's fun to give the 'tards lots of dexedrine!" (http://thingsihate.org/view/447, retrieved 7 January, 2004)

- An online essay entitled "Retards in School" began with the statement that "In general I think that all retards should be shot in the face." After a long discussion of this topic, the essay concludes: "So here is my plan, I think that we should take all the retarded people in the country, gather them at a big rally, then while they are having fun, if they even know why they are there or where they even are at, then the military should fence [sic] in to a big building that the construction companies want to blow up, you gather them in there lock them in then line the [sic] in and outside with the most powerful explosive you could find then blow the shit out of the building. And if there are any survivors, have guys with m-16 [sic] ready to shoot them down. Then you keep doing that until all of the retards in this country are gone. In my way you would kill two birds with one stone. All of the retards will be gone and you would remove the buildings that you want to get rid of. And then after they are all gone if a baby ever turns out retarded it should be a responsibility of all citizens of the united states to kill them [sic] if they cant [sic] do it they take the babies to a special are where one a week all the retarded people their [sic] will be killed for the good of the u.s. [sic] and for the good of humanity". (http://hellncphs.20m.com/Retardsinschool.html, retrieved 7 January 2004).

- One website expressed many of the common themes of disability hate, so I will quote it at some length. It was written by someone using the pseudonym of "Vicious Headbutt" and was entitled "Cripples, Retards, and the Other Untouchables". This webpage states: "Useless self-pitying cripples and bothersome retarded fucks alike are all extraordinarily worthless. What is their purpose in society? Exhausting our precious resources while annoying the fuck out of us: the hard working American public. I hate crippled people, with their close up parking spots and their defective appendages. I especially hate lamenting cripples demanding compassion and consolation while being enormous assholes. The biggest assholes are those hopeless cripples new to the experience via some horrible accident or illness. These so called 'new' cripples always demand solace while nostalgically remembering how they used to able to move without a machine to propel them. 'I'm handy capable! I'm differently able!' No you aren't, fuck you. I detest retards immensely. The babbling, drooling, flailing fuck ups irritate me to no end. When a one-year-old baby pisses itself and cries to be changed it's acceptable. However when a thirty-year-old balding fat man pisses himself and hollers incomprehensibly while violently thrashing about its [sic] just down right [sic] disturbing. Retards coast through life unknowing of the massive drain they put on society. These massive drains are nothing more then disgusting sub-human nuisances. The worst of these untouchables is the combination of the two, the crippled retard. These sad sacs of human refuse have serious defects and don't deserve to live. What the hell is the point to keep these crack baby, drooling retard, wheelchair bound, disgusting fucks?" (www.murderize.com, retrieved 29 January 2003)

- An editorial on this site stated, "Mentally handicapped individuals are bad enough, but what's worse is when they are also fat and ugly. The unsightly chunksters I'm referring to are people with Down Syndrome. A dumpy Down Syndrome baby is a huge drain on society and every parent's nightmare. These genetic screw-ups hog an extra chromosome, but they pay for it by being gruesome Quasimodoesque retards. Every goofy looking Down Syndrome fat-body wearing a bicycle helmet and running spastically at 2mi/hr should die an early death so they can be put out of their misery. And they do. However, I say before they die we should put the fatties to work. Here's the plan. Load them on a caravan of short buses and make them sweat off a few pounds picking lettuce or strawberries in a field. This guarantees the hideous chubbsters some good cardiovascular exercise, and if a few die in the process of manual labor, who cares? They were worthless anyway." ([www.murderize.com/ Editorials/Headbutt/retards2](www.murderize.com/Editorials/Headbutt/retards2), retrieved 7 January 2004)

Examples of Disability Hate Crimes

On January 30, 1999, Eric Krochmaluk, a cognitively disabled man from Middletown, New Jersey was kidnapped, choked, beaten, burned with cigarettes, taped to a chair, his eyebrows were shaved, and he was then abandoned in a forest. Eight people were subsequently indicted for this hate crime, the first prosecution of a disability hate crime in America. Similar attacks had occurred on two previous occasions. Monmouth County Prosecutor John Kaye said, "They tormented this mentally disabled man because of his disability… They did it to him because they could – because they could manipulate him, and because they believed he could not tell on them, which was almost true."(see Sherry, 2002). Other examples of disability hate crimes have been cited by the disability

organization Protection and Advocacy. They have cited cases such as the assault against a man with cerebral palsy in Oklahoma who was taunted with the use of epithets such as, "You belong in the trash, you cripple" and who was then stuffed into a trash can, unable to call for help because of his speech impairment (see Sherry, 2003).

Abuse is a ubiquitous synonym for crimes against disabled people. Serious crimes (including rape, theft, assault, vandalism and so on) are frequently mislabeled as "abuse". For instance, the schoolmates of an 18-year-old North Carolina high school student with a developmental disability soaked his lunch in cleaning fluid and watched him eat it. He experienced life threatening poisoning and had to be taken to intensive care (Consortium for Citizens with Disabilities, 1999). This example suggests to me that it is not useful to label every crime against a disabled person "abuse". These acts are crimes, and they need to be punished as such. The sexual harassment of Deaf people by nuisance callers sending obscene and malicious messages via text phones is also a unique form of disability hate crime which may be mislabeled as "abuse" (Shakespeare, Gillespie-Sells and Davies, 1996).

Failure to recognize a crime as a disability hate crime may also occur if the investigating officers from law enforcement agencies do not have significant disability awareness. Their lack of disability awareness may also mean that they overlook evidence indicating the bias element of the crime. For instance, the organization Consortium for Citizens with Disabilities (1999) has reported the case of a man living with AIDS who was attacked on a New York subway by a group of young men and women who screamed abuse at him, kicked him in the face, and left him with serious injuries. A law enforcement officer with limited disability awareness may not realize that AIDS fits the legal definition of a disability, and may not report such a case as a disability hate crime.

The connection between disability and homelessness is well established, so it would be remiss not to acknowledge the hundreds of hate crimes which have been reported against homeless people. Many of these crimes are documented in the report *Hate, Violence and Death on Main Street USA: A Report on Hate Crimes and Violence Against People Experiencing Homelessness from 1999-2002*, published by the National Coalition for the Homeless (2003). This report details 212 hate crimes in 89 American cities – with many crimes that are shocking in their brutality. For instance, the report cites cases of people being set on fire, shot, beaten to death, run over, kidnapped and even beheaded. An earlier report on hate crimes against homeless people had included the case of a wheelchair user from Hawaii who died after he appeared to have been beaten, experiencing head and facial wounds, and who was found lying unconscious, out of his wheelchair, five feet away from a fire in a trash can (National Homeless Civil Rights Organizing Project, 2000).

Responding to Disability Hate Crimes

This paper has suggested that the problems of disability hate crimes needs to be explored in far more detail. There may be unique dynamics involved in disability hate crimes which have not been explored in previous studies and further research into this topic is clearly required. Disability hate crimes need to be acknowledged, reported, and investigated thoroughly, and victims need appropriate support. Further research is also required on disability hate speech, and its connection to hate crimes.

Legislative Responses

During 2002, there was some hope that disabled people would receive enhanced protection from hate crimes under the Federal Local Law Enforcement Enhancement Act (S.625), which proposed to expand federal jurisdiction over violent hate crimes. It would have enabled Federal law enforcement agencies to investigate hate crimes which caused death or bodily injury, or which were committed with a firearm or explosive device,

regardless of whether the victim was exercising a federally protected right. Current Federal law only covers hate crimes based on race, national original, and religion, and only protects citizens who are threatened or attacked while they are exercising a federally protected right. Such rights include renting a house, riding public transportation, or eating in a public restaurant. Many other forms of hate crimes (including hate crimes based on disability, gender and sexual orientation) are ignored in the current law, which is 32 years old. The hope that this Federal legislation would be extended was shattered when the Law Enforcement Act was permanently shelved in the Senate.

Improved Reporting of Incidents

Many hate crimes are not reported at all. Reasons for the failure to report a hate crime could include the victim's shame, fear of retaliation, or fear of not being believed. We need to provide more support for disabled victims of hate crimes, and encourage more people to recognize that some of their experiences of "abuse" are actually "hate crimes" Also, there is a need to remove bureaucratic inefficiencies which impede the hate crime reporting process. Balboni and McDevitt (2001) suggest that lack of departmental infrastructure, lack of training and supervision, and communication breakdowns between line officers and those responsible for reporting the crimes may inhibit accurate reporting of hate crimes. Submitting hate crimes reports is voluntary, not all jurisdictions within states submit reports, and time frames for reporting are uneven – ranging from one month to one year (American Psychological Association, 1998). A related problem is that there is a great deal of inconsistency in the location of hate crime units, in the nature and amount of training received by responsible officers, in procedures for screening and handling cases, and in record keeping systems (Martin, 1995).

Community Interventions

One of the most comprehensive guides for community responses to hate crimes has been produced by the International Association of Chiefs of Police (1998). Their 22 recommendations for responding to hate crimes recognize the complexities of the causes of hate crime and work to reduce prejudice and bigotry at the individual and the societal level. Their recommendations include:

- increasing public awareness and community involvement in responding to prejudice, intolerance and hate crime;
- developing coordinated planning processes, task forces and institutional frameworks to promote community stability and to respond to hate groups;
- providing adequate support to victims;
- reforming school curricula to include diversity training, conflict resolution and information about hate crimes;
- developing more effective sanctions for perpetrators;
- encouraging responsible and accurate media coverage of hate crimes; and
- establishing mechanisms for repairing harm to communities.

Valuable resources which have been developed specifically for an educational context include *Healing the Hate: A National Hate Crime Prevention Curriculum for Middle Schools* by McLaughlin and Brilliant (1997) and *Preventing Youth Hate Crime* published by the U.S. Department of Education (2002).

One of the areas which is not addressed by these reports is the role of social movements in politicizing hate crimes. In *Making Hate a Crime*, Valerie Jenness and Ryken Grattet (2001) highlight the roles of social movements in politicizing the issue of hate crimes and in drawing attention to the high levels of hate crime victimization experienced by specific groups. Social movements gather data on hate crime and publicize this information, which is then distributed to policy makers, law enforcement agencies and the general public. Jenness and Grattet suggest that the first stage in the

public policy process is for social movements to publicize the problem of hate-motivated violence and pressure politicians to pass legislation, well before courts and police administer and interpret those laws. The implication of this argument is that the disability movement must engage in more lobbying to have disability hate crimes included in the political agenda.

Assistance for Individual Victims of Hate Crimes

For legal action following a hate crime incident, individual victims should contact law enforcement. Other community organizations which may be helpful to victims of hate crimes may include the following:

- Local Protection and Advocacy Organizations
- The Southern Poverty Law Center
- The Anti-Defamation League (ADL)
- The Asian American Legal Defense and Education Fund
- The Center for Democratic Renewal
- LAMBDA Community Services
- The Hate Crime National Hotline (1-800-686-HATE)

Disability-Specific Challenges

In another paper, Sherry (2000) discussed some of the specific social changes needed to reduce the incidence of disability hate crimes. These disability-specific changes include: a change in negative attitudes towards disability, improved background checks for caregivers, enhanced accessibility to domestic violence shelters and women's refuges, and development of alternatives to segregated institutions because they often foster a culture of abuse. There may also be unique disability-related forms of victimization which need to be recognized as "hate crimes" rather than abuse, such as overmedication, withholding medications, and so on.

Conclusion

This paper has suggested that it is useful to understand hate crimes as two crimes in one act – an initial crime, and a parallel bias crime. It has also identified two victims of hate crimes – individuals and communities. The paper distinguishes between hate crimes and hate speech, and notes that hate speech is not illegal. Nevertheless, the rapid growth of disability hate sites on the internet is an alarming feature of contemporary society which suggests that hatred of disabled people is not unusual, but is in fact quite widespread. Finally, the paper suggests a number of possible avenues for responding to disability hate crimes, including legislative responses, improved reporting procedures, community interventions, and assistance for individual victims.

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Attitudes Toward Persons With Disabilities Among Japanese Social Work Students

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Abstract: The Modified Issues in Disability Scale (MIDS) was implemented on 194 social work students in Japan in order to assess their attitudes toward people with disabilities. Findings indicate that students do not hold strong prejudicial attitudes. Results also show gender differences and a lack of knowledge and experiences regarding disability issues among students

Key Words: social work, Japan, attitudes

The Disability Paradigm and U.S. Social Work Education

Theoretical perspectives on disability have changed over the past few decades in the United States. The medical model of disability, which focuses on functional limitations of individuals with disabilities, was replaced by a new disability paradigm that emerged from the disability rights movement of the 1960s and 1970s. In contrast to the medical model, the new disability paradigm focuses on the whole person functioning in his or her environment. This paradigm rejects the idea that disability is a tragedy. It asserts instead that disability is a natural part of the human experience, and disabling social environments are the source of problems – not the disabilities themselves (Pfeiffer, 1993). Since the 1970s, the new disability paradigm has influenced the development of public policies and was articulated in the Americans with Disabilities Act (ADA) of 1990. The law identified disability issues as civil rights issues, and people with disabilities as oppressed members of society who deserve justice (Burgdorf, 1991; Silverstein, 2000; West, 1991). In social work education, however, disability content is still taught largely from the diagnostic perspective of the medical model (Gilson & DePoy, 2002).

In light of the failure of social work education to change with the times, it is not surprising that the relationship between the disability community and social work professionals is not entirely positive. Mouth Magazine, a disability rights publication, often introduces stories about the dehumanizing treatment disabled individuals receive from these "helping" professionals (Kleinmann, 2002). Thompson (2001) warns that the positions of power and influence occupied by social workers in the social welfare field provide abundant opportunities for discrimination and oppression whether intentional or by default. Lipsky (1980), while analyzing the roles of front-line public service employees, also warns of the misuse of power by social workers.

The poorer a person is, the more likely she or he is to be the non-voluntary client of social workers. For example, a disabled individual in poverty who needs personal care services has no choice but to become a client of a social worker from a government or private agency that provides public services. Those non-voluntary clients cannot discipline social workers, and social workers usually have nothing to lose by failing to satisfy clients. Social workers can be neglectful or impose inconveniences on their clients with little concern for retaliation. It is ironic that the mission of the social work profession includes the advancement of social justice and elimination of oppression.

A Brief History of Social Work Education in Japan

In contrast to the United States, where professional social work education was established by the early 20th century (Abramovitz, 1988; Jansson, 1992), social work education in Japan is still in its infancy. Until recently, social welfare issues in Japan had been handled mainly by local government agencies whose employees rarely held social work degrees. Only a few colleges provided social work education. In 1987, in response to a rapidly aging society and increasing demands on the long-term care field, Japan's Congress enacted the Social Worker and Care Worker Act that established the professional status of people working in the social welfare field. National exams for social work and psychiatric social work certifications were implemented for eligible applicants (MHLW, 2002a). The Japanese Association of Certified Social Workers (JACSW, 2002), Japan's counterpart of the National Association of Social Workers in the United States, was founded in 1993.

The Long-Term Care Insurance Act of 1997 further expanded opportunities for Japanese social work professionals. Several levels of additional professional and paraprofessional certifications for those who work in the long-term care system were created in addition to those for "social workers" and "psychiatric social workers." In response to these new expectations, many social work programs were created in four-year universities, junior colleges, and technical schools. Depending on their level of education, graduates of those programs could apply for various levels of national certification exams (MHLW, 2002a). Thus, the professionalization of social work in Japan is now being formalized.

As the status of social workers and the social work education system are being established in Japan, educators should pursue the integration of the disability paradigm in curricula and practice. It may be easier to introduce a new paradigm while the system is emerging rather than to try to reform a system with the medical model firmly entrenched as it is now in the U.S. social work educational system. Japanese social work educators and practitioners should collaborate with disability rights organizations that are active in the disability rights movement to incorporate the disability paradigm into social work education.

A Brief History of the Disability Rights Movement and Policies in Japan

The moral model of disabilities (Mackelprang & Salsgiver, 1998) was widely accepted by Japanese society in the 1970s. This view held that persons with disabilities were suffering the consequence of

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wrongdoing that they or their ancestors committed in their current or previous lives. The medical model of disabilities was also pervasive in the 1970s. The model promulgated the message "be cured or you are better off dead" (Mackelprang & Salsgiver, 1998; Longmore, 1985). Many disabled people were leading lives completely segregated from the non-disabled society in pursuit of a cure. Within this social milieu, a disability rights movement emerged. To combat the stigmatization and subsequent shame felt by people with disabilities and their families, disability activists took direct action. They staged sit-ins to protest against human rights violations in residential institutions, they loudly condemned the discriminatory policies and practices that were rampant in society, and they demanded integrated schools, access to transportation, and support for community living (Hayashi & Okuhira, 2001).

The implementation of the "Compulsory K-12 Special Education System" was one of the policies that the disability community fought against in the 1970s. Despite strong opposition from the disability community, the policy was implemented throughout Japan in 1979. This policy established the special education system in elementary, junior high, and high schools. While the system reduced the number of disabled children exempted from primary education (Ministry of Education, Culture, Sports, Science and Technology [MECSST], 2002), it institutionalized the segregation of children with disabilities from the larger society.

The next decade started with the 1981 International Year of Disabled Persons that prompted visits by advocates from the United States. These advocates introduced the independent living model (a version of the disability paradigm) to Japan (Lifchez, 1979; DeJong, Batavia, & McKnew, 1992; Pfeiffer, 1993; Shapiro, 1993). The idea that people with disabilities should make decisions concerning their own lives, operation of the independent living centers, and should conduct advocacy work to disabled persons living in the community was astonishing as well as empowering for disabled people in Japan. The U.S. advocates

invited Japanese people with disabilities to the U.S. for training, and in 1986 those newly trained personnel helped establish the first independent living center in Japan (Hayashi & Okuhira, 2001). Also in the 1980s, disability rights organizations in Japan focused more energy on negotiating with regional governments to improve the daily lives of disabled persons rather than on organizing protests in response to discriminatory incidents. As a result of these efforts, the first publicly funded personal attendants program for disabled persons living in the community was started in Osaka City in 1986 (Onoue, 2000).

By 2000, there were 90 independent living centers in Japan. In addition to providing services, the centers negotiate with government agencies to increase official support for attendant services (JIL, 2000). Both national and regional governments have gradually recognized segregation does not enhance the quality of life of disabled persons and that organizations run by people with disabilities can be proficient service providers. The Government Action Plan for Persons with Disabilities of 1995, which promotes the inclusion of disabled persons in community living, demonstrates the influence of the new disability paradigm in government policy (Ministry of Health, Labor & Welfare [MHLW], 2002b).

Research Questions

As the field of social work education develops in Japan, exploring students' attitudes toward people with disabilities will provide the background information to gauge the effort needed for the integration of the new disability paradigm into social work education and practice. Young social work students who grew up in the 1980s and 1990s were born around the time that the segregated school system was established. Non-disabled students generally had little contact with persons with disabilities as they progressed through the primary education system. Lack of contact with people who have disabilities may have influenced the attitudes of non-disabled people toward persons with

disabilities. Further, the moral and the medical models of disability, which many of the previous generations held and may still promote, could also have affected their attitudes. Social work students may see disabled persons as objects of pity.

On the other hand, the social norms may have changed through the global exchange of ideas since the 1981 International Year of Disabled Persons and through the advocacy work done by independent living centers and other advocates. Although Japan does not have a civil rights law equivalent to the Americans with Disabilities Act (ADA), government policies now promote more inclusion of people with disabilities in community living (Ministry of Health, Labor & Welfare, 2002a).

Lastly, studies done with U.S. college students show a significant gender difference in attitudes toward people with disabilities, with women tending to have more positive attitudes (Granello & Wheaton, 2001; Esses & Beaufoy, 1994). As gender socialization is still strong in Japan, an attitude difference by gender may also exist among Japanese social work students.

Specific research questions for this study were:

- Do Japanese social work students overall have positive or negative attitudes toward persons with disabilities?
- Are there specific situations in which they have positive or negative attitudes?
- Do opportunities to have contacts with persons with disabilities affect their attitudes?
- Does gender play a role in their attitudes?

Research Methods

The Modified Issues in Disabilities Scale (MIDS) (Makas, 1993) was translated into Japanese and implemented on a convenience sample of 194 students who enrolled in an introductory social work course at a school of social work in the Osaka area of Japan. The scale (a 33-item self-report Likert-scale questionnaire) was formulated based on the concepts of the disability paradigm

and intended to measure both cognitive and affective components of attitudes toward persons with physical disabilities. Participants were asked to indicate the degree to which they agree with a particular statement, with responses ranging from 1 (strongly disagree) to 7 (strongly agree), with 4 (the midpoint) representing no opinion. To minimize the possibilities of response set bias, 15 statements were written so that "strongly agree" (7) indicated the most positive attitude toward people with disabilities, while the remaining 18 statements were written so that "strongly disagree" (1) indicated the most positive attitude. For analysis, the latter 18 were reverse-scored so higher scores would indicate more positive attitudes.

The scale includes statements about people with physical disabilities in general as well as statements about three specific disability groups: blindness/visual impairment (a visible, sensory disability); mobility impairment (a visible, non-sensory disability); and hidden disabilities, including diabetes, cancer, and epilepsy (invisible, non-sensory disabilities). The scale measures a participant's attitudes in several areas, including education (e.g. "The majority of adolescents with physical disabilities should attend special schools which are specifically designed to meet their needs"), laws (e.g. "Zoning laws should not prohibit group homes for people with disabilities from being established in residential districts"), contact with disabled persons (e.g. "If you are talking to a blind person, it is all right to use words such as 'see' or 'look' in a conversation"), physiological abilities of disabled persons (e.g., "Drivers with physical disabilities have more automobile accidents than drivers without disabilities"), and psychological characteristics of disabled persons (e.g., "People who have disabilities are generally no more anxious or tense than people who do not have disabilities") (Makas, Finnerty-Fried, Sigafoos, & Reiss, 1988).

MIDS also gathers the demographic information of participants, includinggender, age, race/ethnicity, presence or absence of a disability, and amount of contact with persons with disabilities. The "contact" variable had five value levels: no con-

tact, very little contact, some contact, quite a bit of contact, and a great deal of contact. All student participants were given the questionnaires during one of their regularly scheduled classes.

Data Analysis and Findings

The SPSS program was used for data analyses. Three questionnaires that had more than three blanks were considered invalid and eliminated. The final sample included 191 participants. Blanks up to the maximum of three were coded as "4" (Makas, 1993). The 18 reverse-scored statements created to minimize the response set bias were recoded to indicate the higher the score the more positive the attitude.

Scores for the 33 statements were added and a variable "MIDS Total" was created. A higher "MIDS Total" score by a participant indicates a more positive attitude toward persons with physical disabilities. The possible range of "MID-T Total" was 231 (the highest score) to 33 (the lowest score).

Descriptive Statistics

Frequencies and percentages of participants' demographic information were calculated (Table 1). Approximately three-fourths of the participants were female. All were Japanese. The mean age of the participants was 18.6 (sd = 0.72). More than 90% were freshmen. Only three participants (1.6%) had disabilities. More than 70% of the participants have had little or no contact with persons with disabilities.

The alpha coefficient for the MIDS scale was 0.71 for this study. The "MIDS Total" mean score was 153.51 (sd = 14.19), with a range of 108 – 198. Dividing 153.51 by the number of statements (33) gave a mean statement score of 4.65, showing a slightly positive overall response. To check the tendency to choose positive or negative responses to the statements, the number of positive responses (values 5, 6, & 7) and negative responses (values 1, 2, & 3) were counted for each participant. It showed that 173 (90.6%) participants chose more positive responses than negative ones.

Item Analyses

To see which statements tended to get very negative or very positive responses from participants, the number of 1 and 2 ("very negative") values and 6 and 7 ("very positive") values were counted for each statement. Statements that received four most negative and four most positive responses are listed in Table 2. The statement that received the highest tally of very negative responses was, "Most people who have physical disabilities expect no more love and reassurance than anyone else." More than 60% of participants disagreed or strongly disagreed with the statement, only 7.9% agreed or strongly agreed. The statement that received the third highest tally of very negative responses was, "For a person with a severe disability, the kindness of others is more important than any educational program." More than 36% of participants agreed or strongly agreed with the statement, only 8.4% disagreed or strongly disagreed. These two statements describe persons with physical disabilities as more in need of affection than non-disabled persons and that the kindness of others is more important to them than education. The statement that received the second highest tally of very negative responses (41% agreed or strongly agreed) was, "Building adequate housing for people with disabilities is too expensive or too difficult."

On the positive side, more than 85% of participants disagreed or strongly disagreed with the statement that a doctors' special certification is

Table 1.   Demographics

Demographic Variables	Frequency	%
Gender		
Male	48	25.1
Female	142	74.3
Missing	1	.5
Age		
18	97	50.8
19	74	38.7
20	14	7.3
21	4	2.1
Missing	2	1.0
Educational Level		
Freshmen	173	90.6
Sophomore	17	8.9
Junior	0	0
Senior	1	.5
Having a Disability		
Yes	3	1.6
No	186	97.4
Missing	2	1.0
Contact with Disabled Persons		
No contact	68	35.6
Very little	74	38.7
Some	34	17.8
Quite a bit	7	3.7
A great deal	8	4.2

necessary when people with physical disabilities apply for a marriage license. More than 76% disagreed or strongly disagreed with the statement, "It is more humane to allow a child with a severe disability to die at birth than for her/him to live as a person with a severe disability." And more than 75% of participants agreed or strongly agreed that it is logical for a woman who uses a wheelchair to consider having a baby. There was no statistical difference among male and female participants on this statement. This is a remarkable result since disabled women in the 1960s and 1970s were not considered as potential mothers and were often co-

erced into having hysterectomies (Hayashi & Okuhira, 2001).

All statements that related to civil rights received high rankings in positive responses. It appears that the majority of participants believed that persons with disabilities should be treated equally with non-disabled citizens under the law regarding marriage licenses, automobile insurance, income taxes, zoning laws, the right to procreate, and the right to live. Additionally, more than 70% of the participants agreed or strongly agreed that placement of children with disabilities in regular classes would increase their acceptance by their non-disabled peers – a remarkable response from students who went through the segregated primary school system.

It is notable, however, that 20 out of 33 statements received more middle scores (somewhat agree, no opinion, somewhat disagree) than "very positive" or "very negative" scores. This suggests that many participants do not have clear opinions about disability issues. This may stem from their lack of contact with persons with disabilities, and a subsequent lack of opportunities to think about or analyze these issues.

ANOVA

To examine the effects of the factors "gender" and "contact," and their interaction on "MIDS Total," an analysis of variance (ANOVA) was conducted. Data was first screened to ensure that the assumptions of factorial ANOVA were fulfilled. One outlier (MIDS Total = 198) was altered to a

Table 2. Responses Showing "Very Negative Attitudes"
and "Very Positive Attitudes" on Selected Statements

Statements	Item Mean	% Very Positive Response	% Very Negative Response
Most people who have physical disabilities expect no more love and reassurance than anyone else.	2.54	7.85	60.21
Adequate housing for people who have disabilities is neither too expensive nor too difficult to build.	3.03	8.90	41.36
For a person with a severe disability, the kindness of others is more important than any educational program.	3.14	8.38	36.13
People with severe disabilities are no harder to get along with than those with minor disabilities.	3.39	10.47	26.70
The placement of children who have physical disabilities into regular classes improve the acceptance of children with disabilities by their peers.	5.84	70.16	.00
It is logical for a woman who uses a wheelchair to consider having a baby	6.03	75.39	1.05
It is more humane to allow a child with a severe disability to die at birth than for her/him to live as a person with a severe disability	6.01	76.44	3.66
People with physical disabilities should get special certification from their physicians in order to apply for a marriage license	6.33	85.34	1.57

value (191) that is within the extreme tail of the accepted distribution. Then a two-way ANOVA was conducted to investigate effects of the two factors and their interaction on MIDS Total scores. The ANOVA result (Table 3) shows a significant interaction effect ($F[4, 180]=3.32$, $p<.016$). However, the calculated effect size (ES=.065) for the interaction indicates only a small proportion of MIDS Total variance is accounted for by the interaction.

Table 4 shows the interaction effect of "gender" and "contact" on "MIDS Total." While female students with increased contact with disabled persons held more positive attitudes, male students held more negative attitudes with increased contact.

Discussion

Only three (1.6%) out of 191 participants were persons with disabilities. Also 74% of participants indicated that they had little or no contact with persons with disabilities. This may be the result of the failure by the segregated special education primary school system to encourage students with disabilities to go on to college. Given that social work students grew up without disabled classmates around, it is remarkable that more than 70% of participants agreed or strongly agreed with the placement of children with physical disabilities into regular classes to improve acceptance by non-disabled peers.

The findings indicate that the overall response was in a slightly positive direction. It appears that the moral model, which strongly supports segrega-

Table 3.   Analysis of Variance

Source	SS	df	MS	F	p	ES
Between subjects	4213.03	9	468.11			
Gender	1463.07	1	1463.07	8.18	.006	.042
Contact	1490.97	4	372.74	1.88	.096	.043
Gender * Contact	2325.59	4	581.40	3.32	.016	.065
Within subjects	33444.43	180	185.80			
Total	37657.45					

Table 4.   **MIDS Total Scores Based On Gender & Contact**

Contact with People with Disabilities	No contact	Very little contact	Some contact	Quite a bit of contact	A great deal of contact
Male	150.1	156.6	147.4	151.0	131.3
Female	152.5	155.8	152.4	162.3	162.8

tion, is not favored by the participants. Nor do they appear to accept the medical model that emphasizes that disabled persons can be cured in order to gain societal acceptance. Although the scale does not include items directly discussing a cure, participants tended to accept disabled persons as they are. Even though Japan does not have a civil rights law for people with disabilities, participants tended to agree with statements that support equal treatment for disabled and non-disabled citizens. The international exchange of ideas since the 1980s along with continuous advocacy work by the disability rights community may have contributed to this apparent shift in the social norm. At least the Japanese social work students in this study tended to support the civil rights of persons with disabilities.

Although the findings show a tendency of participants to accept disabled persons in terms of their rights, they also reveal attitudes suggesting that disabled people have different "psychological characteristics." Many participants believed that disabled persons need more love and assurance than non-disabled persons, and that the kindness of others is more important than education for disabled persons. Also, it appears that many participants felt uncomfortable when they imagined a situation in which they would have to get along with someone with a severe disability. The high

percentages of middle scores for 22 statements also indicate the ambiguous attitudes of the participants, highlighting the need for more education in disability issues.

ANOVA shows the interaction effect of "gender" and "contact" on "MIDS Total." Female students who had more contact with disabled persons had more positive attitudes than female students with less contact. On the other hand, male students with more contact tended to have more negative attitudes. The recent governmental sanction of social work coupled with a long economic recession boosted interest in caring occupations among men. As gender role socialization is still strong in Japan, young men who enter a so-called "women's occupation" may encounter value conflicts. It will be problematic if young men hold relatively positive attitudes toward disabled persons without contact, but develop negative attitudes as contact increases. Social work education needs to pay attention to value differences due to gender socialization in order to appropriately educate future social workers.

A limitation of this research is that the findings cannot be generalized to all Japanese social work students since this research used a convenient sample of students in a school of social work. Replication of the study is necessary to gain a

more well-defined understanding of the attitudes toward people with disabilities among social work students. Another limitation is that the study focuses only on attitudes toward people with physical disabilities. Since social work professionals also work with people who have disabilities other than physical (e.g. psychiatric, intellectual, and learning disabilities), as well as multiple disabilities, further research will be necessary to gain a more complete evaluation of the attitudes of social work students toward people with disabilities. Lastly, as Japanese and English are very different languages, it is possible that the translation of the original MIDS instrument did not exactly capture and accurately present the concepts intended in the statements.

In conclusion, it is encouraging that the young Japanese social work students in this study did not hold strong prejudicial attitudes toward people with disabilities. At the same time, it is apparent that the students lack the necessary knowledge and experience regarding disability issues to become allies and advocates for people with disabilities. The results of this exploratory study indicate that the social work education system in Japan should ensure that the new disability paradigm is included in their curricula.

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On Behalf of the I.W.W.: Helen Keller's Involvement in the Labor Movement

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Abstract: The paper describes Helen Keller's role in the labor movement during the 1910s and 1920s as well as the factors that led to her deciding to cease her labor activism. The thesis of this paper is that Helen Keller was first interested in the causes of industrial blindness. Gradually, she came to believe that the greed that caused employers to balk at installing safety equipment (the cause of many blinding accidents) was inherent in the capitalist system. As she made sympathy speeches on behalf of factory workers, she became acquainted with the Industrial Workers of the World (I.W.W.) labor union. She eventually embraced the I.W.W.'s philosophy, and actively worked for its cause. Several factors appeared to influence her decision to leave the labor movement: (1) The arrest of hundreds of I.W.W. leaders during the early 1920s; (2) The reaction of the public that she was being "duped" by I.W.W. leaders; (3) The failure of LaFollette's Progressive Party to do well in the 1924 Presidential election; (4) Pressure from the American Foundation for the Blind out of fear that their chief spokesman would alienate potential donors, and (5) Pressure from motion picture producers who were seeking to make a film about her life and who did not want any adverse publicity. After this period, Helen concentrated on humanitarian work on behalf of the blind, and only rarely spoke or wrote about labor issues.

Key Words: Helen Keller, labor movement, American Foundation for the Blind

"The two most interesting characters of the nineteenth century are Napoleon and Helen Keller"--- Mark Twain (1916).

Introduction

When many people hear the name Helen Keller, vivid images of her appear in their minds. They envision a young girl stumbling around furniture, eating food from her family member's plates, and saying her first word, "water." The play and movie, "The Miracle Worker" (Gibson, 1956), brought the remarkable story of this young Alabama girl to millions of people around the world.

However, few people know much of who Helen Keller grew up to be a college graduate and crusader for the blind. Even fewer are familiar with her political and labor activism. In the 1910s and 1920's Helen Keller became a socialist and spokesperson in support of the Industrial Workers of the World (I.W.W.) labor union. Despite pressure from friends and influential people to keep silent, she spoke adamantly on the behalf of the I.W.W. One purpose of this article is to explore the reasons for Helen Keller's involvement with the I.W.W.; a second purpose is to examine her reasons for ceasing to speak on behalf of organized labor.

An Interest in Causes of Industrial Blindness

As a young woman, Helen Keller began touring the country in hopes of helping others with blindness and educating the sighted so they would realize the capabilities of the blind and the disabled. In her travels, she discovered that often blindness among workers was traceable to on-the-job accidents, which resulted from poor industrial conditions. Helen attributed these poor conditions to "the selfishness and greed of employers" (Bindley, 1916, pg. 5). Many of the victims had lost their sight as children, working under harsh factory conditions. She stated in one of her many writings that "the real cause [of particular cases of blindness] is an employer's failure to safeguard his machines. Investigation shows that there are many clever safeguards for machinery which ought to be used in factories, but which are not adopted because their adoption would diminish the employer's profits. Labor reports indicate that we Americans have

been … dishonorably slow, in taking measures for the protection of our workmen" (Keller, quoted in Foner, 1966, pg. 29). She was saddened by those afflicted with blindness and disabilities caused by disease and malnutrition, but outraged by the fact that many times it was caused by "men of greed". With a heightened awareness of the industrial laborers of the country, Helen became a proponent for the working class. She gradually addressed broader issues than industrial accidents and became highly critical of the free enterprise system. Helen felt that "the means of employment, the land and the factories, that is, the tools of labor are in the hands of a minority of the people, and are used rather with a view to increasing the owner's profits than with a view to keeping all men busy and productive. Hence there are more men than jobs. This is the first and chief evil of the so-called capitalistic system of production" (Keller, quoted in Foner, 1966, pg. 35). Helen saw a parallel between her own struggles in life and the struggles of the workers. Helen's early years were indeed a struggle. Unable to see, hear, or speak, she was in a world of her own, but once she discovered sign language the outside world was open to her. She felt that "the struggle of the workers resembled her own in many ways and she wished them to be helped as generously as she had been" (Brooks, 1956, pg. 49). Factory workers were having trouble communicating their plight to the outside world and the wealthy business owner offered little relief.

Witnessing the hardships of these struggling workers, she publicized their concerns: "Surely the things workers demand are not unreasonable. It cannot be unreasonable to demand protection of women and little children and an honest wage for all who give their time and energy to industrial occupations" (Keller, quoted in Foner, 1979, pg. 446). In her mind, social justice could never be attained until the great masses of the people were filled with a sense of responsibility for each other's welfare. Helen wrote, "We may draw nearer and more near the age when no man shall live at ease while another suffers" (Keller, 1903). She spoke out in a newspaper article, "Their cause is my cause. If they are denied a living wage, I also am defamed.

While they are industrial slaves, I cannot be free...I cannot enjoy the good things of life which come to me if they are hindered and neglected" (Keller, 1918, pg. 1).

Helen's general empathy for others' sufferings came together with her specific interest in social and industrial causes of blindness to create receptiveness to the Socialist ideas to which she was exposed after 1905 (Stineman & Loeb, 1979). Anne Sullivan, Helen's teacher and live-in companion, married John Macy and the three lived together. During the early years of the twentieth century there was much talk about the threesome concerning their views about Socialism: "Contrary to the general belief, Mrs. Macy (Anne Sullivan) did not rush into this movement, pulling Helen in after her. The Wrentham [Massachusetts] household [of Helen, Anne, and John] went into Socialism... one by one, first Mr. Macy, then Helen, and two or three years later, Mrs. Macy" (Braddy, 1934, pg. 224). One historian commented, "For Helen, participation in the Socialist movement was another bridge to the external world, the 'not-me' world, as she had put it. It was an escape from the 'egocentric predicament' to which she in her deaf-blindness was more vulnerable than most. The struggle of the working class had the throb of life in it, a vividness and reality that her life usually lacked. She knew she was stirring up controversy; but that added to the movement's attractiveness, for controversy meant that the world was paying attention to her" (Lash, 1980, pg. 373). Such attention was welcomed by the Socialists. As the Socialist Party daily newspaper, "The Call", wrote on May 4, 1913, "If ever there was a superwoman that woman is Helen Keller. By her indomitable will she wrought a miracle, and when one ponders over her achievements, the brain is dazzled by the possibilities of the human mind. To us Socialist Helen Keller ought to be doubly precious, for she is our Comrade - let us glory in that" (quoted in the Helen Keller Reference Archive, 2000).

Embracing the I.W.W.

As Helen searched for organizations to help her publicize workers' concerns, she became acquainted with the Industrial Workers of the World (I.W.W.). Unlike the conservative American Federation of Labor (A.F.L.), whose leaders represented only those workers employed in the skilled trades, I.W.W. leaders sought immediate improvements in the wages and working conditions of unskilled factory workers. However, the I.W.W. also had broader goals. Its leaders were openly socialist and many were Marxist, repeatedly calling for a workers' revolution. This revolution would lead to the abolition of capitalism, the end of the wage system, and the creation of a worker-run society (Mills, 1989).

Once Helen embraced the I.W.W.'s general aims, she began to speak publicly on behalf of the organization. Did the leaders of this industrial trade union realize what a champion for their cause they had in Helen Keller? People listened to this woman; they were in awe of her courage and triumphs. She wasn't a crackpot on a soap box, but a revered and admired woman speaking out about the injustices of the times.

Helen not only voiced her concerns and feelings, but also contributed financially to alleviate the workers' plight. "While lecturing, instead of thriftily storing up the surplus, they [Anne Sullivan and Helen] were sending it in checks to the blind in Des Moines, to the deaf in Turkey, to strikers in New Jersey, and to the unemployed elsewhere" (Braddy, 1934, pg. 272). The early nineteen hundreds marked a time when labor strikes were a common occurrence: "Helen sent a check for $87.50 to Little Falls [New York] in support of the [1912] strike at the knitting mills, a sum that Helen had received for writing tender messages of Christmas goodwill to be used on Christmas cards" (Lash, 1980, pg. 386). Accompanying the check she enclosed a message: "Will you give it [the check] to the brave girls who are striking so courageously to bring about the emancipation of the workers of Little Falls?" her letter asked. She con-

tinued, "Until the spirit of love for our fellowmen, regardless of race, color or creed, should fill the world, making real in our lives and our deeds the actuality of human brotherhood----until the great mass of the people shall be filled with the sense of responsibility for each other's welfare, social justice can never be attained" (Keller, quoted in Lash, 1980, pg. 386). In 1916, thirty thousand iron ore miners in the Mesabi Range in Minnesota went on strike under I.W.W. leadership (Betton, 1968). Helen sent them, "all I can share of my earnings." She appealed for public support, "Will citizens who believe in justice remain silent while [Carlo] Tresca and the other leaders of the Mesabi Range strikers are being tried for their lives on an utterly groundless charge of murder?" (Keller, quoted in Lash, 1980, 434).

Helen was appalled by what she saw as injustices dealt to the leaders and members of the Industrial Workers of the World by law enforcement officials in communities throughout the United States. Many members of the I.W.W. were arrested without warrants, thrown in jail without access to attorneys, denied bail, put on trial without jury, or even shot at (Anon., "The I.W.W. and the Socialist Party..." 1917; Adams, 1966). Masked men kidnapped Frank Little, an I.W.W. leader, from his bed at three o'clock the morning of August 1, 1917. They dragged him behind a car, and hanged him from a railroad trestle (Anon., "Crime at Butte, Montana," 1917; Gutfeld, 1969). That same summer, twelve hundred miners were deported from Bisbee, Arizona, because of I.W.W. organizing activity there; however, many deportees were not I.W.W. members or sympathizers. They were packed into freight cars and shipped out into the desert of New Mexico. If an outraged society had not protested they would have died of thirst and hunger (Byrkit, 1982). In a round up of officers, members, and sympathizers of the I.W.W., charges of conspiracy were levied against them (Miles, 1986). Helen was shocked and saddened by these horror stories, but more disturbed that newspapers around the country did not denounce such police actions as unlawful, cruel, and undemocratic acts. Most of the newspapers indirectly praised the per-

petrators of these actions for their patriotic service (Keller, 1918, pg. 1).

In her travels, Helen happened to be in San Francisco when she heard of the barbarous treatment of the unemployed in San Francisco and Sacramento. Helen decried what she called the "mental blindness" all around her (Stineman & Loeb, 1979, pg. 437). She declared that she would speak on the I.W.W.'s behalf from the platform. Authorities warned Helen that if she carried out her promise, she would be "hauled down and carried from the city in a cart". She was not intimidated and was so incensed by the actions taken against the unemployed that she spoke out vehemently to reporters, "I think their treatment was outrageous. It is not a crime to protest for your fellows. It is not a crime to be without bread. They say that these men are I.W.W.'s and that means, 'I Won't Work'. I honor these men for their protest, and I am going to say that... tonight" (Keller, quoted in Foner, 1965, pg. 439). Helen felt so strongly for the I.W.W. cause that she risked the alienation of her public, as well as her personal safety, to publicize it.

Helen Keller's Message

Helen felt that individually, workers had no hope for reaching their goals--they would always be kept the underdogs by their employers. The opening sentence in her article, "In Behalf of the I.W.W.", from the *Liberator*, emphatically proclaimed this: "Down through the long, weary years the will of the ruling class has been to suppress either the man or his message when they antagonized its interests" (Keller, 1918, pg. 1). Helen was deeply concerned with the wants and needs of the working class. She understood their desire to get up out of the wallow of poverty, to make a decent living, and to get ahead in the world. She stated, "I know those men are hungry for more life, more opportunity. They are tired of the hollow mockery of mere existence in a world of plenty" (Keller, 1917, pg. 18). Helen saw a society "divided into two great elements and organized around an industrial life which was selfish, combative, and acquisitive,

with the result that man's better instincts are threatened, while his evil propensities are intensified and protected" (Keller, 1929, pg. 330-331).

According to Helen, it was not only industry that was exploiting the workers, but also the government. Apparently, Helen believed that government leaders viewed the working class as an inexhaustible resource for the military during World War I. She opposed the U.S. military buildup (in the name of "preparedness") just prior to the war, because it "means war, and war means that the class of people who are not responsible for the trouble will have to do the fighting. If congressmen, lawyers, and journalists did the fighting, I would not object so strenuously to preparedness" ("Joys of life are pictured," 1916, pg. 10). The belief that workers were about to die while the rich lived in luxury deeply disturbed Helen. She reported that the United States was facing a grave crisis stating, "The few who profit from the labor of the masses want to organize the workers into an army that will protect the interests of the capitalists" (Keller, 1917, pg. 18).

In contrast, Helen was impressed with the strides that Abraham Lincoln had made on the issue of slavery, impressed with the progress of education through past decades, and the ability of citizens to become more involved in governmental processes.

However, she felt these steps were not enough and more progress was needed. It would only be a matter of time, she believed, before the workers would become united and take possession of what was rightfully theirs--the means of production. In a 1916 speech in La Crosse, Wisconsin, Helen publicly announced that she was a socialist (Anon., "Miss Keller has wonderful story; audience pleased," 1916, pg. 8). In 1918, she wrote, "That long struggle in which they have successfully won freedom of body from slavery and serfdom, freedom of mind from ecclesiastical despotism, and more recently a voice in government, has arrived at a new stage. Workingmen everywhere are becoming aware that they are being exploited for the

benefit of others, and that they cannot be truly free unless they own themselves and their labor. The achievement of such economic freedom stands in prospect – and at no distant date – as the revolutionary climax of the age" (Keller, 1918, pg. 1).

In speaking on the Industrial Workers of the World's behalf, Helen did not hold back her growing feelings about the union. She stated, "The I.W.W. was pitted against the whole profit-making system. It [the preamble to the I.W.W. constitution] insists that there can be no compromise so long as the majority of the working class live in want, while the master class lives in luxury. According to its statement by the I.W.W., 'there can be no peace until the workers organize as a class, take possession of the resources of the earth and the machinery of production and distribution, and abolish the wage system'. In other words, the workers in their collectivity must own and operate all the essential industrial institutions and secure to each laborer the full value of his produce. I think it is for this declaration of democratic purpose, and not for any wish to betray their country [in opposing U.S. involvement in World War I], that the I.W.W. members were being persecuted, beaten, imprisoned, and murdered" (Keller, 1918, pg. 1).

Helen felt strongly about protecting the rights of the working class and the interests of the unemployed. In her article in the newspaper, *Liberator*, she stated, "Surely the demands of the I.W.W. are just. It is right that the creators of wealth [i.e. the workers] should own what they create. When shall we learn that we are related one to the other; that we are members of one body; that injury to one is injury to all?" (Keller, 1918, pg. 1).

The exploitation of the working class was not limited to the United States. It was a worldwide problem. Helen felt strongly that it was just a matter of time before workers all around the world would finally stand up and demand their rights – rights, she felt they deserved: "The mighty mass-movement of which they [workers] are a part is discernible all over the world. Under the fire of the great guns, the workers of all lands, becom-

ing conscious of their class, are preparing to take possession of their own" (Keller, 1918, pg. 1). By writing this type of article, Helen sought to inform and reassure American workers that they were not alone in their struggle--as well as warn the wealthy of the impending revolution. Helen believed that the Industrial Workers of the World was the union that could organize the working class so that such a worldwide revolution was possible.

Helen not only spoke for the Industrial Workers of the World, she became a member. In taking this step she turned her words into action. It was dangerous to be known as an I.W.W. member. However, Helen only grew bolder. She began to speak out more, expressing her views and concerns and was even willing to go to jail if necessary, in order to uphold those views: "She became an I.W.W. member because nothing could be gained by political action within the system. She thought that the true test was to unite and organize all workers on an economic basis and it was the workers themselves who must secure freedom for themselves and the workers themselves who must grow strong" (Bindley, 1916, pg. 5). Helen summarized her feelings on revolution, "We have tried peace education for nineteen hundred years. Let us try revolution and see what it will do now. The revolution is bigger than any [political] party and will come..." (Keller, quoted in Bindley, 1916, pg. 5). She discovered that talk was getting the workers nowhere, and believed that revolution might be the only course of action.

Helen hoped that any workers' revolution might be peaceful. She advocated techniques such as the General Strike, which offered the possibility of a successful worker revolt without bloodshed. She said in an article in the *New York Tribune*, "I am for peace because I think workers can gain their ends by putting their hands in their pockets [i.e., by striking]. The world is theirs then. And with the world in their possession, wouldn't the people promptly proceed to build up institutions and situations almost identical with the ones you deplore? The world can be run no worse than it has been by its economic masters, at least the underdog would

have a chance at the envied bone" (Keller, quoted in Bindley, 1916, pg. 5).

Although she did not favor sabotage and violence, she supported Big Bill Haywood, a member of the National Executive Committee of the Socialist Party, and his endorsement of violence to further the worker's cause and so wrote to *The Call*. She pleaded for "harmony" in the party. "It is with the deepest regret that I have read the attacks upon Comrade Haywood which have appeared in the *National Socialist*. It fills me with amazement to see such a narrow spirit, and such an ignoble strife between two factions [the Eugene Debs faction and the Bill Haywood faction] which should be one, and that, too, at a most critical period in the struggle of the proletariat." She protested the moves against Haywood. "What? Are we to put differences of the party tactics before the desperate needs of the workers?" (Keller, quoted in Lash, 1980, pg. 387). How could the workers ever unite as one if there was so much dissension among the leadership? She deplored ideological factionalism within the working class. "Are we no better than the capitalist politicians who stand in the high places and harangue about petty matters, while millions of the people are underpaid, underfed, thrown out of work and dying? While countless women and children are breaking their hearts and ruining their bodies in long days of toil, we are fighting one another. Shame upon us! The enemy is at our very doors... while we leave the victims helpless, because we think more of our own theories---theories that have not even been tested! How can the workers, whom we urge to unite, look to us Socialists for guidance if we fail to unite? What is our chief bond of unity? The welfare of the working class and the abolition of capitalism" (Keller, 1913, pg. 606).

To summarize, Helen's views were as strong and undaunted as she was. She believed that either blindness from industrial accidents had to end or the machinery that caused the accidents must instead be shut down. She further believed that most problems facing workers were rooted in the economic system, and this too had to change. Wealthy capitalists should no longer enjoy the fruits of the poor workers' labor. Every person – whether rich or poor – deserved decent food, shelter, clothing, and an education for their children. If the I.W.W. members united as one, she thought, they could effect changes, even with a revolution if that was necessary. Her feelings and convictions were so strong that she became an I.W.W. member.

A Time to Speak and A Time to Be Silent

Helen seemed poised on the threshold of becoming a national spokesperson, a woman whose admiration from the public allowed her to influence both opinion and policy on behalf of the working class. Thus it is surprising to discover that, after 1918, Helen's labor and political activities faded from the limelight and eventually ceased altogether. Was it pressure from influential friends or colleagues? Was the reality setting in that change was slow in coming? Was there a change in objectives? Or was the cause a combination of all of these factors? There does not seem to be any concrete documentation pointing to a specific reason, but the evidence suggests that it was a combination of forces. Helen had discovered that when she spoke out about something, people listened. If it was unpopular or uncomfortable, it was usually the subject matter and those associated with it (e.g. I.W.W. leaders) that took the heat instead of Helen: "It took her a long time to learn, indeed, she has never quite learned it, that she cannot help an unpopular cause by endorsing it. She was never blamed, this was for her the worst of it, always someone else. When she announced that she was a Socialist, the Socialists were accused of using her to advertise themselves. When she marched in a suffrage parade the same charge was brought against the suffragists [sic]. When during the World War [World War I] she lifted her voice for peace she was called a supermegaphone for undesirable citizens" (Braddy, 1934, pg. 226). "In the eyes of the public if the topic she spoke out for was favorable she could do no wrong. She soon discovered while she was a goddess and an archpriestess so long as she stood with the majority, she was an ignorant wom-

an who did not know what she was talking about if she came out in opposition to them" (Braddy, 1934, pg. 227).

When she was criticized, the attacks were often personal. For example, Helen's disabilities as well as her political positions were mentioned in a critical *Brooklyn Eagle* newspaper editorial. Helen responded, "... Now that I have come out for socialism he [the editor] reminds me and the public that I am blind and deaf and especially liable to error..." She, in turn, criticized the paper and its editor, "The Eagle and I are at war. I hate the system which it represents... when it fights back, let it fight fair... It is not fair fighting or good argument to remind me and others that I cannot see or hear. I can read. I can read all the socialist books I have time for in English, German, and French. If the editor of the Brooklyn Eagle should read some of them, he might be a wiser man, and make a better newspaper. If I ever contribute to the Socialist movement the book that I sometimes dream of, I know what I shall name it: Industrial Blindness and Social Deafness" (W.C.O., 2000).

The making of the movie *Deliverance*, about the story of her life, may have been the event that led Helen to suppress her views. At first, she had been warned by friends and family but she then began to realize the consequences of her actions herself: "Before Dr. Miller had time to finish the first draft of the scenario, Helen precipitated a crisis by publicly deploring the persecutions of the I.W.W. Panic followed. Her teacher was told that if the picture was to succeed, Helen must for the time being, confine her appeals to their great humanitarian effort and let other great humanitarian efforts alone, especially such highly dubious ones as those sponsored by the I.W.W." (Braddy, 1934, pg. 274). In December, 1918, an article appeared in Upton Sinclair's entitled, "The Blind Who Will Not See", which reiterated the fact that Helen's actions were coming back to haunt her. Sinclair stated, "It was difficult to get this picture [Deliverance] financed, because the capitalist world has discovered that Helen is a Socialist, and is afraid of her; the newspapers no longer mention her, and many big pic-

ture people turned down the proposition. And the world is to be given a story of Helen Keller which omits all mention of the fact that she is a Socialist! It would be propaganda to mention that fact, I was told. Imagine! This girl, who is blind to the present, has seen all the future; in the history of her life that is the supreme, culminating fact, that is the great drama, the meaning and justification of all the rest – and it may not be mentioned! The boys and girls in the movie theaters will get a little slushy sentimentality – they will learn that Helen Keller loves humanity and weeps for the world's woe; but they must not be told that she has dedicated her life to the abolition of the profit system!" (Sinclair, 1918, pg. 16).

In 1924, Robert LaFollette of Wisconsin ran for President of the United States on the Progressive ticket. Helen agreed with his political platform and wrote a letter to him endorsing his campaign. In that letter she also confided her predicament, "So long as I confine my activities to social service and the blind, they compliment me extravagantly, calling me 'archpriestess,' 'wonder woman' and 'a modern miracle.' But when it comes to a discussion of poverty, and I maintain that it is the result of wrong economics---that the industrial system under which we live is at the root of the physical blindness in the world---that is a different matter!" LaFollette's loss marked the end of Helen's active participation in party politics. She did not again endorse a candidate until she supported Franklin D. Roosevelt for a fourth term in 1944 (Lash, 1980, pg. 529).

Helen had begun work on behalf of the American Foundation for the Blind and, here too, she encountered pressure to silence her political convictions: "She soft-pedaled her politics, presumably at the request of the Foundation's trustees which were conservative businessmen, as were the men who would have to give the green light in various communities to the Foundation's fund raising effort. Independently of the political convictions of the trustees, there was a cogent case against Helen, the Foundation's chief fund raiser, proclaiming views

that were likely to give offence to many potential donors" (Lash, 1980, pg. 529).

As Helen grew older and became more involved with the American Foundation for the Blind, the worker's revolution became less of a priority. Also, as America entered the 1920s, society was changing. Many of the United States leaders of the I.W.W. had been arrested and either imprisoned or deported during the "Red Scare" panic that followed the 1917 Russian revolution, rendering the union ineffective as a representative of the working class. This left Helen isolated from many of her former sources of Marxist propaganda (University of Colorado, "The Socialist Legacy of Helen Keller," 2000). The Socialist and Communist parties were divided and generally irrelevant, and the Progressive movement siphoned off some of their remaining public support. Even the conservative American Federation of Labor (A.F.L.) union organization declined (Rayback, 1966). Therefore, one explanation for Helen's silence is that she no longer had the time nor the inclination to devote her energy to causes whose success seemed ever more remote (Lash, 1980, pg. 527).

Some years later, in 1937, Helen read an article in *Reader's Digest*, entitled, "John L. Lewis, Labor's Looming Force". In response to the article Helen made one of her last public statements concerning her beliefs on the rights of the working class. She stated, "This is the first time since Eugene Debs' earlier years that I have had any lively hope of a labor movement in this country. Whether John Lewis is a genuine radical or not I am uncertain, but he appears to have courage, wisdom and the wide influence required to organize the majority of the American population. If he succeeds in mobilizing even a part of the laboring class to bargain collectively for wages, hours and better living conditions they will thus secure a voice in the government and make it more truly a democracy. His massive personality, amazing powers of persuasion and defiance of the lightning – corporate wealth mightier than any political empire earth ever witnessed – command my admiration..." (Keller, 1938, pg. 200).

Helen Keller was a woman of courage. Instead of seeking personal gain, she used her publicity and notoriety to help the working class: "Her vision enabled her to see into the future of mankind. She believed that the salvation of humanity would come through an intelligent application of socialism. She stated, 'if the greedy were able to think better, the needy would be able to live better'" (Keller, quoted in Thomas, 1948, pg. 419). Her determination helped lay the foundation for state and federal legislation addressing the concerns of workers and their families. But Helen faced a dilemma that all must consider: How should one best spend one's time and energy to help humanity?

For Helen, this first meant making speeches on behalf of the workers, and then – when those efforts became counterproductive – stopping those speeches and instead concentrating on other causes that would benefit humanity. In choosing this path, Helen Keller truly showed her genius.

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Disability in Chronic Fatigue Syndrome and Idiopathic Chronic Fatigue

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Abstract: The current investigation classified 31 people with chronic fatigue syndrome (CFS) and 44 people with idiopathic chronic fatigue (ICF) into mild, moderate, and severe/very severe categories of self reported functional impairment. Differences in sociodemographic characteristics, symptom frequency, symptom severity, and functional impairment were examined between individuals with CFS and ICF, and were examined among the three categories of functional impairment. Results indicated that there were no differences between the CFS and ICF groups in their functional impairment classification. People who were classified into the more disabled categories reported more severe symptoms, and were more likely to have scores indicating higher disability on other measures of functional status. Implications of these findings are discussed.

Key Words: chronic fatigue syndrome, idiopathic chronic fatigue, disability classification, functional impairment

Introduction

Chronic fatigue syndrome (CFS) is a highly heterogeneous condition, affecting people in various ways and fluctuating in terms of symptoms and severity (Anderson & Ferrans, 1997). Although the pathophysiology of CFS involves severe, prolonged fatigue, as well as neurological, immunological, and endocrinological abnormalities (Friedberg & Jason, 1998), it remains a poorly understood and controversial illness (Jason *et al.*, 1995). Like many other chronic illnesses, CFS has been difficult to define because exact causal agents are unknown, physical signs and symptoms are variant, and di-

agnostic laboratory tests have poor sensitivity and specificity (Holmes, 1991).

One major challenge facing CFS research is patient heterogeneity. Across studies, individuals with CFS have been found to differ across characteristics such as gender, ethnicity, socioeconomic status, symptom severity, functional disability, psychiatric status, and coping styles (Friedberg & Jason, 1998). Failure to address this heterogeneity has likely resulted in study conclusions that are inconsistent. These discrepant findings have caused the field to become highly polarized regarding issues of etiology, diagnosis, epidemiology, and treatment. When unique patient groups are unwittingly combined, important distinctions between specific subtypes of CFS may become blurred. Addressing this issue may improve the validity of future research findings by uncovering symptom variations in subgroups of people with CFS.

Persons with CFS appear to be heterogeneous with respect to the level of disability they exhibit. Compared to other chronically ill populations, persons with CFS experience a markedly higher degree of impaired functioning (Anderson & Ferrans, 1997; Buchwald et al., 1996). When using the Medical Outcomes Survey (MOS), Buchwald et al. (1996) determined that persons with CFS appear to be severely disabled on measures of role functioning, social functioning, and vitality. Scores on these MOS subscales were markedly lower than previous work with other chronically ill populations. Anderson and Ferrans (1997) obtained similar results when examining Quality of Life Index (QLI) scores in persons with CFS. They concluded that QLI scores in the CFS group were lower than other chronic illness groups and healthy controls for all four domains (Health and Functioning, Social-Economic, Psychological/Spiritual, and Family).

One study addressed the issue of heterogeneity by creating four categories describing levels of functioning. Cox and Findley (2000) examined the varying levels of disability that people with CFS manifest and proposed a system of classification based on functional status. Persons classified in the mild category were mobile, providing self-care, and still working. However, in order to maintain work responsibilities they had stopped all leisure and social activities. Persons in the moderate category experienced reduced mobility, restrictions in activities of daily living, and were usually not working. They required many periods of rest, and sleep quality was generally poor and disturbed. Cox and Findley indicated that the moderate group has been most frequently studied in research. Persons in the severe category were able to carry out only minimal daily tasks, were wheelchair dependent, experienced severe postexertional malaise, and substantial cognitive and memory difficulties. Finally, persons in the very severe category were mainly bedridden and were unable to perform substantive daily tasks.

It would be expected that persons meeting the US case definition of chronic fatigue syndrome (Fukuda et al., 1994) experience a greater amount of disability than those who do not meet the current US case definition. The current US case definition was derived by clinical consensus and was not empirically based. Several studies have attempted to empirically validate the diagnostic accuracy of this definition (Hartz et al., 1998; Jason, King, et al., 1999; Komaroff, et al., 1996; Nisenbaum, et al., 1998). The appropriateness of the case definition in accurately classifying persons with CFS continues to be studied. The implicit assumption that individuals diagnosed with CFS using the current CFS case definition have a more severe illness and are more disabled than those partially meeting the current CFS criteria has yet to be empirically examined.

The present investigation examined a group of persons with Chronic Fatigue Syndrome, who fully met the US case definition for CFS (Fukuda et al., 1994), and a group of persons with Idiopathic Chronic Fatigue (ICF), who met partial but not full criteria for chronic fatigue syndrome. This larger sample of persons with chronic fatigue syndrome and with idiopathic chronic fatigue was then classified into the functional impairment cat-

egories proposed by Cox and Findley (2000) using self-reported disability. It was expected that persons with CFS who fully met the criteria for CFS would be more severely disabled than those only partially meeting CFS criteria. In addition, the occurrence of symptoms, the severity of symptoms, and scores on other disability measures were examined across the disability groups. It was expected that persons with greater disability according to self-report would exhibit increased symptom occurrence, more severe symptoms, and greater disability on other measures of functional status.

Method

Procedure

The data are derived from a larger community-based study of the prevalence of Chronic Fatigue Syndrome (for more details of this study see Jason, Richman, *et al.*, 1999). This larger study was carried out in three stages. Stage 1 involved administering an initial telephone-screening questionnaire in order to identify the symptoms of Chronic Fatigue Syndrome. Stage 2 consisted of the administration of a semi-structured psychiatric interview. In Stage 3, participants underwent a complete physical examination. Upon completion of the study, a team of four physicians and a psychiatrist made the final diagnoses of CFS, ICF, or fatigue explained by medical or psychiatric condition. These physicians were familiar with the CFS diagnostic criteria and did not know the experimental status of the participant. Two physicians independently rated each case to determine whether the participant met the CFS case definition (Fukuda *et al.*, 1994). If a disagreement occurred, a third physician rater was used to arrive at a diagnostic consensus. Following this final stage, four physicians and a psychiatrist made a final diagnosis.

Sample

Procedures developed by Kish (1965) were used to select one adult from each household. The birth dates of the adults residing in each household were gathered. The person with the most recent birthday was selected for the interview. A stratified random sample of several neighborhoods in Chicago was utilized. In the first stage, 28,673 residential/working telephone numbers were contacted with 18,675 adults actually completing the initial screening interview (a completion rate of 65.1%).

The Stage 1 screen revealed that of the 18,765 participants who were interviewed, 780 (4.2%) had chronic fatigue. Of these, 408 had chronic fatigue and the concurrent occurrence of four or more symptoms. These participants were defined as CFS-like. The suffix "like" was used to clarify that individuals in this group only met the Fukuda et al. (1994) criteria by self-report and did not necessarily qualify as having a final diagnosis of CFS rendered by a physician.

One hundred sixty-six of the 408 CFS-like participants agreed to complete a structured psychiatric interview (Stage 2) and a comprehensive physical examination (Stage 3). There were no significant differences on sociodemographic (i.e., gender, ethnic identification, age, occupation, education, and marital status) or fatigue scores between these 166 screened positive (CFS-like) participants and the 242 screened positive (CFS-like) non-participants. The control group was composed of 199 individuals selected randomly from the remaining 18,260 screened negatives (seven cases were excluded due to missing data). Of these 199 individuals, 47 completed medical evaluations. There were no significant sociodemographic differences (i.e., gender, ethnic identification, age, occupation, education, and marital status) or fatigue scores between the 152 screened negative non-participants and 47 screened negative participants.

Participants were then classified by independent physician consensus. For participants who reported chronic fatigue, physicians diagnosed 32 people with CFS, 45 people with idiopathic chronic fatigue, and 89 people with fatigue explained by a medical or psychiatric illness.

Participants

The present investigation examined the occurrence of symptoms in two groups of participants. The first group consisted of 32 persons from the larger group of 166 persons with CFS-like symptoms who were diagnosed with CFS by the independent physician review panel (CFS group). The functional impairment status was missing for one person in the CFS group so this person was excluded from all analyses. The second group consisted of 45 persons diagnosed with idiopathic chronic fatigue (ICF) who had unexplained fatigue, but did not meet the current case definition for CFS. One person in the ICF group did not report any functional impairment and was excluded from all analyses. Thus, in the present investigation, the CFS group consisted of 31 participants and the ICF group consisted of 44 participants.

Measures

Screening Questionnaire

The Stage 1 screening questionnaire assessed interviewee's sociodemographic characteristics and preliminary classification into screened positive (CFS-like) versus screened negative groups. This screening instrument has been found to have adequate reliability (Jason et al., 1997). Basic sociodemographic data included age, ethnicity, marital status, and gender. The revised scoring rules for Hollingshead's (1995) scale, developed and validated by Wasser (1991) were used to classify socioeconomic status.

Structured Clinical Interview for the DSM-IV (SCID) (Spitzer et al., 1995)

The SCID is a semi-structured interview designed to yield DSM-IV psychiatric diagnoses. It is a valid and reliable measure that approximates a traditional psychiatric interview (Rubinson & Asnis, 1989). This measure has been shown to offer the most accurate means of diagnosing psychiatric disorder in individuals with CFS (Taylor & Jason, 1998). Master's level psychology clinicians who were trained extensively in SCID administration

were supervised by a licensed clinical psychologist administered the SCID. The SCID was administered in Spanish to Spanish-speaking participants by bilingual master's level psychology clinicians.

Levels of Disability

As part of the Screening Questionnaire, participants were asked to describe the impact of their fatigue during the last month on a seven point scale, with 1 being bedridden and 7 being able to do all work or family responsibilities without any problems. Responses to this question were then used to classify participants into the groups proposed by Cox and Findley (2000). The mild group consisted of participants who reported being able to work full time and on some family responsibilities, but who had no energy left for anything else. The moderate category consisted of participants who reported being able to do light housework or work part time or work on some family responsibilities. The severe group comprised participants that reported being ambulatory, but unable to do light housework. Finally, the very severe group reported being bedridden and unable to work or do other activities. Only two persons were classified into the very severe group. Therefore, the severe and very severe groups were combined and treated as one group (severe/very severe) in the subsequent analyses.

Symptoms

Participants were also asked to complete a detailed medical questionnaire assessing the occurrence and severity of Fukuda et al. (1994) symptoms (Jason et al., 1997). The occurrence of symptoms that had occurred in the 6 months since the onset of fatigue was assessed. Severity of symptoms was rated on a 100 point scale with 0 = no pain or problem and 100 = severe pain or problem.

Fatigue

The Fatigue Scale was originally used in a hospital-based case control study (Wessely & Powell, 1989) and was further refined by Chalder et al.

(1993). This scale was found to be reliable and valid with reasonable face validity and discriminant validity. The 11 items are rated on a four-option continuum with subscales assessing both mental and physical fatigue. Total score range from 0-33 (with higher scores being indicative of greater fatigue). This scale was used in the community-based study of fatigue (Pawlikowska *et al.*, 1994).

Medical Outcomes Study

Participants completed the Medical Outcomes Study 36-item Short-Form Survey (MOS) (Ware & Sherbourne, 1992), a reliable and valid measure that discriminates between gradations of disability. This instrument encompasses multi-item scales that assess physical functioning, role limitations due to physical health problems, bodily pain, general health, vitality (energy/fatigue), social functioning, and mental health. Higher scores indicated better health, lower disability, and less impact of health on functioning. Reliability and validity studies for the 36-item version of the MOS have shown adequate internal consistency, discriminant validity among subscales, and substantial differences between patient and nonpatient populations in the pattern of scores (McHorney *et al.*, 1993; McHorney *et al.*, 1992; McHorney, *et al.*, 1994). The MOS Physical Composite Score (PCS) and Mental Composite Scores (MCS) were also utilized in the present investigation as combined measures of the eight MOS subscales to rate global impairment of physical and mental functioning. These PCS and MCS have appropriate validity and reliability as well as greater sensitivity and specificity in discriminating the gradations of health status among groups (Brazier *et al.*, 1992).

Degree of Impairment

Participants were asked to rate the degree to which their fatigue has impaired their functioning in daily activities on a 100-point scale, with 0 = no difficulties and 100 = total and complete disability.

Statistical Analyses

First, the sociodemographic variables of gender, age, ethnicity, marital status, parental status, work status, socioeconomic status, current psychiatric diagnosis, and lifetime psychiatric diagnosis were compared between the CFS and ICF groups using chi-square analyses. Next, these sociodemographic variables were compared between the mild, moderate, and severe/very severe groups using chi-square analyses. When differences were found in the sociodemographic characteristics between the CFS and ICF groups, and between the mild, moderate, and severe/very severe categories, these variables were entered into the subsequent analyses in order to control for the effects of these variables on the outcome measures.

Table 1   Self-Reported Level of Ability for the CFS and ICF Groups
CFS (N=31   ICF (N=44)

Level of Ability	CFS	ICF
Mild	14	30
Moderate	12	10
Severe/Very Severe	5	4

A chi-square analysis was performed to determine whether the CFS and ICF group significantly differed in the number of participants classified in each category of functional disability. Binomial logistic regressions, controlling for sociodemographic differences, were utilized to examine the occurrence of Fukuda et al. symptoms in the mild, moderate, and severe/very severe groups. ANCOVAs, which controlled for the sociodemographic differences between the mild, moderate, and severe/very severe group, were utilized to compare the severity of Fukuda *et al.* (1994) symptoms and to compare scores on other measures of functional impairment.

Results

Preliminary Sociodemographics Analyses

Using chi-square analyses, participants in the CFS and ICF groups did not significantly differ on sociodemographic variables. When examining differences between the mild, moderate, and severe/very severe categories, significant differences between these groups were found in age ($X2$ (1, N = 75) = 16.58, p < .05) and work status ($X2$ (1, N = 75) = 51.46, p < .01). Therefore, analyses of symptom occurrence, symptom severity, and functional impairment included age as a covariate to control for the effect of this variable. Work status was not entered as a covariate because it was expected that work status would be highly correlated with self-reported functional disability level.

CFS vs. ICF group

Chi-square analyses indicated that the CFS and ICF groups did not differ significantly in the number of persons classified into the mild, moderate and severe/very severe categories ($X2$ (2, N = 75) = 3.97, p>.05) (see Table 1). Because there were no difference between the CFS and ICF groups in whether they were classified as mild, moderate, or severe/very severe, in subsequent analyses, CFS/ICF status was not used a covariate in the analyses examining differences among these three groups.

Symptom Occurrence

Binomial logistic regression analyses were performed to compare the occurrence of the case definition symptoms (Fukuda et al., 1994) across the three disability level groups, controlling for the effect of age. The mild and moderate groups were separately compared to the severe/very severe group (see Table 2). The mild group reported significantly lower rates of postexertional malaise than the severe/very severe group ($X2$ (1, N = 75) = 5.33, p < .05). Furthermore, the moderate group reported significantly lower rates of memory and concentration difficulties than the severe/very severe group ($X2$ (1, N = 75) = 4.13, p < .05).

Symptom Severity

ANCOVAs were conducted to examine the severity of the eight Fukuda et al. (1994) symptoms across the three disability level groups, controlling for the effects of age. The ANCOVA analyses indicated that the occurrence of sore throat (F (2, 75) = 10.85, p < .001), lymph node pain (F (2, 75) = 4.35, p < .05), muscle pain (F (2, 75) = 4.35, p = < .05), joint pain (F (2, 75) = 3.40, p < .05), post-exertional malaise (F (2, 75) = 4.11, p < . 05), memory and concentration (F (2, 75) = 4.42, p < .05), and unrefreshing sleep (F (2, 75) = 5.38, p <. 01) were significantly different across the mild, moderate, and severe/very severe categories (see Table 2). Bonferroni post hoc analyses indicated that participants in the mild group reported significantly less severe sore throat pain (p < .001), lymph node pain (p < .05), muscle pain (p < .05), unrefreshing sleep (p < .05), and memory and concentration difficulties (p < .05) than the severe/very severe group. The moderate group reported significantly less severe sore throat pain (p < .05), lymph node pain (p < .05), muscle pain (p < .05), joint pain (p < .05), post-exertional malaise (p < .05), and unrefreshing sleep (p < .01) when compared to the severe/very severe group. There were no significant differences between the mild and moderate groups in the occurrence of these symptoms.

Functional Impairment

ANCOVAs were conducted to examine differences on the MOS Physical Composite Score, MOS Mental Composite Score, self rated degree of impairment of functioning in daily activities, and fatigue severity scores between the mild, moderate, and severe/very severe groups with age as a covariate. The MOS Physical Composite Score (PCS) (F (2,57) = 11.55, p < .01) and participant self-ratings of impairment of functioning in daily activities (F (2,59) = 9.88, p < .01) were significantly different among the three disability level groups (see Table 2). Bonferroni post hoc analyses indicated that participants in the mild group had significantly

Table 2   Comparison of Symptom Frequency, Symptom Severity, and Functional Impairment for the Mild, Moderate, and Severe/Very Severe Groups[1]

	Mild (N=44)	Moderate (N=22)	Severe/Very Severe (N=9)			
Symptom Frequency	%	%	%	M	M	M
Sore Throat	18.2	22.7	11.1	23.7a	30.7b	78.0a,b**
Lymph Node Pain	13.6	22.7	11.1	22.1a	29.5b	100a,b*
Muscle Pain	50.0	40.9	55.6	51.7a	45.5b	87.5a,b*
Joint Pain	34.1	36.4	44.4	55.8	46.6b	86.4b*
Postexertional Malaise	25.0a	31.8	66.7a*	55.6	47.6b	89.2b*
New Headaches	43.2	27.3	55.6	56.0	53.2	80.0
Memory and Concentration	56.8	40.9b	77.8b*	49.2a	55.0	81.4a*
Unrefreshing Sleep	54.5	54.5	44.4	62.1a	54.4b	90.0a,b**

PCS3	42.8a,c	34.4c	27.9a**
MCS3	38.9	40.5	35.7
Chalder	18.8	20.5	20.7
Degree of Impairment	46.0a	59.0	77.2a

**a,b Similar letters next to two columns indicate that they are significantly different at the p < .05 level using Bonferroni post hoc analyses.

* = P < .05, ** = P < .01   Higher scores on the MCS and PCS indicate less disability.

higher physical functioning as measured by the PCS when compared to the moderate (p < .05) and severe/very severe (p < .01) groups. Further, the mild group reported significantly less impairment of physical functioning in daily activities on a 100-point scale than the severe/very severe group (p < .001).

Discussion

This study examined differences in sociodemographic characteristics, symptom frequency, symptom severity, and functional impairment in individuals with CFS and ICF, and classified persons with CFS and with CFS into mild, moderate, and severe/very severe categories of self reported functional impairment. It is interesting to note that the CFS and ICF groups did not significantly differ in self-reported functional impairment. In fact, fourteen persons with ICF reported functional impairment that could be classified as moderately, severely, or very severely disabled. This finding indicates that while persons with ICF do not fully meet the current US case definition for CFS (Fukuda *et al.*, 1994), many experience disruptions in occupational, educational, social, or personal activities that are similar to those reported by persons with CFS.

Important differences emerged between the mild, moderate, and severe/very severe groups with respect to symptom occurrence and symptom severity. When examining symptom occurrence, differences among the disability groups were found only for postexertional malaise and memory/concentration difficulties. In contrast, differences were found between the disability groups on the severity ratings of all the symptoms except new headaches. This highlights the importance of considering severity of symptoms, not just symptom frequency, in differentiating people of varying disability levels.

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People in the severe/very severe category were more likely to have lower scores in the MOS, indicating more disability on this measure, and higher scores on the self-reported 100-point scale of disability. These findings provided evidence for external validity of this disability classification. Further, there were relatively few differences between the mild and moderate categories. This suggests that there may be little distinction between the mild and moderate category. When examining disability, therefore, it may be useful to contrast those in the mild or moderate category with those in the severe or very severe category. However, in the present investigation, very few people fell into the very severe category, so that the severe and very severe people were considered together in the analyses. Future research should focus on comparing the severe and very severe categories to determine whether important distinctions would emerge between these two groups.

Finally, the current investigation found that very few people fell into the very severe category. It is possible that persons who were very severely disabled people were less likely to participate in the present investigation. Because of their very low functioning, they may have been less likely to answer the telephone in order to complete the initial CFS screening questionnaire, and, likewise, they may have been less likely to agree to complete the interviews and medical examination given to the study participants.

In summary, the present investigation found that people with CFS and ICF did not differ in the level of self-reported functional impairment. Further, when looking at the occurrence of symptoms, only post exertional malaise and memory/concentration difficulties differentiated the disability level groups, whereas the severity of all symptoms in the CFS case definition, with the exception of new headaches, significantly differentiated the disability level groups. The disability classification as proposed by Cox and Findley (2000) appeared to be associated with other disability measures. Future research on this classification system may provide further evidence for its validity. Finally,

future research that classifies people according to their level of functional impairment will likely help delineate important differences among these subgroups of people with CFS.

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Framing Nancy Mairs:
A Documentary Project

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Abstract: This article is an interview and conversation between disability activist and writer Nancy Mairs, and videomaker Janice Dewey. They discuss the making of a documentary about Mairs' life and explore intersects between writing, film, and disability

Key Words: Nancy Mairs, documentary, arts and disability

Most readers familiar with the academic and literary terrain of disability studies know the creative non-fiction work of Nancy Mairs. Her foundational essay, *On Being a Cripple*, is included in *The Norton Reader: An Anthology of Expository Prose*, a tome carried to college classrooms across America and certainly abroad wherever English is the dominant language used in formal education. Mairs writes "through" her multiple sclerosis-disabled body and wheelchair perspective on the world in all seven of her books of essays, most notably, *Waist-High in the World: A Life Among the Nondisabled*.

The recent publication of, *A Troubled Guest: Life and Death Stories* (Beacon Press, 2001) continues Mairs' remarkable production of literary and theoretical work, a body, if you will, that represents a seamlessly integrated world: memoir, politics, theology, philosophy, feminism – all the many sight lines and fault lines that allow us to acknowledge and question the human condition and experience. How do we live? How do we die?

In these essays Mairs marks the inevitable passage into what can no longer be deferred: conscious awareness that indeed one is going to die, in large part due to the deaths of one's parents.

There is no one standing guard anymore (as there truly wasn't anyway) on "generational watch." The path ahead toward death has been completely cleared of those who lead us there. The intensely personal and detailed meditations the writer pres-ents with renowned elegance, intelligence, and wit-full turn of phrase cover her own attempted suicide, the deaths of her father, mother, and step-father, the murder of her son Ron, the importance of creature love and the despair and praise born of pets' passing, the philosophical and political complications of the death penalty. In her opening essay, *A Necessary End*, Mairs writes: "Without death to round our little lives, they have neither shape nor sweetness nor significance... Death makes us who we are" (pages 2, 7).

Nancy Mairs: Waist-High in the World is the title I've borrowed for my hour-long interpretation of the writer's life and work. A digital video made over a 5-year period, the visual narrative unfolds through short sequences to interpret a spectrum of Nancy's extraordinarily ordinary disabled life, a writer's life. I've known Nancy for 23 years. We met in graduate school on our journeys toward a Ph.D. in English and Spanish, respectively. Many years ago, as if the proverbial light bulb switched on, I thought, "Someone should make a film of Nancy Mairs." I couldn't have known then what I now know - I would make my film insight into a significant educational expansion of the study of Mairs' literary and political work. With this film viewers, whether they have read her work or not, glimpse Nancy's whole body and voice - a sensual articulation - through one woman's presentation of a longtime friend.

Following is an interview/conversation I had with my always-agreeable film subject in late 2001:

J: One thing I've never talked to you about, but perhaps has been transferred into the documentary, is that I've always been aware that one of the wonderful qualities about you, besides personality, is a whole sensuality that is there for someone to move into because you're disabled.

For almost as long as I've known you I've cut food for you when we eat together, I sit very close to you, move your hand; I've always felt as a human being that I've been invited to be more physical,

even sensual. It's an invitation to come into your personhood, perhaps.

N: Well, it isn't an insistence. Sometimes I've felt that I've forced people into my world, but the pragmatics are that I can't do things for myself and therefore have to get people to do them. It's a question of what spirit one does this in. I guess it would be possible to set up some kind of distance, or master-servant relationship, remoteness, so that the caregiver becomes kind of an object rather than another person. For me, the person who's cutting my food is also a person, someone I'm interacting with, talking to, being with.

I would go nuts if I couldn't do that with people. I think that's why I don't like having PCAs [Personal Care Assistants].

J: What's the difference between a PCA and having Sally (sister) or George (husband) or me (friend) around? Besides the fact that you know us?

N: I know all of you but it's more than that. There's an intellectual component. I had a wonderful PCA who was terrifically useful to me and I really appreciated that. There was something missing in the relationship that I really value, a level of intellect.

I no longer have this caregiver and it puts me into a terrible bind right now because I know I must get another one, and keep putting it off and putting it off, for I would much rather have George take care of me. But that means it will take its toll on him and he doesn't get much of a sense of freedom. Oh he goes off, but I can't suppose he can keep me out of mind. Most people just go off and leave each other, they don't worry about the other when they're not together. The thing about George is...when he's taking care of me...I can be almost as alone as when I am by myself. And I guess for me that's the nature of intimacy, you know, you don't feel obliged to interact and can be spontaneous. And if you say anything you know there will be a response based on shared life, shared memories, shared cats.

J: Again, there's something present in the relationship between disabled and abled that is missing in able-bodied to able-bodied relationships. Some quality.

N: As a society we are really resistant to any of that kind of "helping," we're so independence oriented..."I can do it myself"... and there are people with disabilities like that. I don't know why it is more possible for me to say, "I can't do it myself" than a lot of other people with disabilities, but I can. I suppose I don't see my disability as a personal fault. I never have.

J: That's a central thesis of your argument about disability.

N: A lot of people do and they are encouraged to, that's the general social attitude toward any sort of difference: it's a personal fault; it's a shortcoming of some sort. For some reason I've just been inured to that. It doesn't make sense to me. I didn't do this on purpose.

J: Let's talk about the history of this project. It was a long time ago when I thought, "someone should make a film of Nancy Mairs." Then, eventually, I started looking for people to accomplish this idea, thinking that I could be involved in someway. I met Jeff Imig, and he said, "My job [at the University of Arizona] is to teach you how to do this." And you, very graciously, allowed yourself to go into the experiment.

N: Well, I'm a teacher at heart.

J: There's an interesting question about this project that's related to what people often ask you - they wonder about how you use your family as your subject matter and present them in a highly personal way. You disclose a lot.

I've often been troubled myself about how this documentary uses you for a large project that will benefit me academically. I feel this use to be exploitive and thus some kind of contamination, even though the project is a creative and educational one.

N: This question doesn't trouble me. Why don't I feel that barrier around privacy that many people do feel? Maybe it's because I've been so cut off in the first place that I don't erect borders/barriers...I've always been behind some kind of wall or secret. So this openness to write about the interior world maybe comes from a sense that no one is listening, so it doesn't matter.

J: But you've become such an intimate writer, a writer about intimacy.

N: It's what I know; it's what I can do. My mother always wanted me to write a novel. I knew it was because she wanted me to write something that was made up, instead of something that was about the family. George and Matthew (son) want me to write a novel too; they love novels as I do. But I've never really wanted to write one and I guess it's because I think this is something anyone can do, not in a sense that it's easy or anything, but nobody else can write the books that I've written, which is why I go on working the way that I do. I can be sure that the work is my own.

J: Perhaps we could talk about "framing," any kind of camera choice made in the taping or editing.

N: That's not different from what I do as a writer.

J: What might be distinguished between how writers frame and videographers frame, that is framing an essay versus framing the visual?

N: Another question might be, what is lost in the process of framing, film or essay? You know, whenever I finish an essay or even a whole book I think, "Well, that's not it." No matter what I do it's not going to be enough, not going to be the whole. The same for you. You're not going to "get" Nancy Mairs. Not even if you shot 100 hours...

J: No, it's not reality TV, nor is "reality TV" ever reality.

N: Maybe the essential truth is we don't know what reality is... we, as humans, frame continuously.

J: And we've become these sophisticated post-modern technological framers who watch TV a lot and can take in cuts, edits, at light speed. Think about September 11th. I've had so many discussions with my students about "reality" versus "pictures," horrendous pictures, and then there's that story about the little girl who called her mother into the room "to see the beautiful pictures." Her mother, quite upset, explained that many people had died, and the very young girl started crying and said, "But still, they're pretty pictures."

N: But I have always seen the world as beautiful pictures and seen the world as stories, and I don't think I'm unusual in that regard. I remember talking to Barbara Kingsolver about this years and years ago. We'd told ourselves since very young, told ourselves the stories of our lives, and that was the writing instinct... but think about what we leave out, and have to or we'd go nuts. The essential part is maybe pre-conscious, or a part of early consciousness, deciding to leave out what can't possibly be taken in at any given moment. I suppose that's the problem of being ADHD, a problem editing out.

J: You're reminding me of a TV story I saw last night. New York filmmakers were called in "to light the stage of the Twin Towers' tragedy." They went in with huge cranes and all the equipment necessary to light the debris field for the rescue workers as if it were a film... and one guy said that no matter how much it looked like a movie, the people carrying out the bodies and the bodies themselves did not look like actors no matter how well an actor could have portrayed the part. The whole process was awful and the imagery awful. I think we are very confused about this, in image making, for example. How can we stand to watch these images replayed? Because we distance ourselves. It's not real.

N: I can remember watching the Challenger disaster over and over. It was so beautiful.

J: A related question: what does it feel like to watch yourself in this documentary?

N: I'm sort of used to it. Video has been around for a longtime. I used to get taped while teaching. So the initial shock, sort of like the first time you hear your voice tape-recorded...that's not what you take for your voice, that's not what you think you look like. You imagine yourself something else. I don't have that shock anymore, but I do have a whole complex of feelings. I've said this about photographs and it's true for video as well, there's always a disappointment. The film doesn't make you more beautiful than you are... you're used to seeing beautiful photos, and you're disappointed in the one of you.

J: One of the reasons this video comes alive is because you are so activated, enlivened, as a body in a wheelchair... I've watched you come down from the trees so to speak, from Nancy walking into Nancy in a wheelchair. You inhabit space very beautifully. It's one of the attractions involved in learning your story: your grace and your face and how you compose yourself.

In the documentary you present the case of a man with MS who has resigned himself to the wheelchair (eventually, and with reluctance) but refuses to take anti-depressants.

N: It was interesting, we (George and I) went to a gathering of alternative education-type people and this man greeted me alright, but stayed as far away from me as he could. He didn't want to have any contact.

J: Now here's a man with disability that will not want to see your film.

N: No, he'd hate anybody who occupies disability in a rather passive fashion - don't know if this is the right word - I'm not particularly passive, but I am passive physically, and "passive" is suffering-related. I'm willing to acknowledge the dimension of suffering that's come with MS and that's something a lot of people with disabilities hate,

won't do. They deny that they have any (suffering, disability).

There are a lot of people with disabilities who think "we're not disabled" and there's a whole political contingent of people with disabilities who say "if society didn't erect all these barriers, if society provided plenty of ramps, interpreters, Braille, and all of that we'd be just fine."

I'm all for accommodation and as much as possible but I cannot believe that my life would not have some lack I directly connected to my disability.

J: Your essays (particularly in *Waist-High in the World*) suggest much to think about with regard to the disabled body in the non-disabled world, that it is but one more difference we've got to acknowledge within the diversity of human experience... the difference created by the entry of the disabled into the non-disabled world.

N: Even with all the changes, ramps, space considerations, etc., I still don't have an able body, because of my disability, not because of society's failure to build enough ramps. That's particularly true and evident when my grandchildren are around. I can't scoop them up because I can't... that's a kind of suffering that can't be compensated for. I'm suspicious of people who reduce their disability to a series of compensations... like that would be enough. I think they're emotionally stopping at some point before the fullness of reality when they say that. But it's definitely from a disability rights point of view "un-PC" to acknowledge suffering.

J: What would you hope an audience could take from seeing this video documentary?

N: I haven't thought about this.

J: Well, I can say what I would like people to get. I want them to receive the visual world that you present so beautifully in words in your own work, especially since it is so personal. I immediately thought it would be a good educational tool when teaching your essays.

N: There are films about writers that I've seen used in conjunction with their work. It always does add a dimension to the whole person, but a glimpsed person. It's more than you have without it. I've always been sad that Virginia Woolf died too early for video... I think there is a sound recording of her done by the BBC. A film is not a substitute at all for the work, but a supplement, it's like going to Monk's House and seeing the studio in which she wrote... it doesn't explain the work or necessarily illuminate any particular work, but it integrates the work of the person. I always look at the photos on jackets of books.

J: Yes, something there animates the life of the person. It also satisfies some desire to know something about the life of the writer behind the work.

N: My mother brought me a rose I still have somewhere that she had plucked from Isak Dinesen's garden, so even an object... but I don't know if I'm able to explain that, there's something mysterious about it... because obviously that rose has nothing to do with Isak Dinesen, and yet I was moved by it.

J: I have a maple leaf from Emily Dickinson's front yard... perhaps this is about making contact in some way. You write very eloquently about reading and what reading does for the reader, how it creates a world... so now you have this rose or leaf that you connect to that world. With this video your writing is given your own voice and particular accent.

N: And a world. Barbara Kingsolver talks about people asking her how to get to a town in *Animal Dreams*, a town she completely made up. So people will enter any world, a real world or not. We do that all the time.

J: Let's get back to that earlier question: what do you suppose someone who has read your work would take from this documentary? Lots of fans show up at your readings, your "gigs," as you say. And they show up in the damndest of places. What would a fan get from this?

N: I guess a sense of connection.

J: You're eminently "connectable," I know that about you. However, some might have that odd reaction to you due to your Northeastern Yankee accent - it can be a class marker.

N: Oh, definitely. I don't think I was aware of that until I went to a presentation on Old English when I was first in graduate school... a paper read by a Southern scholar... and I found myself totally disengaged from it because of the Southern accent, and then I thought, "Wait a minute! This is an expert in Old English poetry and of course knows what he's delivering despite the accent"... and then I thought "well, my mother did this to me. She reared me with that "not our kind, dear"... right out of the Preppy Handbook, which was all about my life: Eastern establishment types, WASPS.

J: This is important about the video, too, because those who would, like you, respond to your accent as you did the Southerner, I hope can see that your accent is not you. It's not you in any of your writing.

N: No, inclusivity is one of my strongest values, and it's not condescending... it's soup kitchen, Catholic worker, really believing... you know the story about Dorothy Day told by Robert Coles... he went to see her and she was deeply engrossed in conversation with a woman who was really mad, schizophrenic, and Dorothy interrupted the conversation and looked up and said, "did you want to speak to one of us?" She did not assume that the person had come in to speak to her. I can't claim to have achieved that level, but it's ultimately desirable. I see myself in relation to that... my goal is to experience, act, in a manner that says, "I'm just like others." I want people to know I'm more like them than the "odd duck," that they can identify with me in some way.

J: Are there any particular cuts or sections in the documentary you react to in any specific way?

N: Well, I certainly notice how crippled I am, appallingly crippled. And now I'm even more

crippled. So shock is always one of my reactions to seeing the video.

J: This reaction is very much the substance of what you write about, a foundation for your thinking and writing, Nancy disabled in a non-disabled world.

N: Yes, but this is different than talking about it or writing about it. It concretizes disability...in the abstract I'm still very crippled but I don't have to look at it.

J: What do you see that you don't carry conceptually within you? Is it very particular, your feet or your hands?

N: No, no, but it is perhaps posture and gestures, the awkwardness of how I do things, my weakness. Interestingly, when George watches the video he isn't affected this way for he sees me all the time. But George is funny. He thinks I look beautiful. He dresses me and then he looks and says, "You're such a good-looking woman."

J: Aren't you glad you still hear that?

N: Just amazed, since I was 17 when we met and now I'm 58!

J: One thing the video can do for readers is present George...you write about him so much in your essays.

N: Yes, people always ask about George. One time a reporter from the Tucson Weekly was here interviewing me and George walked in... She said, "Well there's George; I feel like I've stepped into a novel." He was a character who had come to life.

J: Here was a journalist thinking of your non-fiction as a whole personal world. You elaborate in a highly writerly way.

N: Yes, I'm a literary writer who "literizes," makes literary, everything.

J: You come through your writing very much as a character, a consistent "body in the world, voice in the world" observer, and give us so much about your whole spectrum of feelings, how you act, what you see.

N: I'm a character all right. One of the advantages of getting old is the sense of the time things take, so when I don't like something I assume that I don't like it at this point. I no longer assume that I don't like it absolutely. Two decades ago I went to Bread Loaf Writer's Conference and was just miserable, and a shift took place there into an understanding that it was all right to be miserable. The same with a project like this. If it's not going well maybe it's not going well now, but later... We're a society so driven to have everything right and right now. It's just not the way things really work. Failure is much more common and much less terrible than people tend to think.

Janice Dewey <jdewey1@mindspring.com> is a professor in the Humanities Program at the University of Arizona. She holds a Ph.D. in Spanish with emphasis on Latin American literatures. Her work with Nancy Mairs has moved her into the world of disability studies. The documentary will be a valuable educational tool in the discussion of Mairs' work and disability issues in general. Dewey is also a poet with a recently published chapbook, *The Daybreak and Willingness Club*.

The DVD version of this documentary is available for purchase.

Correspondence regarding this manuscript should be sent to jdewey1@mindspring.com, subject line, Mairs Movie. In addition to the one-hour documentary the DVD features Mairs reading a chapter from her latest book: *A Troubled Guest: Life and Death Stories*, plus other features. VHS available on request without additional features.

The Role of Occupational Therapy in Rural Healthcare: A Case Study on Farmers with Disabilities

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Abstract: The impact of disability on farmers' personal affairs and work capacity has consequences not only on farmers, but also on their families, farm operations, and communities. Living in a rural area can play a role in recovery after disease or injury in that beneficial therapy services may not be available due to barriers such as meeting the needs of a widespread population, lack of physician referral, and travel time. To gain the perspective of the impact of disability on farmers' lives, face-to-face interviews were conducted with two farmers in rural Nebraska. Through these discussions five similar themes emerged which include: adaptations, safety, family assistance, therapy services, and specialty services.

Key Words: Rural Health, Occupational Therapy, Farming Injury

Introduction

Farmers with disabilities are a unique population in that their quality of life and financial resources are dependent on their ability to return to work. A farmer's ability to return to farming is not only important for his or her family, but also for the economic production of the state in which he or she lives. Often, farmers with disabilities might find their medical needs may be overlooked not only by the medical field, but also by their community.

A challenge facing healthcare delivery today is understanding how services may be provided by occupational therapists and what needs can and should be identified within a rural setting. Occupational therapists can become involved in the return to work of these farmers by maximizing function and minimizing the impact of the disability. By inquiring about the life of a farmer with disabilities, the awareness of need for occupational therapy in a nontraditional rural setting may motivate other occupational therapists to provide service to this population.

This study sought to find if farmers with disabilities return to farming after work related accidents and if occupational therapy intervention would be of benefit to adapting their farm, farm equipment, and method of carrying out their daily activities.

Literature Review

National Statistics

Fiedler and Associates (1998:13-22) noted that agriculture, as an industry is very dangerous. Agriculture has one of the highest fatality rates in the United States. Agricultural related accidents account for approximately 20.7 to 24 deaths per100,000 workers as compared to approximately four deaths per 100,000 workers in other United States industries. Margentino and Malinowski (2002) provided safety statistics which indicate that farm-related injuries happen most frequently between the hours of 10 a.m. and noon, and 3 p.m. and 5 p.m. These times appear to be periods when fatigue is most likely to occur, contributing to decreased concentration and greater risk of injury.

Nebraska Statistics

Fiedler and Associates (1998:13-22) state that in Nebraska, within a ten-year period from 1987 to 1997, 245 total farm-related deaths were reported. Of this group of fatalities, 124 occurred in the age group of 55 years and older. The leading cause

of death in these accidents occurred while working with tractors. Work with other types of farm machinery (combines, power take off (PTO) shaft, etc.) is the second leading cause of fatal injury in farmers. Farmers that are 55 years and older often experience age related changes that increase their chance of suffering a work-related injury. Vision changes such as a decrease in dark adaptation, color sensitivity and the size of the visual field are all factors that affect a person's ability to work safely. Hearing and slowing of afferent sensory impulses that delay motor response are also of great concern.

Possible Barriers to Receiving Service in a Rural Area

As evidenced by the above research, farm-related accidents and subsequently farmers with disabilities are a growing population in rural communities. Occupational therapy is one of the many services that are not met in a rural community. One of the biggest trials is how to meet the needs of such a widespread population. Rural communities are composed of small, spaced apart towns and wide-ranging farms. Larsen and Foley (1992:30-39) found that both occupational therapists and consumers meet barriers when it comes to transportation both to and from the clinic or home. Kent, Chandler and Barnes (2000:481-491) reported that most research about meeting rehabilitative needs has been done in urban areas where it has been found that accessibility to service and public transportation are not major issues. This type of research cannot be generalized to the needs of rural areas.

Another issue contributing to the lack of occupational therapy services for farmers with disabilities may be the perceived extent of injury. The individuals with greater disability usually require and have access to more organized services. It is possible that these individuals, along with the elderly, are more visible to service providers and have a better recognition of need. These potential clients therefore begin to rely on themselves and family members to solve day-to-day problems that they encounter because of their disability.

It may also be that physicians practicing in rural areas do not have the knowledge or resources to learn about occupational therapy and its services. Rural health care is primarily through general practitioners, and Kent, Chandler and Barnes (2000: 481-491) found that these professionals did not have the time, training, or knowledge of how to refer their patients with disabilities to services such as occupational therapy.

For that reason, there are many areas of service with which occupational therapists can be associated in rural areas. However, meeting the needs of farmers with disabilities is an existing problem for the occupational therapy profession. An individual therapist may not see the appeal in spending more time traveling between fewer clients than they would have if working in an urban area. Solomon, Salvatori and Berry (2001:278-285) noted that recruitment and retention of therapists in rural communities also poses challenges. Therapists with families may look at the availability of spousal work. Therapists may also be influenced by the lack of management support available in a rural workplace, which Bent (1999:203-212) found to be a factor in a high turnover rate of staff. Kohler and Mayberry (1993:731-737) suggested that the lack of availability of continuing education and other support systems such as other therapists or access to current literature may also have an impact on the retention and/or recruitment of therapists in rural areas. Wills and Case-Smith (1996:370-379) found that many therapists in rural communities are required to take on the role of being a generalist in the field of occupational therapy. There is no way of determining which client or diagnosis requires assistance. Because of the extreme need for therapists in these regions, therapists may begin to feel overwhelmed in that they have to do it all. Realization that this goal is not possible by one or a few allows therapists to reduce stress levels and focus on a realistic mechanism to meet the demands of practice.

Russell, Clark and Barney (1996:72-78) suggested that the initial reluctance by therapists to enter a rural environment may be because of the limited opportunities available to them as students to experience a rural fieldwork setting. Millsteed (1997:95-106) states that schools need to prepare students by encouraging work in these areas not only in fieldwork experience, but also for a career choice. The occupational therapy profession also has to recognize the need for education and training in rural areas. The profession needs to mandate changes within the education and preparation of therapists for practice and identify competencies and standards for rural practice.

In reviewing the literature, it was found that no published research exists that is similar to this research proposal. Therefore, it was determined that further study involving the lives of farmers with disabilities and their associations with occupational therapists during their rehabilitation phase was warranted.

Design and Method

A qualitative research design was appropriate for this study due to the lack of research done specifically regarding individuals in rural areas. Existing research includes descriptions of rural healthcare designs, rural injuries, and rural mortality rates. This study will focus on the individual's perspective of his or her life and his or her ability to work with a disability.

A case study is "an exploration of a bounded system over time through detailed, in depth data collection involving multiple sources of information rich in context." (Cresswell, 1998:12) The context of the case requires the case to be studied within the natural setting that may be physical, social, historical, or economic. The purpose of focusing on a particular set of cases is due to their perceived uniqueness of issues.

Sample

In this study, examining the influence of disabilities on farmers, a case study was chosen as the method of inquiry. This case study focused on two farmers with disabilities. Through the case study the data collected provided a detailed picture of these farmers' lives and how disability has affected their lives. Time was spent describing and understanding the context of the case and the challenges faced by disability. Through the collection of data, an occupational therapy viewpoint was used to determine the need and effectiveness of occupational therapy within this unique rural population.

The sample population of farmers with disabilities was found through contacts with the AgrAbility Project of Nebraska (2002), wherein two members of this organization agreed to participate in the case study. The AgrAbility project assists people with disabilities employed in an agricultural setting. Data Collection and Analysis Data were collected through the use of face-to-face interviews and observation. To ensure accuracy during transcription and for the development of themes, interviews were audiotape recorded. These tapes were destroyed immediately after final transcription took place to guarantee confidentiality. Together, interviews and reflective notes were analyzed for categorization of occurring themes over the course of this study.

Limitations

This study is not generalizable to a larger population, as only two farmers were interviewed. The results were also confounded due to the farmers being located in rural Nebraska. The researchers have not participated in qualitative research prior to this study.

Discussion

Background Information: Farmer #1 Jon

Jon is a self-employed livestock and crop farmer in rural Nebraska who is in charge of the day-to-day operations of his farm. He is an active participant in his community, the AgrAbility Project of Nebraska, and a grassroots lobbyist for farmers with disabilities. Jon's disability history began when he was a child. He was born with a rare disease that caused his bones to grow too fast. At 16 months old he lost two fingers on his right hand due to amputation. As he aged, the bones in his left leg grew out of proportion with the rest of his body, requiring multiple surgeries to stop the growth. As a result of this disease, Jon's right upper extremity is longer than his left. At the age of 40, Jon suffered a right hemisphere stroke, leaving the left side of his body paralyzed. Jon stated that he did not have any signs or symptoms forewarning a stroke, and that it occurred in his sleep.

Background Information: Farmer #2 Cletus

Cletus and his wife owned their own milking production until 1985. After relocating to a new farmstead, he began to provide farming services for other local farmers. In September of 2000, Cletus was harvesting seed corn for his employer. While repairing a bearing on an elevator of the corn picker, another crewmember started the machine, throwing Cletus about 15 feet to the ground. Subsequently, he broke a vertebra and was paralyzed from the waist down.

Emerging Themes

Through analysis of the transcribed interviews, five themes emerged: *adaptations, safety, family assistance, therapy services, and other services*. The first theme, *adaptations*, emerged after learning about their types of disabilities. Both farmers had professional and homemade adaptations to their homes and farms. Professional assistance was most needed for major renovations, such as in the bathroom or kitchen. For both of the farmers, developing their own adaptive equipment for motor vehicles, farm equipment, tools, and furniture proved to be the beginning of a lifelong hobby. Cletus stressed the need for professionals in rural areas to be knowledgeable about adaptations to be done correctly the first time, as his bathroom was not adapted according to recommendations and guidelines. Jon suggested that farmers are a "unique kind," therefore professionals must be willing to collaborate with the farmer who knows the best way of achieving adaptations for tasks and equipment that they have been familiar with for years.

The second emerging theme from the interviews was *safety*. Both Jon and Cletus stressed the importance of using designed safety equipment as well as having someone nearby in case of an emergency. Cletus invested in a leather safety suit to use while welding in his shop. He purchased this after a fire nearly started from a spark that fell on his shoe. Due to his lack of sensation, he was not able to detect the warmth, but luckily his son saw the danger and quickly extinguished the spark. Jon realizes that due to his stroke, his reaction time to possible emergencies is lessened. Therefore, he appreciates that he must take his time and be more alert to his surroundings while driving.

The third theme, *family assistance*, demonstrates the power of family involvement during and after an injury. Both farmers highlighted the role that their families played both in the hospital and transitioning to home. Families were involved in medical discussions, therapy treatment, and community reintegration. Both the farmers and their families received services regarding emotional/mental health issues following their injuries.

The fourth theme, *therapy services*, emerged in discussions about acute, subacute, and rehabilitative stages of recovery. Both farmers identified therapy as a major challenge, but agreed that therapy services were necessary to function independently upon returning home. Due to workman's compensation, Cletus still receives out-patient therapy services, but must travel to the capitol city

of Nebraska to receive services. Jon does not receive continuing services, but independently contacts occupational therapists regarding any hand splint issues that arise. Both farmers commented on their lack of understanding of how therapy progressed as it did. Often, the men felt as though their input and personal goals were not taken into consideration in therapy.

The fifth theme, *other services*, materialized following an interview question which asked what type of services the farmers would have liked to receive during their hospital stay or after their return home. Jon believes that the help one receives is only good if the person helping truly knows and understands the challenges and tasks that a farmer faces on a day-to-day basis. He shared that vocational rehabilitation professionals visited his farm, but were not able to provide him with information on how to adapt his daily chores and farm equipment needs. On the other hand, Cletus stated a need for help with legal issues. Many issues with insurance companies have complicated his financial situation and have caused major frustration.

In accordance to these five themes, occupational therapists can have a role among farmers with disabilities by taking their services to rural areas and applying their knowledge to adapting equipment, providing safety precautions, involving families, and seeking provisional services for farmers.

Conclusion

Two occupational therapy student researchers using a qualitative methodology in the form of a case study completed this study. Questions were posed to two farmers with disabilities in rural Nebraska to gain a better understanding of how their lives are affected by injury. Throughout this study, five themes emerged that might help occupational therapy practitioners and other service providers understand the challenges faced by farmers with disabilities. These themes can provide information to professionals working in a rural area to understand the unique needs of farmers with disabilities.

Keeping these themes in mind, professionals can then evaluate their services and adapt them to best suit farmers.

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Infusing Disability Studies into "Mainstream" Educational Thought: One Person's Story

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Abstract: The purpose of this article is to explore how ideas from disability studies can inform "mainstream" educational practice. In this autoethnographic narrative I describe a personal journey of planning, teaching, and evaluating a 3-hour "in service" presentation for high school principals. In my account of this event I alternate between a description of the content, my personal reflections, and participant reactions. I demonstrate how the content and format of this kind of presentation can serve as a formalized context for generating a much needed dialogue between disability studies and current practices in the field of education.

Key Words: Education and disability studies, in-service, secondary education

Introduction

"They're in another world."

"They need to come down from the ivory tower."

"It's been so long since they've been in a school – if they were ever in one."

"Some of their ideas are great – they just wouldn't work with my staff."

"They wouldn't last five minutes in my classroom."

"Courses in education do not prepare you for the reality of teaching in a school."

These are typical of the comments I have heard about university instructors from teachers and administrators over my fifteen-year career in education. Each comment reflects the disparity between

what is taught at the university level and what is needed to survive and flourish in a school setting. As a professional development specialist in a large urban school system, I have often been required to promote mandated policies and locally-chosen instructional initiatives. Much of my work has been to support "change," and I am always intrigued by people's acceptance of, or resistance toward, change.

As a part-time doctoral student, I am no exception when it comes to contemplating the usefulness of theories taught at the university level. I often ask, "How can I make what I learn practical for school staff? How can I teach administrators, teachers, paraprofessionals, and other school personnel new information that assists them in working with students?" In short, "How can I link theory and practice?" My own ongoing attempts are, in part, a result of my dual identity as student of education who is interested in theory, and as an educational practitioner interested in creating social change.

The purpose of this article is to explore how ideas from disability studies can inform "mainstream" educational practice. Within the "mainstream" field of education, scholars, policy makers, and educators have long conceived disability within narrow and oppressive frameworks that unquestioningly uphold dominant paradigms of thought. While scholars of disability studies acknowledge this, and offer different paradigms, noticeable silences exist about the field of education within disability studies. Conversely, in the field of education, silence exists around studying people with disabilities in a multi-dimensional, interdisciplinary manner. Though these dilemmas are underdiscussed within and across both fields, they are inextricably connected.

By introducing "mainstream" educators to disability studies in professional arenas, long-resisted conversations I am interested in pursuing are orchestrated. In focusing on one such event, I desire to share a story that reflects the struggle to bridge theory and practice. Through personal narrative, I capture my journey of planning, constructing,

presenting, and evaluating a 3-hour "in service" presentation for school personnel. As such, this methodology is an example of what Richardson (1994) calls "a highly personalized, revealing text in which an author tells stories about his or her own lived experience" (521).

Potential Significance

This article is about fostering dialogue between advocates of academic disability studies and practitioners of K-12 education. As Corker and Shakespeare (2002) write, "Theory has to be conceived as a means to an end, rather than an end in itself" (15). Originally, I felt it was a risk to create an "in-service" that incorporated disability studies because of the entrenched attitudes about disabilities held by most able-bodied school personnel. Like teaching the concept of "whiteness" to whites, it evokes an emotional response that implies a complicity in the status quo of dominant discourses that shape societal practices. In brief, the presentation was designed to make people conscious of that which is often relegated to the dysconscious or "uncritical habits of mind" (King 1991, 131). Nonetheless, I now believe that disability studies is a powerful tool in destabilizing traditional thinking within "mainstream" education venues. Furthermore, I hope that the structure, format, and information I chose to include can serve as an example of a change agent model that could be utilized by others.

Questions

In planning the project, I posed two questions to contemplate and asked myself why they were important to me. The first is "How can I infuse disability studies into 'mainstream' educational thought?" Though I work with hundreds of educators, I have never had a conversation about disability studies with any of them unless initiated by me. Is that surprising? I did not know about disability studies until fairly recently. This is ironic given that I have considered myself to be within the field of

special education for my entire professional career, despite questioning the majority of its practices. I am therefore led to ask, why is disability studies not addressed in "mainstream" academic journals, most universities, and in actual schools? Clearly it is a conflict of interest with almost all publications and educational institutions operating within the institutionalized special education-general education dichotomy. Given this dilemma, what then is the best way to liberate voices that appear continually silenced within and outside of academic thinking?

The second question is, "How can disabilities studies be introduced and used to challenge entrenched belief systems and attitudes towards the education of students with disabilities?" I have supported the notion of inclusive education[30] since I came into contact with it in the early 1990s. I have spent years working with general and special education teachers and administrators, many of whom have resisted the integration of students with disabilities into general education classrooms based upon their self-conviction that current practices are in the best interests of students. However, I have always been disturbed that the dual system allows educators to conceive of two "types" of human – one general and one special, thereby actively participating in transforming students with disabilities "into a breed apart from other students" (Karagiannis 2000, 129).

Why Disability Studies?

After working for years in special education I came to question school structures that segregated students classified as disabled, causing them great emotional and psychological pain. As I began to read literature by people with disabilities written from a disability studies framework (Rodis, Garrod, and Boscardin 2001) and research that actively sought out their usually silenced voices (Ferri, Keefe, and Gregg 2001; Gabel 2001), I developed an increasing awareness of *their* insider perspectives and interpretations of school experiences as students and as teachers. Many had internalized a sense of failure by virtue of being placed in special

education classes (Varenne and McDermott 1998), some conveyed school as a site of oppression (Reid and Button 1995), while others expressed anger at their isolation (Piziali 2001; Vee 2001).

Foucault (1977) called attention to "the indignity of speaking for others" (209), yet the field of special education is traditionally comprised of non-disabled people making profoundly life-shaping decisions for people with disabilities. School structures are microcosms of the macro-culture, and as such they influence each citizen's understanding of the *place* and *value* of disabled people. As they stand today, most school structures still support the placement of students with disabilities in *separate* locations from "mainstream" peers.

Disability studies challenges such structures and the assumptions on which they are founded. Instead of perceiving disability as a deficit (physical, sensory, emotional, or intellectual), disability studies scholars assert that disability is caused "by the failure of society to remove its disabling barriers and social restrictions… in other words, disability is something wrong with society" (Oliver 1996, 129). Wendell (2001) criticizes the non-disabled's obsession with prevention and cure that "focus public attention on the medical model, which leads us to ignore the social conditions that are causing or increasing disability among people with impairments" (31). The claim is clear: people are not inherently disabled. *It is society that disables them.*

The dominant paradigm that medicalizes disability is directly challenged by advocates of the social model who have sought new ways of conceptualizing disability. The former paradigm has reigned since the rise of the medical profession in Western society (Foucault 1994), while the latter is ideologically located in a framework of social change akin to the Civil Rights movement pioneered by African-Americans in the 1950s (Hampton and Fayer 1990).

In many respects disability studies is a relatively new discipline, exploring different ways of thinking about the world in relation to the phenomenon of "disability." As such, disability studies does not

claim to be a unified field of inquiry, but rather reflects multiple perspectives simultaneously. And while the social model is the primary conceptual framework within the emerging canon of disability studies, its own hegemony is challenged from within. Shakespeare (1994) feels the social model is overly simplistic and needs a more complex definition that considers various social phenomena because "people with impairment are disabled, not just by material discrimination, but also by prejudice. This prejudice is not just interpersonal, it is also implicit in cultural representation, in language and in socialization" (296). While concurring material societal barriers exist, Shakespeare also raises questions about *attitudes* toward people with disabilities and how *attitudes are formed.* Wendell (1999) points out that in their haste to challenge the medical model, some disability scholars may contribute to replacing one restrictive paradigm with another, minimizing the complexities of disabilities, and neglecting the medical connection altogether – which is, in fact, a large part of reality for many people. She writes, "We must learn how to live with the suffering body, with that which cannot be noticed without pain, and that which cannot be celebrated without ambivalence" (332).

However, these conversations typify discussions in the emerging field of disability studies, reflective of a common desire for multidimensional and critical understandings of disability, hitherto neglected in dominant scientific-medical paradigms. People with disabilities have reason to mistrust traditional research methodologies and conceptual frameworks of disability, characterizing them as "at best irrelevant, and at worst, oppressive" (Oliver 1996). Prevailing scientific-medical notions of prevention and cure associated with disabilities deflect attention from the actual lived experience of disabled people, while simultaneously fostering strong associations of pity and patronization thereby effectively furthering oppression (Shapiro 1993).

Disability studies is therefore an academic discipline invested in challenging traditional thinking. At its core is an increasing number of people with disabilities – be they scholars, research participants,

or both – speaking from center stage, with and without able-bodied allies. This central positioning gives rise to opportunities for the non-disabled to establish "a permanent relationship of dialogue with the oppressed" (Freire 1970). In redefining "disability" and "normalcy," scholars in disability studies challenge the presumed hegemony of the non-disabled; the namers are now questioned by the named. As hooks (1994) points out, the privileged act of naming:

> "…Often affords those in power to access modes of communication and enabled them to project an interpretation, a definition, a description of their work and actions, that may not be accurate, that may obscure what is really taking place" (62).

What takes place in our schools is an example of the subjugation of the disabled by the non-disabled. It is these pervasive and seemingly taken-for-granted policies and practices that scholars in disability studies actively seek to transform. The reasons or justification of this subjugation and its results will be addressed and challenged throughout the course of this article.

Theoretical Framework

A disability studies lens is valuable because it seeks to actively challenge societal practices in and out of the academy. As Linton (1998) notes, "The enormous energy society expends keeping people with disabilities sequestered in subordinate positions is matched by the academy's effort to justify that isolation and oppression" (3). She also claims that "the term *disability* is a lynchpin in a complex web of social ideals, institutional structures, and government policies" (10). In untangling and illuminating parts of the web, I seek to bring a more complex understanding of disability – including social, cultural, and political ramifications – for those who are identified with this label.

Method: The Value of Story

This study is a personal narrative; a story by and in part about me and the people with whom I came into contact. I chose personal narrative as methodology for several reasons. First, narrative inquirers often work in a particular context and "on a small scale" (Elba-Luwisch 1997). For these reasons, namely "the study of the unique and the contextual," Gudmundsdottir (1997) concurs that "narratives have succeeded where other methods have failed" (1). Because I describe a highly contextualized specific event, I believe narrative a fitting choice. Second, this presentation is a seemingly ordinary occurrence in which the power of narrative can be demonstrated because I seek to "capture events and phenomena in such a way that we are [I am] able to bring them 'up close' as opposed to 'out there,' distant and abstract" (Gudmundsdottir 1997, 1). Fairbanks (1996) believes that narratives yield a particularly valuable form of knowledge. He explains, "Analyzing the complexities of the ordinary through the stories individuals tell us or the events they experience together in light of theoretical concepts is one of the primary means of constructing knowledge through narrative" (327). Third, narrative is inextricably meshed with the *act* of teaching itself, as "teaching can only be known through story" (Doyle 1997, 93). As a presenter I knew I would encounter audience members with stories they needed to share, tales of self, family, school, etc. I also knew I would engage in swapping some stories, and recognizing their stories as part of *my chosen material*. As Anderson (1997) notes, "Knowledge communities provide bridges between theory and practice and are 'seeding grounds' for competing stories that may lead to meaningful, enduring, educational change" (132). Fourth, it is this very process of dialecticism that is part of narrative research. As a method, it "redraws the distinction between public and private, holding the materials of one's personal life as essential to an understanding of one's work, and particularly so, when one's life and work are concerned with education" (Elbaz-Luwisch 1997, 81).

As a *personal* narrative, this article can also be viewed as autoethnographic. Bullough and Pinnegar (2001) have asked the question, "Shouldn't teacher educators study their own practice, since one's practice is… who we are?" (14). I agree with Ellis (1997) when she writes, "Autoethnography should be self-absorbed" (122), and the autoethnographer "... also needs to be absorbed within the world she inhabits and the process she finds herself a part of, which also work their way into one's identity" (123). Furthermore, I believe that autoethnography is not self-absorbed in a merely narcissistic manner. Rather, it allows the author to be the prism through which meaning is being made. In this article, I am not saying look at me, but rather *look with me* and *look through me*. Researchers must be self-reflective about their own knowledge and beliefs, and the relationship these play in the constant reshaping of our own identities. We must remember our "… stories we bring as researchers are also set within the institutions within which we work, the social narratives of which we are a part, the landscape on which we live" (Clandinin and Connelly 2000, 64). With such knowledge, claim the authors, comes responsibility and the need to act on beliefs because, "We are complicit in the world we study… [and therefore] we need to... offer up research understandings that could lead to a better world" (61).

The pursuit of a better world can mean questioning established practices. As a methodology, autoethnography contravenes an accepted notion of social science, that of separating subject and researcher, thereby rejecting objectivism and what Johnson (1987) calls its "god's-eye view about what the world is really like" (x, cited in Clandinin & Connelly 2000, 36). This study is a text I have created, and I readily acknowledge it as "a construction rather than realist interpretation, one version of reality rather than the only version" (Tierney 1997, 25). As Lincoln (1997) has attested, "all texts are created from partial perspectives, and that furthermore, that is the best we can hope for" (37). My partial perspective, therefore, has been framed through the use of autoethnographic narrative in which I am:

> "An object of inquiry who depicts a
> site of interest in terms of personal

awareness and experience; it utilizes the self conscious or 'pervasive nervousness' referred to by Geertz (1988) to reveal subjectively and imaginatively a particular social setting in the expressions of local and grounded impressions" (Crawford 1996, 167).

Background and Context

In this research I describe and reflect upon a presentation I did during the spring of 2002. First, I will describe the context from which it evolved. This information is important because it demonstrates how educators can be proactive in introducing disability studies by seeing new opportunities in familiar situations. Originally, I was asked to present "The First Year of Implementation of The New Continuum of Services" to 50 counselors, educational evaluators, school psychologists, and teachers of speech (many of whom prefer to be referred to as "clinicians"). This "new" continuum is the response of the Board of Education to the Reauthorization of the Individuals with Disabilities Education Act (IDEA) (1997). Having presented on the same subject for the same group twice the year before, I was wary of having little more to say than in previous times. After deliberating, I agreed to do it if I could spend fifty percent of the time on "increasing disability awareness" before I delivered the content of the workshop presentation, as described in the originally proposed title. I informed the administrator that I wanted to introduce new material and would take risks that may intrude upon people's comfort zone. Despite trepidation – I did it. According to my own impressions, and the written feedback, the presentation went well. However, I noticed by reading facial gestures, body language, and covert exchanges that it *was* discomforting at different times for different people.

The following month I was asked to present to two groups of principals on the topic of team teaching. As I co-planned each session with representatives from their groups, I suggested a slight modification of the presentation on disability stud-

ies already developed to be an equally weighted piece preceding their targeted content. I explained that this would generally deepen their understanding of (re)integrating disabled students into general education classrooms.

For the second presentation I was a guest speaker in a different school district, but the third presentation I was on "home ground." My narrative in this article will focus on the third presentation, although I refer to other sessions occasionally. I drew on material from a variety of sources, most notably my Advanced Seminar in Disability Studies at Teachers College.[31] Other sources included film clips and videos I have used in previous staff development sessions or graduate courses, along with materials I constructed.

I am aware that I cannot capture three hours of an interactive event within a few pages, so I have taken some liberties. I write the following section in the present tense, which draws readers into the text, making them feel more like they were there. The section weaves the content of the presentation with audience responses. I convey this information as text, rather than dialogue, although, I recognize that in doing so, I lose the excitement and immediacy of discussion and debate in which knowledge is constantly (re)contested and (re)appropriated (Bakhtin 1986).

I have included my thoughts in italics. This reveals – among other things—my decision-making, personal reflections on the way we operate as schools in a society, and my hopes for new ways of thinking. I acknowledge that there is a risk of these two devices becoming blurred, but hope this serves not as a distraction, but rather a way to convey a richer, more complicated text.

To avoid interrupting momentum, my narration moves between sections without stopping to introduce each one. However, for those who may wish to utilize the format or a variation of it, I have also outlined the presentation in a linear manner, as shown below:

1. Popular Notions of Special Education.
2. Framework: Reconsidering Disability as Private Citizens and Public Employees.
3. Objectives of Presentation.
4. Choosing and Using the Lens of Disability Studies.
5. Calling on the "Minority Model."
6. Listening to "The Disabled."
7. "What does it mean to be 'able'?"
8. "What is meant by 'disability'?"
9. Foregrounding Privilege.
10. Challenging the Status Quo.
11. The Politics of Exclusion: Contemplating Brown v. Board of Education (1954) and the Reauthorization of the Individuals with Disabilities Education Act (1997).
12. Issues of Access and Integration in Schools.

Note that each segment is of a different length, depending on the overall flow of the workshop. Different methods of instruction were utilized to facilitate the process of information. Each presentation fluctuates depending on what needs to be stressed. In section 11 it may be interesting to target different "minority" groups to explore similarities and differences.

I used different methodologies within the presentations to promote active participation. These took the form of individual reflections (silently or in writing), frameworks for guided note-taking when watching videos, interactive dyads, conversations in small groups, and whole group discussions.

Presentation

The title of the presentation is "Students with Dis/abilities: Team Teaching as an Option in The New Continuum of Services." One of my aims is to challenge (and derail) the way principals think about disability. I purposely do not use "Special Education" in the title, as that concept has ossified into signifying a segregated place, rather than a ser-

vice. The "/" in "dis/ability" serves to disrupt expectations. Though the term may appear awkward, it is designed to jar initial associations non-disabled people have in relation to the word "disability" which is to immediately emphasize what people cannot do, over what they can.

I had many concerns before this presentation. It is has been my experience that principals dread meetings about special education that they see as overly bureaucratic, self-consumed with regulations and mandates, and view as "kids with problems." Most issues are immediately deferred to the assistant principal for special education. I also know that principals are extremely busy, overwhelmed people with incredibly difficult jobs. I was going to take them into areas many had previously resisted.

My superintendent and a host of other high-ranking administrators would be there. What if the presentation didn't go well? What if it was too ambitious, too jarring, too "off-putting"--perceived as disconnected from their schools? These thoughts were always at the back of my mind, yet I convinced myself that mine was the right approach, no previous strategies over the years had created the change I had hoped to see by this time.

For the opening section, I have chosen a clip from the television show, *The Simpsons*. In this two-minute snippet, Bart arrives at his new school, and instantly becomes popular with his classmates. However, when the teacher calls upon him to read cursive script, Bart is unable to do so, never having been taught it—this results in his being escorted to the "Leg Up" program. His peers here include a student who speaks another language and is assumed to be slow, a girl who bumped her head one day and woke up in the program, and a boy who starts fires. The teacher asks students to take out a safety pencil and a circle of paper, to "finish work on the letter 'a.'" When Bart asks, "Let me get this straight – I'm supposed to be in the 4th grade, and I'm going to catch up by going slower? Goo-goo." The entire class begins to chant "goo-goo, goo-goo." Soon, Bart looks dejected as he half-heartedly joins in a game of musical chairs (in which none

are taken away), and the teacher claps her hands to proclaim, "Everyone's a winner!" Once the clip is over, I pose two questions for participants to discuss in groups--What did you see? What is the message?

The Simpsons clip is a good "opener" because, through exaggeratedly comic stereotypes, it clearly illustrates a school in which: (a) there is a place to put students who do not meet grade-level expectations; (b) that place is filled with other stigmatized children; (c) they exist in a land of perpetual remediation with a deceptively artificial reality (is everyone a winner--or a reject?). To substantiate this critique, I relate a personal anecdote about a recent school visit I made to a special education class. A student said she wanted to sit out of sight from people passing in the hallway, for fear she would be identified as retarded. When the teacher said, "You're here because you're special," the student replied, "Bullshit."

I transition to articulate that we are going to contemplate "disability," not "Special Education" *per se*. To do this, I ask audience members to think in dual terms for the entire duration of the presentation--along one track for themselves as individuals (who they are, what they believe, and why they believe) and along another track as an employee (working within bureaucratic parameters, legislative issues, and other buffers). I want to acknowledge the tension between both "situations" and have a discussion that is not only confined to schools, but encompasses how non-disabled people generally view the disabled.

I think everyone is connected to "disability" in some way. For those not personally disabled, a family member or friend connects them to the issue. The duality of thought that I want to encourage helps me ease people's thinking between educational practices and societal practices at large. It needs to be highlighted that further access to classes for the "general" population is only one step in the larger struggle for access in society.

At this point I explicitly state my objectives--participants will: (a) compare the implications of being labeled "disabled" v. "non-disabled"

in school and society; (b) examine and analyze their individual knowledge and belief system about people with disabilities; (c) hear the perspectives of people with disabilities (d) explore team teaching as one option to support the increased integration of students with disabilities.

The agenda is heavily frontloaded with disability issues, yet their application to classroom experience will be demonstrated when I shift the presentation to the practicalities of team teaching. It is important to connect practice to theory throughout, and especially to partake in conversations about classroom practices.

I now bring their attention to the important point that this presentation will be using the lens of dis/ability Studies. I ask rhetorically, "Why have I chosen this lens?" I share my impression that the skin around special education is extremely thick, yet needs to be penetrated in order to reach a place in individuals where they can begin to see what is not usually seen, and that what we take for familiar can be seen as something else. Sharing my belief that the framework of disability studies affords me this opportunity, I make clear that our conversations will not be about business as usual; we will be taking risks. I introduce them to Linton (1998) and the notion of seeking to re-conceptualize disabilities:

> "Disability studies has arisen in the past twenty years to focus an organized critique on the constricted, inadequate, and inaccurate conceptualizations of disability that have dominated academic inquiry. Above all, the critique includes a challenge to the notion that disability is primarily a medical category" (2).

I decide not to problematize the notion of the social model. For most, if not all, participants it is their introduction to the notion. Recognizing the asymmetry of knowledge and therefore power (Foucault 1980), I consciously decide to aggressively emphasize the social over the medical model in order to make an impression.

For the purpose of this presentation, I next suggest people think of disability within a "minority model." For some, it is useful to picture people with disabilities as a "minority" similar to people of color, women, gays and lesbians, Latinos, Native Americans, Asian-Americans, I lead a discussion on how minority groups came to be formed, how various disciplines of study have evolved and are represented in many academic departments. I ask people to privately identify with one or more "minority," and to keep that identification at the forefront of their thoughts for the balance of the presentation.

I know almost everyone can relate to some aspect of being minority. I want to connect emotionally with people, to make personal these issues of exclusion and powerlessness, to acknowledge how marginalized people with disabilities are in our society. In using this ongoing analogy, I hope I do not make anyone too uncomfortable. However, I believe a certain amount of discomfort and tension in pedagogical practice can serve as an opportunity to grow (Kumashiro 2000).

I ask that we be always mindful of the question, "Who is speaking?" I explain that one of the things that attracts me to disability studies is the opportunity to listen to the voices of people considered disabled. If we think of how the minority with whom participants have identified are portrayed or described without members of the group having a voice in proceedings – how do they feel? People in such positions often get angry, feeling "wrongly" portrayed and stereotyped. I know that if I want to learn more about a particular group that is not like me, I have to go to the source. I either talk *with* "them" or read books *by* "them." Scholars and research participant in disabilities studies have described being systematically kept out of mainstream dialogues. I ask, "When do we listen to the voices of the disabled?" People slowly concur that in most situations rarely, if at all. For this reason I have brought their voices with me. I proceed to share overheads of quotations from young adults with disabilities who have gone through school systems and survived. Marshall (2001) describes, "As a child, it was very shameful to be in the Learning Disabled classes or be considered 'retarded' in any

form… Having a learning disability is only a small part of who I am" (120). Pelkey (2001) claims, "... I was taught to hate myself… my foundation for hating myself grew out of my much noted shortcomings and lack of abilities deemed positive… I became less than" (18). In challenging the negative associations with having a disability, O'Connor (2001) seeks to redress the imbalance and provide a more accurate description:

> "There are so many positive aspects of ADHD. For example, I can do many things at one time successfully… My main goal is to be able to control my ADHD in certain settings, and to use it as an advantage, rather than taking drugs to suppress all my creative energy… The problem is that most of the literature about ADHD is written by people who do not have ADHD. They generalize… and say the symptoms are concrete. This is extremely offensive to me… [As] my situation can be totally different from another person with ADHD" (71).

What do these quotations tell us? In contrast to Marshall's (2001) description of his LD, we are all too familiar with the label of disability coming to dominate the school identity of a child. Pelkey (2001) describes how her abilities are de-emphasized until the picture she has of herself is that of a person lacking something, making her less valuable than others. O'Connor (2001) conveys the annoyance of having a meaning made by others imposed on her, when she knows differently, knows better.

Together, these three testimonies convey the stigmatization, shame, and misunderstanding experienced by students with disabilities in schools. Almost all quotations I use are from people with disabilities and/or disabilities studies scholars. I want to turn the tables, and invite participants to hear some points of view that do not usually get much attention.

Bearing in mind we have established that people with disabilities often perceive schools and society quite differently from the dominant group, I now move to how people with disabilities primarily stress the problem of social barriers. Furthermore, a stress on social barriers deemphasizes, and ultimately rejects, the medical model of disability. A quotation from Wendell (2001) is shared:

> "Prevention and cure both focus public attention on the medical model, which can lead us to ignore the social conditions that are causing or increasing disability among people with impairments. Moreover, given the history of eugenics, there is a reason to be skeptical about whether prevention and cure are intended primarily to prevent suffering or eliminate 'abnormalities' and 'abnormal people'" (31).

This is a simple but fundamental idea that is capable of moving people's thinking. However, people seem so invested in the "objectivity" of science as the ultimate "solution" to "problems." Mitchell and Snyder (2000) link the responsibility of science to how it has shaped widespread thought, casting various "groups" of people as inferior and/or undesirable:

> "Physical or cognitive inferiority has historically characterized the means by which bodies have been constructed as "deviant"; the Victorian equation between femininity and hysteria; the biological racism that justified slavery and the social subordination of racial minorities; psychiatry's categorization of homosexuality as a pathological disorder; and so on" (2).

Scientific beliefs and practices can and should be questioned. Scientists have been mobilized at various times to defend practices in the interest of dominant groups. They have supported female biological inferiority, people of African descent being valued as three-fifths of a Caucasian, and the electrocution of gay people as "aversion therapy." It seems we still struggle through the damaging vestiges of 19th century medicine. I wonder, for what oppressive practices will our society be remembered?

I turn the tables, by asking "How do the disabled view the able bodied?" This is a provocative question, akin to more familiar (though arguably equally discomforting) notions of "How do blacks perceive whites, women perceive men, gays perceive 'straights'?" I reveal Morris's (2001) opinion to them:

> "Generally, non-disabled people are undecided about whether they want a society which contains people who look different, who need support, who need to make changes to make buildings and houses more accessible to them, who need more resources for education and health, etc. In a lot of situations they would rather we weren't born, or were 'allowed to die'" (12).

This is a visceral statement and is included because it strikes a chord. I am able to remind people that the disabled were the first to be systematically killed in Nazi Germany. Referred to as "useless eaters," "Nature's mistakes," and having "lives not worth living" (Proctor 1995), they were eliminated by the hundreds of thousands, yet are rarely commemorated in Holocaust museums. I also ask about contemporary issues such as amniocentesis, and how any suspicion of an abnormality in the fetus usually means pressure on the mother to terminate. I probe, even if we do not take Morris at face value of literally "dead," then what about symbolically? Do not many "able bodied" people want the disabled out of sight--in institutions, special facilities, special schools, and special classrooms?

After this discussion, can the audience still be so sure that Morris's sentiment is too strong? I do not want people to be overcome by guilt or feel defensive to the point that they are no longer receptive, but I

do want to show how everyone is implicated in these issues—and how we must weigh our complicity or resistance. There are so many sources from which to draw, and many points to make, however, I chose the quotations above because, together they make a powerful statement that cannot be ignored; the disabled are systematically discounted and marginalized by the able bodied, including in institutions of education in which we all work.

I now link this train of thought to special education. Linking special education as it is currently configured with broader issues of accessibility, I share Skrtic's (1991) comment that "Special Education…[is] the profession that emerged in twentieth-century America to contain the failure of public education to educate its youth for a full political, economic, and cultural participation in a democracy" (24). I ask a series of questions--Is it democratic to remove students from access to the same instruction as their non-disabled peers? In the case of high school – how do we justify placing students who must take rigorous exams into classes not taught by content area specialists? How many people in the room would like their own child placed in high school special education classes, knowing they had to be as prepared as the next student for the world beyond school?

The questions, in turn, provoke a series of discussions. I believe linking access to democracy and highlighting the absurd illogic of mandating examinations for everyone but not requiring everyone be taught by content-certified specialists confronts current inequities that are deliberately ignored within current school systems. The last question also hits a nerve because they know, and I know they know, the inferior education the majority of students receive in segregated environments. Part of me winces when I push this question, yet I feel it is making the emotional connection I desire by calling forth acknowledgement in our complicity in oppressive school structures. However, what ultimately propels me are the sentiments expressed by Delpit (1995); such classrooms are acceptable for "other people's children" and "those with power are frequently least aware of—or at least willing to acknowledge—its existence" (24).

In wanting to link the asymmetry of power between those considered able and disabled, I now ask groups to discuss the question, "What does it mean to be able?" I ask this because I want to see how (or if) people come to reflect upon what they assume is "normal". The question is puzzling to some, intriguing to others. I decide to share with them some written responses I had collected from a previous version of the presentation with "clinicians". They read, to be "able" means:

> To be free from prejudice.
>
> To have access to all places.
>
> To be able to help others.
>
> Not to have needs or behaviors that others find annoying.
>
> To be within the group.

I ask, "What do these statements tell us about the able reflecting on being able?" In short, they do not have to concern themselves with (ableist) discrimination; they can go where they want when they want; they are in a position to be magnanimous; they do not annoy people through their differences; and perhaps most of all – they belong on the "inside;" they are part of society.

Once we have contemplated different versions of what is meant by able-bodied, it is necessary to contrast that with the question, "What does it mean to be disabled?" To facilitate this, I show an image of a five-piece jigsaw. The middle piece reads "Disability." Others contain the words "Physical," "Sensory," "Emotional," "Cognitive/Intellectual". I encourage an open discussion. What exactly is it that unites these words with the lynchpin of "disability"? We inevitably arrive at the concept of "normal," which is critical to our thinking. As we gravitate to the topic of "normal" I ask - "What is normal? Where did it come from? Who gets to decide? What happens as a result of these decisions?" I watch and listen as small groups and sub-group conversation spin off in multiple directions.

Now that I have participants troubling the concept of "normal," I ask them to focus on a quotation by Davis (1995), "When we think of bodies in a society where the concept of the norm is operative, people with disabilities will be thought of as deviant" (29). We now broaden the conversation about the mythical norm and its relationship to the concept of average. By virtue of having a norm, we must also consider those that fall outside of it in terms of physical, emotional/behavioral, sensory, and cognitive differences. In terms of the latter, two standard deviations from the norm in scientifically sanctioned IQ tests means you do not belong to the "average" group. In the subsequent segment, I attempt to draw from our previous discussions on ability, disability, and the concept of "normal" through asking, "What kind of privileges do the non-disabled have, and by implication, what are some of the privileges that the disabled do not have?"

I wonder if the frankness of this question is off-putting for participants? If so, why? This question is indirectly asking, "Who labels who? What benefits do the labels bring--to the labeler and the labeled?" I contend that it is demeaning for students to be designated as belonging to special education. As witnessed by the student who wished to stay out of view of her passing peers, this is a form of public humiliation that remains deliberately unrecognized by educators who work with students labeled with various classifications.

I remind people that my interest in creating and delivering this presentation is to challenge the status quo of the perceptions of people with disabilities. I ask them to contemplate some commonplace practices that disability studies scholars believe harm individuals, including the idea of normalcy and its relationship to IQ tests (Davis 1995; Linton 1998). I briefly paraphrase the history of the Bell Curve and its origins in astrology (Gould 1996) – noting how it became transformed from the "error curve" to the "normal distribution curve," thereby supporting the wholesale theory of innate intelligence. A frightening part is the still widespread use of such tests in evaluating students for disabilities. Parents are often informed that

their child "is" literally a number as if fated to be cast in fixed digits (Valle and Aponte 2002).

Though I question how much we can change the monolithic structures embedded within our education system, I would rather challenge them than work without questioning them. However, I have noticed that they appear as a given to many colleagues. At a previous session, I asked psychologists and educational evaluators to reflect upon the origins and history of the tools of their profession—particularly notions of IQ and the Bell Curve and share their knowledge with others present in the room. I was met by what I can only describe as "stunned silence," as if I had crossed an invisible line by asking them to say why they believed in what they were doing on a daily basis. This reticence to question and reflect on one's professional epistemological stance, confirms my belief that many professionals accept their role as "willing agents in their own discipline" (Allan 1999, 24). In doing so, they absolve themselves of complicity in current practices, regardless of the damage done to those labeled (Gartner and Lipsky 1987; Karagiannis 2000; Lipsky and Gartner 1997; Skrtic, 1991.)

In order to bring into focus the actual experience of segregation, I associate disability issues regarding access with what I call "The Politics of Exclusion". By this, I mean systematic efforts by institutions to "contain" a group of people perceived as markedly different from the norm; the difference regarded as grounds to deny social inequality. In the next segment I ask participants to contemplate Brown v. Board of Education (1954) and the Individuals with Disabilities Education Act (1997). I ask how justifications for exclusion been made? What can we learn from examining them? I am careful to note that I do not conflate disability with race. However I do want us to contemplate connections and differences to deepen our thinking. I show a video clip from the television documentary series *School* (2001) that vividly portrays life for students and teachers in segregated settings, how parents mobilized to fight for access to better conditions for their children in a country deeply divided on issues of race, and the passing of legislation that led to major social changes.

I do not wish to offend African-Americans by incorporating this segment. It is powerful to examine moral inequalities, and contemplate why they were segregated in the first place, and who benefited from maintaining exclusionary practices. "Separate is inherently unequal" is a phrase that is clearly articulated in the video. I have noted other connections between exclusionary practices such as labeling, segregation, attitudes, fear, dependency, value, behavior, language, and access to school supplies. There have been connections between disabled and moral "minority" groups throughout the literature for decades (Oris and Landers, 1984). In contrast, one disconnection is the provision of Least Restrictive Environment (LRE) in IDEA that stresses the option of placements on a continuum of services, thereby not guaranteeing general education classes for all students. Martin, Martin, and Terman (1998) have noted that, "There is a persistent tension between the requirements of appropriate education and least restrictive environment" (35).

In many respects, the concept of LRE has been interpreted to justify segregation. As we are approaching the end of the first segment, I ask how integrated students with disabilities are in the schools of the principals in attendance? Though this question may appear outmoded, in my experience the overwhelming majority of schools still have separate staff, classrooms, and locations (often attic, basement, or wing) for students labeled disabled. I ask why are schools vehicles where integration is supposed to take place? Disability studies supports the civil right of the disabled to have access to life among the able. Is public schooling representative of the way the nation is envisioned at large?

In the group discussions that follow, I wonder how people describe their schools to peers.

Schools vary so much – the ones that opened in the early 90s are mostly inclusive, while the older and larger schools have experienced a two-steps-forward, two-steps back approach during the last decade. I wonder to what degree the principals are moved, or unmoved, by this presentation. I also wonder what

might they do to improve the quality of experience for students with disabilities?

At this point, we take a break. When I invite the participants back, I link these philosophical and theoretical conversations to practical matters by demonstrating how team teaching is one way of supporting students with disabilities in the general education curriculum. I also shared a synthesis of recent findings about principals and inclusion and distributed self-made materials designed to help them create and nurture team teaching arrangements. At the very end of the session, I distribute a short feedback form consisting of three questions: (a) What did you think was useful? (b) What questions are still circulating in your mind? and (c) What pieces need to come together to make this [inclusive practices/stress on team teaching] work?

Discussion of Audience Response

The information I have chosen to analyze is the principal's engagement in and reaction to the presentation. Comments made during the event, along with anonymous written feedback, and personal anecdotes are discussed. As I was packing my materials to leave, one principal said, "What you are doing is trying to change the way people think." That was true, but how successful was I?

Epiphanies

Among the 26 responses from principals, some tapped into the direct challenge posed by disability studies. One wrote that s/he appreciated my "effort to affect the belief system of the solidly bell-curvy/innate paradigm [of intelligence]." Another wrote, "[the] discussion on personal thoughts/beliefs was powerful." Many commented upon the opportunity "for exchange of thoughts," especially one who shared that inclusive practices are "a special challenge in our building." One wrote of the need, despite the odds, to attempt "changing the mind sets of some adults that are suspended in time." Several thought it "helpful seeing the bigger picture," and one claimed "all of the analogies dealing with 'sepa-

rate but equal' helped to better understand the way segregating students with disabilities should be perceived." These comments suggest that some participants were provoked into contemplating familiar terrain through a new lens.

Resistance

At one point in the presentation, my supervisor whispered to me, "It sounds as if you are beating up on medicine." I was, I preferred to think, challenging the objectivity of science, and the unquestioned reverence it receives. Several people spoke defending science and the progress it has made to help many disabled and ill people. This gave me the opportunity to reassert that I was consciously using the voices of the disabled in their critique (and distrust) of medicine. What good is a "cure" if you are comfortable with who you are? Do "cures" negate those that already exist in their specific incarnation, reinforcing their devaluation? Do telethons and other fund-raisers actually improve the *participation* of people with disabilities in society? If a particular condition, such as atypical craniofacial characteristics for a person who has Down Syndrome, or the removal of a breast due to cancer, a common response is plastic surgery. This often involves procedures that can be ongoing, expensive, and painful. However, surgery is a medical response to what is in essence a social issue: the intolerance of non-disabled people toward people with physical differences, be they congenital or acquired.

Another principal wrote, "How can we get students to behave in accordance with school rules so that they learn society cannot/will not provide the same support?" This question is problematic for several reasons, as it assumes students with disabilities are rule breakers, and their actions inherently wrong, while failing to ask schools to reflect on pedagogical and structural practices that are not necessarily in the best interests of students with disabilities (who often know this). It is clear that the notion of students in special education inevitably

having behavior problems is a pervasive byproduct of the bifurcated system.

On another note, a principal wrote, "Not everyone thrives in full inclusion. This needs to be addressed as well." Though I understand this point, believing – due to particular contexts and circumstances – students and their families should have the choice of non inclusion in general education classrooms for all or part of the day, my thoughts are foremost with students currently segregated with little or no choice. Justifying exclusionary placements would have been counterproductive.

I have noticed that a shift from "we cannot do this" or "do we have to do this?" to "How can we best do this given our resources?" and, "What else might we need?" Still, there is ambivalence and misunderstanding that exists at this level. One principal commented that in inclusive classes in her school, "you can't tell the difference between who is and who is not a 'special education' student." As Sapon-Shevin (1996) points out, it is the expected assimilation, the homogenization of normality that needs to be questioned.

Intersections

It is noteworthy that two female African-American principals expressed discomfort in considering the analogy of legislation giving access to "mainstream" schooling according to categories of race and disability. One said within earshot (but not to the entire group) "I thought this was supposed to be about special education." Clearly, the connection was not explicit to everyone. However, the other had moved beyond her initial reticence by end of the presentation, asking me to repeat it with her school staff. Analysis of intersectional ties of multiple markers of identity such as ability, race, class, gender and sexuality, can complicate how we understand existence by adhering to categories often assumed as independent.

One restraining force that pervades most people's thinking is the medical model of disability. In challenging the primacy of this model, audience members experience a jarring of entrenched beliefs.

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One participant vehemently defended the use of Ritalin as it has helped his disabled son adapt to college life. This sparked a rich discussion of the use of drugs to control people versus examining the environment and tasks individuals are expected to perform within it.

Reflection on Practice

While one administrator described the presentation as "theoretical, philosophical, and practical," the majority of responses debated the pragmatics of seeing the video examples of team teaching and documents about lesson planning. In examining responses to "What questions are still circulating in your mind?" several comments stand out. One principal asked, "When will the State Education Department understand that 'one size does not fit all'?" Is this a cry of frustration at the restrictive options imposed by the state or does it absolve principals from promoting increased integration of students with disabilities and changes in teaching methodologies and curricula? Another wrote, "Will they change? Will they be more accepting of kids in general ed?" These are commonplace thoughts, but they are also formulated from a passive stance. Could the question be phrased actively as, "How can I promote and support change? How can I influence teachers to accept diversity within the classroom?" The original response prompts me to ask how ready, willing, and able are administrators? Equally important, how can they be supported in their efforts?

Re-imagining Education for All Students

Can the invisible lines between general and special education be re-imagined for the benefit of everyone? One principal wrote, "General educators need to be taught to be special educators. Special educators need to be taught to be more assertive and participatory." This indicates the belief that this blurring of lines is not just possible, but preferable. The same person also asked, "How are students taught to be their own advocates?" This is an extremely important question, as it conveys the need to shift how we think about and work with students to facilitate self-empowerment.

One principal asked, "If we were to mainstream more kids, what would happen to our special ed. teachers?" This is interesting for several reasons. It echoes the concern from the *Brown v. Board of Education* video clip, that many of the African-American teachers in the dual system did lose their jobs. Perhaps more realistically, many special educators are currently reevaluating their role as they become increasingly connected to inclusive practices within the general education classroom. Probably, this question exemplifies how the able-bodied population is supported by the management of those labeled disabled, and the interests of the former often appear to supercede the concerns of the latter.

In responding to "What pieces need to come together to make it [increased inclusive practice] work?," many principals wrote of common planning time for staff, professional development, and financial support. Several did address the notion of how best to change perceptions. One principal believed s/he needed "open minded teachers and ritualized reflection around instruction," while another wrote, "viewing a heterogeneous classroom as beneficial to all students." In these comments it is possible to see an understanding of disability as diversity. Can this belief be internalized by an entire staff? Many feel the need to have a common belief system among staff. One principal described the problem of "changing the mind sets of some adults that are suspended in time," while another stressed that "exceptionally strong, open-minded staff must be selected."

Personal Feedback

Finally, several people talked to me after the presentation. One told me I "was a little opinionated" but he liked that. Another described how my

passion and sincerity for these issues came through, making it hard to imagine someone else presenting the same material. Yet another principal complimented me on a good job saying, "You managed to include revisionist history, the Holocaust, and abortion – all topics people avoid in after-dinner conversations." How should I interpret these comments? Regarding being opinionated… who is not? Even those who resist change embody an opinion that the status quo is the preferred state. I recognize that aspects of disabilities studies are controversial, but *every* position is ideological. Regarding passion… I am glad it shows. Disability studies has enabled me to access new tools to further ideas I have held. I think the embrace of human difference is desirable in a heterogeneous society and disability *is* part of difference. As for including material that may trouble some… we need to be challenged to see things from multiple vantage points. Historical treatment of people with disabilities and contemporary practices *must* be discussed among others to create a greater understanding of these constructs as well as their connections. Together, these three comments from participants invoke the need for disability studies: (a) to criticize dominant ableist discourse, (b) to challenge oppression, and (c) to achieve a just society.

Conclusion

I have narrated my journey of using theoretical concepts within disability studies to serve practical ends in the field of education. Returning to my first question, I asked, "How can I infuse disability studies into "mainstream" educational thought?" For the duration of the presentation I believe I purposefully challenged entrenched attitudes toward the education of students with disabilities. I cannot say for sure how many had a "turning point" (Titchkosky 2002, 103), and there were more signs of resistance than epiphanies, but I did witness struggles in people's adjustment to this information. I will optimistically align myself here with researchers who claim *resistance is engagement* (Ellsworth 1989, Lather 1992). I believe my strategically chosen points started the audience into

beginning the examination of their deeply rooted beliefs.

My second question was, "How can disability studies be used to challenge entrenched belief systems and attitudes toward the education of students with disabilities?" This narrowed the theoretical breadth of the first question to a specific area of practice. In connecting powerful ideas from disability studies to the practical needs of the school district, a space was created to engage in issues with depth and seriousness I had not witnessed before. Lines between personal and professional melded as schools and educational practices were contemplated.

Despite my satisfaction with the presentation, I am mindful of its singular venue. In the world of professional development significant change does not result from a "one-shot," unless it is followed up and such practices are incorporated within school cultures (Guskey and Huberman, 1995; Sparks, 1994). However, I am confident that the push to re-conceptualize disability in this and future, "in-service" presentations contains seeds of change. Ultimately, disability studies introduces the possibility of a re-imagined educational landscape in which human diversity is not weeded out, but cultivated and celebrated. The growing number of schools contemplating how best to reintegrate students with disabilities can find ideas from disability studies as they restructure their classrooms. This is the juncture where we now find ourselves.

Postscript

What needs to be done in order for disability studies to be embedded in teacher discussion groups, school-based action research projects, curricula-writing groups, Parent-Teacher Association agendas, and cabinet meetings of administrators? As Ware (2001) has demonstrated, "daring" to do disability studies is essential, in schools, universities and in-service staff development. Though theories circulate in universities, if they are to become reality, they must continue to be propagated among

educators and in schools. By mutually developing means for the implementation of theories educators at both university and school levels can collaboratively *demonstrate* a commitment to change. Let us not wait and only hope for the better world envisioned by Clandinin and Connelly (2000); but create more dialogues that will bring it about.

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Endnotes

[1]It cannot be automatically assumed that those who consider themselves disabilities studies scholars believe in educational inclusion for all students with disabilities.
[2]Taught by Beth Ferri at Teachers College, Columbia University during the spring 2002 semester

Slipping the Surly Bonds of the Medical/ Rehabilitation Model In Expert Witness Testimony

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Abstract: This essay asserts that the new academic discipline of disability studies challenges the medical/rehabilitation models of disability and that this challenge has an impact on expert witness testimony. This assertion is based on the author's experience in a civil sexual assault trial involving a male resident of a group home facility assaulted by another male resident of the group home. The author was surprised to find that her status as a visiting professor in the new academic discipline of disability studies trumped the testimony of the clinical expert witnesses, including a licensed psychologist, a behavioral specialist, and a case manager.

Key Words: expert witness, sexual assault, medical model

Introduction

Just as the Civil Rights Bill of 1964 fostered the development of black or ethnic studies and women's studies, the Americans with Disabilities Act of 1990 has fostered the evolution of disability studies in colleges and universities across the nation. Many institutions of higher education including, the University of Toledo, University of California Berkeley, University of Wisconsin Madison, University of Illinois Chicago, and the Ohio State University [Ed. note: See Taylor and Zubal-Ruggieri elsewhere in this issue for a more complete list] have developed interdisciplinary undergraduate disability studies courses, minors, majors, and graduate concentrations and programs in disability studies.

A new social constructionist model of disability has emerged out of the framework of "cultural studies" that developed in English, ethnic studies, and women's & gender studies research and theory scholarship in the last twenty years. It includes historical research, literary and art criticism, the study of representations of disability in film and drama, critiques of eugenics, holocaust studies, public policy, history, architectural and urban design research, as well as a lively critique of special education and medical models of disability.

Although the author had originally been engaged by the plaintiff's attorney for her background in vocational rehabilitation, quality of life issues in sexual assault and personal injury cases, and for her credentials as a Certified Rehabilitation Counselor and diplomate status with the American Board of Vocational Experts, by the time the case came up for deposition and trial, the author was deeply engaged in creating a disability studies program. As a result, the author subscribed to Linton's (1998, p. 118) claim that

A disability studies perspective adds a critical dimension to thinking about such issues as autonomy, competence, wholeness, independence/dependence, health, physical appearance, aesthetics, community, and notions of progress and perfection—issues that pervade every aspect of the civic and pedagogic culture.

All of these issues were present in the civil sexual assault trial where the plaintiff was suing the group home for its lack of care and supervision of its residents. The plaintiff, a thirty-year-old man with developmental disabilities including cerebral palsy and cognitive disabilities, also used a wheelchair. On a field trip, ironically to train people with developmental disabilities in self-advocacy, the plaintiff was sexually assaulted by the perpetrator after he fell asleep in his bed. The plaintiff woke to find the perpetrator undressing him and attempting to penetrate him anally. He resisted and the perpetrator left his room.

Only one paraprofessional attendant accompanied the residents on the field trip. Ordinarily, two staff members from the group home accompany residents on such trips. The plaintiff was too embarrassed to report the assault to this lone female staff member and he did not report his experience until his male case manager came for a visit a few days later. The case manager immediately called the local police and an investigation ensued. The

perpetrator, a large man with cognitive disabilities, admitted the assault and arrangements were made with the district attorney to charge him with a misdemeanor sexual assault. The perpetrator was not incarcerated, but returned to the facility. When the plaintiff realized that no steps would be taken to protect him in the group home, he left to live with his mother in a nearby large city. Unfortunately due to substance abuse, the mother was not able to provide her son a home but after the plaintiff left the facility his state and federal funding streams were cut off. Both mother and son found themselves homeless on the streets for nearly a year before funding could be reinstated. In the meantime, the plaintiff lost access to the training he had been receiving in independent living skills such as cooking, housekeeping, and working in a janitorial and file clerk capacity. His long-term goal was to live independently in his own apartment and work on a part-time basis. That is, the plaintiff was struggling with the very issues Linton notes: a*utonomy, competence, wholeness, independence/dependence.*

Although homelessness, living on the street, and caring for a parent addicted to alcohol could be framed as the ultimate bootcamp in terms of struggling with autonomy and independence, none of these experiences lead to what Linton refers to as *health, physical appearance, aesthetics, and community.* That is, the plaintiff's physical and psychological health were at further risk due to poverty, homelessness, and substance abuse by others including his mother and people confronted on the street... Even after the plaintiff designated his mother as his caretaker, thereby enabling the funding streams to flow, he ultimately fired her because of her destructive influence on his well-being. After more than 4 years the plaintiff was able to locate stable housing in a family home with only one other resident with development disabilities. He had his own room and a part-time job, but still found himself afraid of men in general, and men who were strangers to him in particular. He found it difficult to leave his new home for any purpose whatsoever. The plaintiff lost his community at his group home and lost the opportunity to make a gradual transition from a group home to

independent living while maintaining his ties with friends in the group home. His physical appearance improved after he located housing (being able to bathe, get dental care, purchase clothing), but since he used a wheelchair, the plaintiff was always marked as disabled and he could never escape this identity and all of the socially constructed meanings associated with such an identity. As we shall see, this disability identity was integral to the jury trial.

When Linton refers to *aesthetics* as part and parcel of the examination of disability, in my opinion, she refers to a whole complex of ideas about disability including desirability, beauty, sexuality, and even a sense of rightness. In any sexual assault case, these are always underlying themes which sometimes emerge as what the plaintiff was wearing, the gender, age and beauty of the plaintiff, and the plaintiff's sexuality. A male on male assault by one disabled man on another disabled man and the perpetrator able-bodied and the victim in a wheelchair and not mobile without it challenges all of our stereotypes about sexual assault, sexuality, beauty, and rightness. The idea that people with disabilities have any sexuality at all is suspect although the dangerous sexuality of men with cognitive disabilities is a common theme in film and literature (e.g., John Steinbeck's *Of Mice and Men*). Gender stereotyping is also in play here since sexual assault is generally understood to be a male on female crime. Beauty is also not ascribed to men, but in this case a sense of rightness and a sense of its opposite, wrongness emerged. The sense of rightness came from the demeanor of the plaintiff. The plaintiff was a credible witness. His bearing was dignified. His speaking was calm and clear. His confusion about whether or not he had experienced penetration was innocently believable. His vulnerability became apparent when he had to crawl from his wheelchair to the chair in the witness stand. The plaintiff did this with no shame and great cheerfulness. The plaintiff survived the questioning about his sexuality. The big question was: "Are you homosexual?" The purpose of this question was to lay the groundwork for a possible consensual sexual experience between the plaintiff

and the perpetrator, but the plaintiff responded that he hoped to find a nice woman and marry some day.

The perpetrator, on the other hand, did not testify but glowered and loomed as the large able-bodied man with a previous history of sexual assault. Although this was not known by the jury, it was information possessed by all of the attorneys and expert witnesses. However, the jury did know that the perpetrator had been convicted on a felony sexual assault on the plaintiff in the criminal adjudication of this case. The misdemeanor sexual assault charges had been replaced by a felony conviction when the group home interfered with the criminal case by hiring an attorney with the perpetrator's Social Security Disability Insurance checks. Despite this conviction, the perpetrator never went to jail and no counseling was provided to him. After more than 4 years, the perpetrator still resided in the group home. The perpetrator never testified at trial. However, the act of sexual assault loomed over the entire proceedings and invaded the courtroom with a sense of wrongness.

Disability Identity

Disability identity played a key role in this civil trial for two reasons. First, the plaintiff was marked by a disability identity because of his wheelchair use. Secondly, the plaintiff claimed a disability identity because he has a cognitive disability and is involved with the self advocacy organization, People First. As pointed out above, the jury had already been presented with a powerful image of the plaintiff's disability when he had to clamber out of his wheelchair down to the floor and up the one step into the witness box and then climb up into the chair placed on the elevated platform. The jury was jolted again when a bomb scare interrupted the trial and the courthouse had to be evacuated. Although the use of elevators is not recommended in such a situation, it was clear to all the parties in the trial that the plaintiff would use the elevator even at risk of his life. No one volunteered to carry the plaintiff down nine flights of stairs to the

street. When the trial resumed an hour later, the plaintiff's disability identity was powerfully present in the minds of the jury. Neither the plaintiff's nor the perpetrator's cognitive disabilities were salient factors during the evacuation procedure, but the plaintiff was marked by his wheelchair use whereas the perpetrator had made his way down the stairs with the rest of us.

As Linton (1998, p. 12) points out:

"While retaining the term disability, despite its medical origins, a premise of most of the literature in disability studies is that disability is best understood as a marker of identity. As such, it has been used to build a coalition of people with significant impairments …"

She continues:

"When disability is redefined as a social/political category, people with a variety of conditions are identified as people with disabilities or disabled people, a group bound by common social and political experience. These designations, as reclaimed by the community, are used to identify us as a constituency, to serve our needs for unity and identity, and to function as a basis for social activism."

The plaintiff's attitude toward his mobility impairment was casual. If he needed to get out of his wheelchair down to the floor and climb up into the witness box, he did it with a shrug. His passion was in self-advocacy, control over his own life, and a determination to assert himself despite his cognitive impairments. In short, the plaintiff claimed his disability identity through his political activism with People First. The People First organization is part of what Shapiro (1994, p. 186) refers to as the "second wave against the professionals who have run programs for people with retardation." (The first wave was advocacy by parents for their children with cognitive disabilities.) Without the

plaintiff's claiming of this aspect of his disability identity, it is unlikely that he would have had the internal strength to stand up against the professionals in the group home when he reported the sexual assault to his case manager. It is not accidental that the plaintiff selected an outside professional to report the assault and not a permanent member of the group home staff. Although the case manager could be characterized as the hero in this cast of rehabilitation professionals, when he was provided with an attorney, he ultimately failed to advocate for the plaintiff. Obviously, the case manager who had reported the assault to the police and to the group home professionals was to be restrained and silenced because he risked his company's lucrative contract with the group home. His subsequent testimony in depositions and trial was weak and non-committal.

The plaintiff's self-advocacy background also meant that the case came to trial. That is, even the plaintiff's own attorney admitted that he was reluctant to bring the case forward but the plaintiff's assertion of his right to dignity and justice kept all of the professionals in his case on track. The plaintiff, because of his activism, had transcended the old idea promulgated by psychologists "that people with retardation could have no sense of self and therefore were incapable of making decisions" (Shapiro 1993, p. 195). Although the jury's grasp of this aspect of the plaintiff's disability identity was more subtle and perhaps even easy to erase, it was there. The plaintiff's cognitive impairment became obvious when he testified but so was his determination to be heard, for justice to be done. The plaintiff was able to assert his personhood to the point that in testimony he was listened to with an attentiveness so careful that breathing became a disruption to concentration.

The Expert Witnesses

In addition to the case manager, the defendant's attorneys brought forward a behavioral specialist and a clinical psychologist who was also a tenured professor at the local state university. It should be understood that it was the group home which was on trial here since they were the "deep pockets" in this case. Certainly, the perpetrator was the defendant as well but since his only access was to SSDI income, there was no gain be had in bringing a civil case against him alone. The problem then was to prove or disprove that the group home was liable for the actions of the perpetrator.

The behavioral specialist was so caught up in the medical/psychological model of disability that she was patently unaware of the past 30 years of development in interpersonal violence literature and had no awareness of the emerging literature on disability and violence (Krotoski, *et al.* 1996; Murphy 1993, 1996, 1998; Sobsey 1994). Instead she verged on presenting the stereotype of persons with cognitive disabilities as being incapable of providing credible testimony on their own behalf, particularly sexual assault claims. She was hired to assist clients in changing their behaviors after they had claimed a sexual assault and indicated that the sexual assault would have to be "proven" in order for her to acknowledge that such an assault had ever taken place. Interestingly, this expert had never been hired to work with perpetrators in order to change their behaviors and no such services had ever been provided to the perpetrator in this case. This expert also had a contractual relationship with the group home and therefore it was not in her interest to suggest that such sexual assaults took place at the group home or between clients from the group home on field trips.

The clinical psychologist had been hired to evaluate whether or not the plaintiff had suffered any long term psychological damage as a result of the sexual assault. The position of the defendants in this case was that the sexual contact was consensual and even if it was not consensual, there was no impact on the plaintiff. The psychologist stated he could not determine if the sexual contact was consensual or not but that the results of his testing indicated that the plaintiff was not now experiencing any post-traumatic stress disorder. The psychologist then launched into a monologue about whether or not penetration had actually oc-

curred. This was done in a booming voice with language such as: "Did the penis touch the anus? Did the penis penetrate the anus one inch or three inches? If this happened, it would be upsetting no matter how far the penis penetrated the anus, but it had no impact on the plaintiff anyway." In this testimony, the psychologist managed to force the jury into facing what everyone knew but wanted to avoid --- the details of the sexual assault.

The testimony of these two expert witnesses placed the responsibility for the sexual assault on the shoulders of the plaintiff. Their testimony did not address any of the issues faced by residents in the group home. The social/political implications of the sexual assault were never addressed and perhaps never even noticed. Instead, the experts focused on the case model of disability, which reduces the experience of disability to an individual medical/psychological/behavioral problem to be fixed. Ultimately, their testimony proved to be irrelevant, but that was not their fault in that the attorneys for the defendants also perceived the case to be about an individual problem and not a social issue.

This is not to say that the author was not fuddled as well. The old tried and true rehabilitation model of disability came to the forefront in discussions with the plaintiff's attorneys, reviews of the case documents, and interviews with the plaintiff, but the case just didn't fit into the usual mode. There was no way to assert lost earnings since the plaintiff's income was based on his disability and the resulting funding streams from state and federal government. His work experience had taken place in a rehabilitative or sheltered workshop environment and therefore was irregular, subject to being paid on a piece work basis, and usually below minimum wage. Records of such earnings proved impossible to obtain. Addressing vocational potential was tricky since supported employment in his community was a myth and it was unlikely that he would be able move beyond the usual muddle of sheltered workshop settings, piece work, and occasional employment.

Quality of life issues seemed to be a more promising arena for documenting damages and indeed living on the street with his substance abusing mother and the more than 4-year disruption in his attempt to learn independent living skills in order to live in his own apartment with a part-time job had been derailed, perhaps permanently. Assigning a monetary value to quality of life issues continues to be problematic in the courts and the attorneys did not hire an economist to provide testimony on this issue (Murphy and Williams 1998, pp. 15-20).

So even though the author's background in rehabilitation was certainly helpful, ultimately it was the new knowledge found in disability studies that allowed the plaintiff's attorneys to move the case away from the medical/psychological/ rehabilitation model and to the social/political model of disability. That is, the focus turned away from the individual experience of the plaintiff and the perpetrator to the group home.

Disability Studies and Expert Witness Testimony

> *"As with many of the new interdisciplinary fields, creating the category "disability studies" didn't create the scholarship. Instead, the name organizes and circumscribes a knowledge base that explains that social and political nature of the ascribed category, disability. The formal establishment of the field provided a structure for research and theory across the disciplines focused on disability as a social phenomenon, a perspective largely ignored or misrepresented in the curriculum."* Simi Linton (1998, p. 117)

The category of disability studies allows one to cross disciplinary boundaries in a way not permitted as a vocational rehabilitation counselor or vocational expert. It provides a context in which

to place expertise in interpersonal violence and its relationship to disability. Hence, the author did not have to compete with the psychologist over expertise in this field since she was not addressing a clinical, individual issue but a larger social issue. Her new status as a disability studies academic allowed her to provide testimony on the abuse of people with disabilities and more particularly the sexual abuse of men in institutions or group homes (Sobsey 1994, pp. 51-88).

Sobsey's (1994) path-breaking book, *Violence and Abuse in the Lives of People with Disabilities: The End of Silent Acceptance?*, summarizes five studies of sexual abuse patterns of people with disabilities, most of whom had developmental disabilities (Sobsey and Doe 1991; Sobsey-current; Sullivan, Brookhouser, Scanlan, Knutson and Schulte 1991; Turk and Brown 1992; Wescott 1993). The prevalence of abuse for adult male on adult male abuse in this population ranged somewhere between 18 to 30 percent in four of the five studies. The Sullivan, *et al.* study (1991) indicated a 57 percent of male on male sexual abuse. It was not clear why this study showed such a higher rate of abuse, but Sobsey (1994, p. 78) suggests that the study may have confounded the abuse rate when they included children with adults in their sample numbers.

Sobsey (1994, pp. 81-82) pondered the high rate of the sexual abuse of boys and men living in institutions and he suggested that the simple answer appears to be institutional structures. Because all of the studies agree that the great majority of offenders (about 9 out of 10) are males, we consider whom males have the greatest opportunity to abuse.

The traditional segregation of institutions clusters male staff together with male residents and female staff together with female residents (partly as a means of minimizing heterosexual interaction). Thus because most offenders are male, gender-clustered service systems permit greater access to male victims.

The author provided the judge and jury with this information and asked some pointed questions

directed at the group home staff. Given that this research has been available since 1991, what was the institution's response? That is, did the group home staff have training in the prevention and response to sexual and physical assault within their facility? Did the staff provide sexual education training for residents? Did the staff provide sexual assault education, prevention, and awareness training for residents? Were there procedures in place for response to complaints and care of residents in the employee manual? Were there procedures in place for dealing with alleged perpetrators? Were there procedures in place for protecting victims? Were staff and residents encouraged to bring forward sexual assault complaints? In other words, the author provided testimony on liability issues and the lack of ethical behavior of the so-called rehabilitation professionals employed by this CARF certified facility.

No such procedures nor sexual assault awareness and education training sessions were in place at this facility before or after this sexual assault case came to trial and the group home most likely followed the pattern seen in other group home and institutions, which is to cover up the abuse. Sobsey (1994, pp. 90-93) points to four factors that can be identified in institutional abuse:

1) Institutional abuse is characterized by the extreme power inequities that exist between staff and residents.
2) Institutional abuse is collective in nature.
3) Institutional abuse is characterized by the cover-up, largely due to conflicts of interest.
4) Institutional abuse is characterized by clearly defined patterns of environmental influence brought about by staff who are given very few resources but a great deal of power over residents.

The plaintiff was given a six-figure award by the jury. This money was put into a special needs trust so that the plaintiff would not face losing his funding streams once again. The trust will allow the defendant extra income over his lifetime thereby

improving the quality of life with such things as his own television set, a computer system, etc. The perpetrator has been returned to the group home where he remains to this day with no treatment or re-education to assist him in changing his behavior.

Olmstead vs. LC and Institutional Abuse: Implications for the Future

On June 22, 1999, the United States Supreme Court held in Olmstead vs. LC, 119 S.Ct. 2176 (1999) that the unnecessary segregation of individuals with disabilities in institutions may constitute discrimination based on disability. The court ruled that the Americans with Disabilities Act may require states to provide community based-services rather than institutional placements for individuals with disabilities.

Lois Curtis and Elaine Wilson, two women with mental illness and mental retardation, were confined in a Georgia state psychiatric hospital. They wanted to live in the community and receive community-based services. Their doctors agreed that the women were ready to do this, but the state had a long waiting list for community placement and, as a result, the women were institutionalized unnecessarily for years. The women filed suit against Tommy Olmstead, the Commissioner of Georgia's Department of Human Resources. After years of litigation, Olmstead asked the Supreme Court to decide once and for all whether unnecessary institutionalization of individuals with disabilities is a form of discrimination prohibited by the ADA. The Supreme Court ruled that the ADA has an "integration mandate."

As a result, the states are obliged to develop a comprehensive plan for community-based care. The sticking point is the movement of money from institutional care to community-based care. Although some states have demonstrated great resistance to formulating and implementing such plans, it has been true that since 1981, states have had an option under the Medicaid program to apply for funds to pay for a number of home and community-based services for people with disabilities. The number of states providing such services under this program is expanding steadily and rapidly each year (National Association of Protection and Advocacy Systems 1999).

Olmstead vs. LC creates a tremendous pressure on group homes and other facilities such as nursing homes which serve people with disabilities. The pressures are not only financial but raise complex issues in changing an institutional culture into a community-based, person-centered culture where a person with a disability can exercise the right to live where one wants to live, to live with whom one wants to live, with whom one wants to socialize, how one wants to spend one's time, and what jobs one wants (National Association of Protection and Advocacy Systems 1999). The resistance to such change should not be underestimated, but the rise of people with disabilities in our culture should not be underestimated either. As the self-advocacy movement for people with developmental disabilities matures, we will see more and more plaintiffs who will demand justice for themselves in not only sexual assault cases, but in the right to be free of incarceration in the name of treatment, to live independently, to be acknowledged as full citizens participating in every aspect of community life.

Unfortunately, this transition from institutional care to community-based care and independent living for people with cognitive disabilities promises to be difficult and problematic. As a result, we can expect to see more and more civil lawsuits emerge as more people with disabilities demand their right to live in the least restrictive environment, and in an environment free of the threat of sexual assault. The new discipline of disability studies offers a methodology for providing expert witness testimony beyond the medical/rehabilitation model of disability in such cases.

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Researching the Social Construction of Blindness

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Abstract: Research on blind people has been dominated by literature written from the perspectives of medicine, rehabilitation and psychology, focusing on disease and its effects, psychological aspects of blindness (grief and loss), adaptation and coping strategies, and employment. Blindness is positioned absolutely on the individual, as if it occurs in a social vacuum. This approach assumes that blindness is solely a medical event, and not a social process. One exception to this pattern is Scott's (1969) groundbreaking social constructionist approach to blindness and society. Scott's phrase "blind men (sic) are born, not made" emphasized the role of blindness workers in the socialization of blind people. Scott's work on the social construction of blindness has been built upon in the last decade by interdisciplinary blindness literature, strongly influenced by disability studies (e.g., Michalko, 1999, 2001, 2003; Kleege, 1999; Kudlick, 2002; French, 2001, 1999; 1993). This paper will analyze the contributions of this new literature, and highlight gaps which still exist within the literature on the experience of blindness both as an impairment and as a set of disabling social processes. In this context, I will briefly discuss my plan to do insider research with legally blind people. This paper asserts that doing social constructionist research on both impairment and disablement will help fill gaps in both the blindness and disability studies literature. My own research on blindness seems to be the first study in the United States which utilizes the British-born emancipatory social model of disability. By infusing this model into American blindness research I hope to contribute to the expanding international discourse on disability studies.

Key Words: insider research, blindness, social construction

Introduction

Research on blind people has been dominated by literature written from the perspectives of medicine, rehabilitation and psychology. The focus of these studies has tended to be disease and its effects, psychological aspects of blindness (loss, grief, and, eventual "acceptance"), adaptation and coping strategies, and employment of blind people.

Blindness is positioned absolutely on the individual with little societal context taken into consideration, as if blindness occurs in a social vacuum. This approach tends to assume that blindness is solely a physiological event, and not a social process.

One exception to this pattern was Scott's (1969) pioneering social constructionist approach to blindness and society. Scott's phrase "blind men [sic] are born, not made" emphasized the role of blindness workers in the socialization of blind people. Scott's work has been built upon in the last decade by interdisciplinary blindness literature, strongly influenced by blind disability studies scholars, (e.g., Michalko, 1999, 1998; Kleege, 1999; Kudlick, 2001; French, 2001, 1999; 1993). This paper examines the contributions of some of these new works in re-theorizing blindness both as impairment and as a set of disabling social processes.

Current Trends in Blindness Literature

One need only type in "blindness" on any Internet search engine to understand the nature of available blindness information – disease, rehabilitation and counseling services, product catalogues, blindness "etiquette," blindness prevention, and medical research. A sparse sprinkling exists of information about organizations *of* the blind, which are most often initiated and controlled by blind people themselves, and are consumer and rights oriented. The more prevalent (and more well-funded) associations *for* the blind have deep historical roots in the medical model and are usu-

ally administered by sighted people. Often charity-based, these organizations promote blindness prevention media campaigns, information about specific eye diseases and related services and product information, reports of medical research aimed at prevention and cure. Generally, neither type of blindness organization engages in social or even medical research.

Although some charity-based organizations sometimes raise money to help fund prevention and/or cure research (and to fund their own jobs), the actual protocols regarding decision-making and research work are left to medical and educational establishments. Medical institutions devote their energies to prevention, diagnosis, treatment, and cure while educational institutions attend to matters of adaptation, accommodation, and rehabilitative training.

Even as I laud the value of the medical, rehabilitation, and educational establishments' work in helping to improve the lives of blind people, I also understand that medical model research focuses on the function of the eyes, on the body, and largely fails to inquire about social processes or even about the personal experience of blindness. Disability Studies is changing all that by re-theorizing blindness within socio-cultural contexts.

However, current disability studies literature is often based in the humanities, and actual participant research projects are rare. Historical literary analysis, memoir, autobiography and auto-ethnography appear to be the preferred genres of study thus far.

Kudlick and Weygand (2001) translated writings of a young blind girl in post-Revolutionary France. The first half of the book contains Adele Husson's writings while the translators devote the second section to commentary. What is remarkable and valuable about this small volume of one person's blindness experience is how things remain the same with regard to dominant societal attitudes toward blindness and blind people. Husson writes:

When they [blind people] appear in public the stares of the multitude are fixed upon them, and agonizing words strike their ears: 'what a shame!' 'How unfortunate!' 'Death would be preferable to such a cruel privation!' There are even some people who seek out the blind to tell them these things so that they don't miss any of the sad exclamation (Husson in Kudlick and Weygand, 2001, p. 25).

Kudlick (2001) further utilizes historical documents to frame blindness within the cultural context of Victorianism. She traces the roots of an ideological split within the blindness community, which exists to this day. Movements are often measured by new interest in their histories; therefore, Kudlick's commitment to recording the cultural aspects of disability history is important, especially when understood as a marker of the growing strength of the disability civil rights movement and respect for disability studies as a legitimate, serious discipline.

In her memoir, *Sight Unseen (1999)*, Georgina Kleege describes her experience of growing up with progressive vision loss. Kleege uses examples from her own life to place blindness within a cultural context. The book is divided into three main sections: Blindness and Culture, Blind Phenomenology, and Blind Reading: Voice, Texture, Identity. Even though these topic headings convey the idea that the book is oriented within the social model, Kleege's exaggerated emphasis on impairment rather than disability often contradicts such an approach. For instance, she writes, "Writing this book made me blind" (p. 1), "This book made me understand for the first time how little I actually see" (p. 2), and, she characterizes the book as "my attempt to specify my own visual experience" (p. 103)… "A coming out narrative." Clearly, the main theme of her memoir is identity formation.

Rather than embracing blindness as an alternate ontology, Kleege writes that blindness is "not

so bad" (p. 32) and "this really isn't as terrible as you were always led to believe" (p. 34). Throughout the book, Kleege mentions "normal," sans italics or quotation marks to contest the concept. Apparently she accepts the notion of normality, e.g., "normal daily activities" (p. 167), which is highly problematic from a social model perspective. By using such simplistic descriptions of the blindness experience, Kleege unconsciously endorses a non-disabled, medicalized discourse that positions blindness as a loss and an exclusively negative experience. Many other personal narratives from blind people suggest that the experience is far more complex and has more nuances than such simplistic descriptions suggest.

The humanities play an important part in the interdisciplinary nature of disability studies, and Kleege's memoir is, in that regard, a good contribution. Even though French (December, 2002) found *Sight Unseen* "unsurprising," she states that it "provides good material for anyone interested in the meaning of visual impairment and the growing field of disability studies" (p. 859).

Even so, as one would expect of the genre of memoir, the heart of Kleege's work remains largely with the individual's adaptation to blindness rather than turning the gaze back onto society's treatment of blind people. One danger of disability memoirs is that readers may understand them to be "inspirational" stories about personal triumph over tragedy, or other medical model stereotypes about disability as an individual problem.

Another shortcoming of memoir is that it relies solely on personal outlook, which grants the author gratis permission to espouse theoretically based opinion without being required to apply the rigors of social scientific citation, which builds upon prior academic knowledge and provides substantiation to the authors' positions. Consequently, even when an author committed to the social model of disability writes memoir, theoretical re-framing of disability and impairment may fail to be noticed or understood.

In contrast to literary analyses and memoir writing, White (2003) uses queer theory, disability studies, and blindness literature to analyze the social construction of heterosexuality in blindness sex education for young blind people, and concludes that it socially creates blindness as a heterosexual experience. White delves into dominant beliefs about sexuality being a visual process, and how this construct frames young people as sexually underdeveloped. He writes, "blind people are in a sense queer, in that heterosexuality, at least in its institutionalized forms, presumes a sighted subject" (p. 134).

Sally French (2001, 1999, 1996, 1993) uses prior social models of disability literature to buttress her analysis of how society works to manage the blindness experience. She writes, "Conflicting discourses arise when sighted people define what is 'acceptable' and 'normal' behavior for a visually disabled person and use these definitions to contest that person's identity" (1999, p. 21). In her study of visually impaired physiotherapists, French (2001) uses a grounded theory approach to address both issues of impairment and disablement. Through the use of questionnaires and semi-structured interviews, she examines, for example, how society has perceived physiotherapy as a legitimate profession for visually impaired persons, and then uses participant interview transcripts to elucidate how visually impaired physiotherapists perceive their engagement in the profession as points of advocacy. Her participants discuss how they meet and manage barriers that arise in their everyday work lives. French's growing body of work incorporates both her personal experience and social model analysis; thus, her work helps shape the future of disability studies literature, in general, and blindness research in particular.

Rod Michalko, a postmodern sociologist, uses social constructivist theory to deconstruct medical, psychological, and societal ideas and practices around blindness. Chapter Four in *Mystery of the Eye and the Shadow of Blindness* (1998) is devoted to a critical examination of blindness rehabilitation. Noting that once ophthalmologists

have prognosticated their patient as destined for permanent blindness, they refer the patient out for rehabilitation, Michalko writes, "Ophthalmology is recommending *agency* as an *actor* presented as qualified to speak about, and act upon, permanent blindness. This suggests that blindness requires agency and needs to be acted upon in order for it to be lived with. Rehabilitation, too, conceives of the seeing life as the only good life" (pp. 66- 67).

In his second book, *The Two-in-One*: *Walking with Smokie: Walking with Blindness* (1998) Michalko employs auto-ethnography as a methodological framework to describe and analyze his experience of vision loss and acquisition of a dog guide. He uses postcolonial concepts of "home" and "exile" to describe his personal experience of living in a world built by and for sighted people, how his dog, Smokie, lives in exile in a world built by and for humans, and how their relationship brings "home" into both of their lives. Michalko also deconstructs how the dog guide school creates expectations of blind students' behavior and the school's physical environment based on sighted notions about the blindness experience. According to Sherry (2003), Michalko's most important contribution to blindness and disability studies literature is his postmodernist deconstruction of the blindness/sightedness binary, which extracts blindness from its perceived "lack," and places it, instead, on its own merit as an alternate way of knowing the world. Michalko writes: "Blindness, when compared with sight, becomes a thing of shadows… Anything seen as a mere shadow of its former self is understood as less than or not as good as the original… Sight *is* status and is a status *former* to blindness. Sight is not a mere shadow of its former self since it has no former self. Thus sight is not regarded as needful of restoration" (Michalko, 1998, pp. 67-68)

Michalko's work will have far-reaching impact on both blindness research, and, hopefully, on how societal institutions perceive, teach about, and treat blind people.

Conclusion

This small representation of four genres within the disability studies literature on blindness, i.e., literary analysis, memoir, queer studies, and social constructionism, has brought to surface three general shortcomings. First, the writings are mostly housed in the humanities, although there is a bit of limited research in the social sciences. Aside from Sally French's recent study of visually impaired physiotherapists, there appears to be a lack of applied research about the blindness experience. Even though Michalko used ethnographic methods to theorize and analyze blindness, he has, to date, not yet expanded his research beyond his personal experience.

Secondly, none of the work employs a materialist analysis, which is a fundamental and significant factor in the social model of disability. Blind people experience economic oppression and social isolation in even larger percentages than many other disabled people, i.e., unemployment and underemployment rates, and lack of access to basic print information. Potential employers, community development and urban planners, mainstream technocrats, rehabilitation agencies, and retailers alike balk at the financial cost of environmental barrier removal and universal design, leaving blind people stranded in or altogether shut out of the workplace, hence, out of a consumer economy. What is more, government agencies, nonprofit charities and for-profit businesses employ tens of thousands of sighted workers engaged in maintaining institutionalized oppression of blind people. Failure to examine these factors as influences in blind people's lives is failure to mine a deep and rich source of research data.

Moreover, the literature generally focuses *either* on impairment or disability, but not both. Distinctions between impairment and disability are muddied because authors often use these terms interchangeably. This causes theoretical confusion and linguistic chaos because it becomes difficult for readers to grasp theoretical concepts when the terms

of the language used to align oneself with a particular ideology speaks for all sides of the arguments.

Finally, none of the studies claim to be using an emancipatory research design. This paradigm involves change at every step in the research process, including "the relationship between disability researchers and those they research; the ways in which the products or findings of research are written up, disseminated, and utilized" (Ward & Flynn, p. 31). This can be especially meaningful for blind people who have often been shut out of disability research altogether because many researchers fail to make the research itself or the results in accessible formats.

It is in this context that I am undertaking a project which combines emancipatory and insider research, and develops an analysis based on theories of social constructivism, embodiment, and materialism. I intend not to shy away from discussing the impact of participant impairments because blindness does, indeed, affect how people conduct their daily living. However, in addition to asking participants to reflect on their individual lived experience, I will ask them questions about the power dynamics involved in interpreting that experience, such as "Where did you get the idea that you should adapt in order to appear *normal*?"

Doing social constructionist research on both impairment and disablement will help fill gaps in the blindness and disability studies literature. My own research on blindness seems to be the first study in the United States that utilizes the British-born emancipatory social model of disability. By infusing this model into American blindness research I hope to contribute to the expanding international discourse on disability studies, in general, and blindness, in particular.

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Tunes of Impairment:
An Ethnomusicology of Disability

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Abstract: "Tunes of Impairment: An Ethnomusicology of Disability" contemplates the theory and methodology of disability studies in music, a subfield currently in only its earliest phase of development. The article employs as its test case the field of Western art ("classical") music and examines the reasons for the near total exclusion from training and participation in music performance and composition by people with disabilities. Among the issues around which the case is built are left-handedness as a disability; gender construction in classical music and its interface with disability; canon formation, the classical notion of artistic perfection and its analogy to the flawless (unimpaired) body; and technological and organizational accommodations in music-making present and future.

Key Words: music; disability; classical

Introduction: The Social Model of Disability

Current scholarship in Disability Studies (DS) and disability rights activism both subscribe to the social model[1] that defines disability as a construct correlated to biological impairment in a manner analogous to the relationship between gender and sex in feminist theory.[2] Disability is thus a largely oppressive practice that cultures visit upon persons with, or regarded as having, functional impairments. While social constructs of femininity may not always be oppressive, the inherent negative implications of 'dis-ability' automatically imply oppression or at least dis-advantage. Like constructions of gender, categorizations of disability are fluid; variable between and within cultures. Activism by persons with disabilities (PWDs), which includes DS, seeks accommodations to the differences of PWDs rather than "cures." Indeed, the older "medical model" regards disability as deviance needing correction and grants authoritative

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voice to the medical professional rather than the disabled subject. This model is widely regarded among disability activists/DS scholars as the "opposition."[3]

Disability as defined by the social model is, like race, gender, or sexuality, culturally contingent. At times, impairment may be as well. While this may seem to contradict the characterization of impairment as biological, impairment matters only when identified. While, for example, total blindness/low vision may be regarded as an impairment in all cultural settings, profound hearing loss is not. For example, owing to a genetically inherited condition, at one time over 25% of the population of the island of Martha's Vineyard, Massachusetts was deaf and non-speaking.[4] Deafness was regarded as common, "normal" variation of the human condition. Martha's Vineyard Sign Language was universal and deafness was regarded as neither a disability nor an impairment.

Today, profound hearing loss is regarded by the Deaf Culture--including both hearing impaired and hearing people fluent in sign language[5] - only as a difference which, though culturally oppressed by the hearing community, lacks inherent functional disadvantages. Thus, hearing loss is regarded by the Deaf[6] as a disability but not as an impairment.

Another instructive example of disability sans impairment is fully correctable low vision. The admonition, "Boys don't make passes at girls who wear glasses," illustrates perfectly how a condition readily "fixed" and thus not generally (or legally) regarded as an impairment is nonetheless a disability in cultures that consider corrective eyewear unattractive.[7] Elsewhere, there have doubtless been (and may still be) cultural spaces where some low vision is irrelevant, perhaps even undiscovered, because tasks such as reading or driving are not performed. (Shortly, I discuss a common physical condition that is both impairment and disability in the context of musicking[8] but rarely elsewhere.)

I propose here an ethnomusicology of disability. The emergence of DS's unique modes of inquiry, numerous unanswered questions about disability and music, and the ascendancy of autonomous Disability Culture combine to motivate this new window through which to contemplate musicking.

What might an ethnomusicology of disability be? It would examine how musics construct disability and negotiate--that is, heighten and/or accommodate--impairment.[9] It would distinguish between disabilities of musical praxis – composition, performance, reception – and disabilities of representation - the rendering of the disabled subject as a theme in musical works. The temptation to designate praxis "fact" and representation "fiction" must be mitigated, as music communities often mythologize their important figures. Some of the most important historical – thus legendary – figures in Western Classical Music have been PWDs, including Beethoven – his deafness well-known – and Mozart, often posthumously diagnosed with various disorders associated with behavior and socialization, including Tourette's Syndrome.[10] Both have been subjects of postmodern cinematic fictions: Beethoven in *Immortal Beloved*, Mozart in *Amadeus*.[11]

Case Study: Western Classical Music

To advance this project, I will illustrate here with a consideration of Western Classical Music (WCM) performance. Data is drawn from extant participant observation – that is, recollection – mine and that of my wife, Dr. Iris Shiraishi, over nearly sixty years combined experience as academic and professional musicians.[12] We recall only ten student musicians with disabilities, from elementary school through doctoral programs, six blind, four with mobility impairments,[13] out of thousands of students in varied settings.

While numerous ways/sites of musicking have afforded exceptional opportunities for employment and expression to PWDs, especially blind musicians, WCM presents formidable impediments to full participation, most notably to the vision-impaired. Foremost is WCM's exceptional

dependence upon written notation, especially sight-reading. (Braille music usage is mostly mnemonic since, of course, reading Braille occupies the hands.) Visual communication with a conductor presents additional difficulties.

Some activities, such as piloting a motor vehicle, cannot currently be accommodated for all PWDs. While playing an instrument in a conducted ensemble *may* be such an activity, the blind student musicians I have known have indeed participated in such groups.[14] Unlike driving, performing in orchestra, band or chorus without benefit of sight is not hazardous. It is an activity vision-impaired people both choose and, as music majors, must fulfill as a curricular requirement.

Only one of the blind music students in our data, a violist, fulfilled her large ensemble requirements in an instrumental ensemble. The conductor of her graduate school's orchestra did indeed object to her participation; she lasted only a semester, although she told me she had been highly regarded in her undergraduate orchestra. (She did not major in performance as a graduate student and had no ensemble requirement there.) We have never observed a vision-impaired musician in a professional symphony.

It is too simple and facile to excuse barring of blind instrumentalists from Western symphony orchestras as a necessary exclusion based on a bona fide occupational qualification. I am not (yet) insisting the contrary – that such exclusion is unambiguous marginalization due to disability rather than a necessary if unfortunate consequence of impairment – but I am positing that hypothesis.

What follows contemplates whether absence of blind musicians from orchestras is reasonable or oppressive, based on principles of DS/disability activism. It begins by introducing basic DS concepts that initially appear far afield but eventually reveal new means to contemplate musicking.

Disability activism emphasizes demands for accommodation rather than "cure."[15] Accommodations employing principles of Universal Design

(UD), in facilities such as transportation systems or buildings, are incorporated from a project's inception and are as broadly applicable as possible. Curb cuts, electric doors, and closed-captioning have proven not only unobtrusive to the non-disabled but widely useful. While supertitles originated as captioning for the deaf, they now also enhance the enjoyment of opera for the hearing.[16]

Universal Instructional Design, the application of UD principles to teaching, was initially developed at the University of Massachusetts, by Silver, Bourke, and Strehorn.[17] UID integrates pedagogies to determine what may be transformed to accommodate special needs without sacrificing essential content. During a UID curriculum transformation project in which I participated in 2000, I eliminated timed tests and distributed my own course notes explicitly to accommodate non-native English-speaking students since, as noted, music students with disabilities are rare[18] - while enhancing the learning environment of all.

Applying UID thinking to the question of blind orchestral musicians, one asks, "What is the essential experience of orchestral music? What is gained by accommodating blind musicians? What is lost by the non-blind through this accommodation?" The value of DS/UID methods here is not necessarily in finding a "right" answer, but in framing questions that would not otherwise be asked. DS requires an epistemology of difference that differs from – and is arguably more radical than – ethnic, gender, or queer studies. Transcending impairment in the interest of equality can be more complex – sometimes requiring technological solutions – than transformation of the marginalizing attitudes/discourses that lie at the heart of these other discriminations.

Sight is not needed to sing or play. When I observed blind students in conducted ensembles, I did not notice delayed responses to cues or other detriments, though these surely could happen. Conductors of professional ensembles would doubtless regard even the possibility of flawed entrances intolerable. The stakes in the participation of blind

musicians in conducted ensembles differ considerably from fields like auto racing or neurosurgery, thus problematizing values quite differently. What is gained by blind people's participation are greater utilization of human resources and the improved quality of life for all that comes from eliminating the oppression of any. What is feared is some loss of the precision extolled by WCM, although the growing number of conductorless groups like the Orpheus Chamber Ensemble – who certainly rely less on visual cueing – indicate a willingness even among orchestral musicians to forsake authoritarian control in favor of interplay. A joke that circulated at the 2001 Minnesota All-State Orchestra Camp is instructive: Why is a conductor like a condom? Safer with one, more fun without one.[19]

That a competition of musicking values worthy of consideration even exists – between the precision that comes with having a conductor and the risk to that precision that derives from the inclusion of musicians whose low vision prevents her being seen – is a question that likely emerges only from a DS perspective within ethnomusicology. Elsewhere in musical discourse, WCM's quest for technical perfection would prevent the issue from even being raised.

A logic lies behind exclusion of blind musicians from conducted ensembles, thus from professional, academic, even amateur opportunities. But full representation of WCM's construction of disability must integrate a fuller range of impairments. DS identifies disability as the oppression of all people with impairments, much as queer theory recognizes the oppression of all non-heterosexuals. To determine conclusively that a way of musicking is disabling requires demonstration that impairments that clearly have (little or) no bearing on performance nonetheless result in marginalization.

The Disability/Impairment Status of Left-Handedness

WCM may be unsurpassed in creating a major impairment from a common human variation that presents few if any limitations elsewhere; left-handedness.[20] Unlike left-handed orchestral string players, left-handed guitarists are fairly common. Several rock and blues players, including Jimi Hendrix, Albert King, and Paul McCartney (mostly a bass guitarist), have been justly famous. While adaptive options for lefties exist,[21] some players like Hendrix simply invert right-handed instruments. Others, like Bob Dylan, Mark Knopfler, and even country singer Lefty Frizell simply play right-handed.

The situation for performers of bowed strings in WCM is quite different. Rarely does one see young left-handed players, let alone adults. We have never seen one in even a beginning orchestra.

Left-handedness is a complex phenomenon. The degrees to which nature (genetics) and nurture contribute are controversial.[22] Unlike writing, string playing of course requires both hands. While right hand plucking/bowing-left hand tuning appears to be the universal standard division of labor, the more challenging work is by no means always assigned the right hand, particularly on fretless instruments like violin. No less a violinist than Jascha Heifetz, who of course played right-handed, was elsewhere a lefty.[23] Heifetz notwithstanding, the guitarists who, in a less hostile environment than for bowed strings, opt to play left-handed may indicate that many people achieve less than full potential in the right-handed world of orchestral strings. Either their playing suffers for their having been switched, they opt for more ambidextrous instruments, or they eschew music making altogether. A common human variation that should present no functional limitations thus becomes an impairment in WCM.[24]

A sidebar is apropos here. What may first seem a tangent illustrates clearly the value of DS thinking for ethnomusicology. My colleague Amy Salmon

(ABD, Education, University of British Columbia) has challenged my characterization of left-handedness as an impairment rather than as a disability. I had pondered the matter myself for some time and our exchange prompted me to explore and explain my position in depth.

Ms. Salmon's arguments have obvious merit. We are both correct. Whether left-handedness is an impairment or a disability depends on perspective. Understanding this illuminates ethnomusicological thinking far beyond disability issues.

That I believe left-handedness is a biological rather than social matter owes to my having personally experienced WCM as a discreet cultural space for 30 years. That WCM is a valid unit of cultural analysis is borne out by significant scholarship, including Bruno Nettl's *Heartland*,[25] Henry Kingsbury's *Music, Talent, and Performance*,[26] and Christopher Small's *Musicking*,[27] anthropologies that contemplate WCM from the vantage points of, respectively, a university school of music, a conservatory, and a symphony orchestra. When these ethnomusicologists interrogate WCM – more or less looking in the mirror – they investigate it *as* community, rather than *in* community, a position similar to Deaf, Disability, and other cultures whose autonomy is far more apparent to insiders.

On Planet WCM, playing instruments of the violin family, the nucleus of the symphony orchestra, is a major life activity. Playing left-handed is quite simply impossible. Thus left-handedness, an immutable, hard-wired bodily fact even if partly nurtured (the parallel with theories of the nature of homosexuality is notable), is an impairment.

However, the perception that WCM is a world unto itself, so strong in WCM musicians themselves, is reflective, not of the "West" *in toto*, but of its classical music "community." It includes the abovementioned scholars who, despite being ethnomusicologists, thus marginalized outliers in this context, having dwelt in this WCM "place" – a community of shared experiences, if not shared values – for decades.

From an etic perspective like Ms. Salmon's, WCM's anti-sinistral bias is not an impairment, but a disability. An irrational prejudice against lefties, who should be entirely capable of playing the violin in their southpaw way if only given permission, is manifest in discriminatory practices. This is borne out because elsewhere in the musical world left-handed guitarists thrive, even in the highest echelons of stardom.[28]

The titles of two popular ethnomusicology textbooks, Jeff Tod Titon's *Worlds of Music* [29]and Elizabeth May's *Musics of Many Cultures* [30](underlines mine) are interesting in this context. People like Ms. Salmon who are not music professionals are more apt to perceive "music" or "the world of music." The concept of "music*s*" *as* rather than *of* communities is relatively recent and of particular importance in ethnographies of WCM.

It is difficult to conceive of a problem whose analysis more strongly reveals the myth of objectivity. Nowhere is the body more of a problem than in DS's contemplation of problem bodies. My choosing impairment over disability in characterizing the experience of WCM's left-handed complement reveals that I, like Nettl, Kingsbury, and Small, have lived and felt WCM as a world unto itself and thus concluded that it is an appropriate unit of analysis from an anthropological perspective.

Ms. Salmon, not a denizen of planet WCM, did not conceive of – or feel – WCM as a cultural autonomy, and thus concluded that it treats left-handedness as a disability, not an impairment. We are both correct from our own standpoints, each inseparable from our lived experience, inherently subjective.

The lesson for ethnomusicology--that perception, even of what is biological and what is social, is a matter of standpoint – is one perhaps it already knows, although most scholarship, written from – or *as if* from – an outsider's perspective, indicates that it is not deeply felt. I am rarely impressed that an ethnomusicologist has reported in a manner that powerfully confesses the influence of standpoint. Writings about WCM – ethnomusicologi-

cal self-studies – are notable exceptions. Applying DS thinking to WCM, ultimately the most emic context for (most Western-trained) ethnomusicologists, reveals that it is an imagined community insofar as those who do not share our repertoire of experiences perceive it as something far less autonomous than the world unto itself we feel it to be.

Unlike ethnomusicology, insider perspectives are privileged in women's, ethnic, and, perhaps even more, queer studies. This is similarly and powerfully true in DS as well, where life as a PWD (and sometimes as a family member of a PWD) is regarded as providing insight that is difficult to supplant through any kind or amount of non-experiential learning. It is interesting that white ethnomusicologists overwhelmingly choose to study the other, while ethnomusicologists of color tend to be self-studiers.[31]

Back to our story.

The rationale for exclusively right-handed string sections is principally visual effect, although sound might also be very slightly affected by having a few fiddles facing the opposite direction. Such fastidiousness, which could seem hypersensitive from an etic perspective, is quite consistent with the attention to detail currently so highly valued in WCM. In a music culture principally engaged in propagation of a canon of old works that permits relatively little latitude of interpretation or improvisation, attention to minutiae becomes a principal arena in which artists and ensembles compete for attention.

The ideal of uniform direction of bowing, part of the impression that the ensemble plays "as one," is consistent with the desire for perfectly unified responses to conductorial cues. The former requires the impairment of left-handed string players, the latter the exclusion of the visually-impaired, two classes of musicians who flourish beyond WCM, under different rules and value systems. Like (or more than) the symphony orchestra, rock music is both sonic and visual art, where groups like the Beatles and the Jimi Hendrix Experience displayed

uniquely elegant symmetries around their left-handed stars.[32]

Aesthetically and metaphorically, inclusion of either of these marginalized classes of musicians in an orchestra might give the impression that this body, judged above all by its technical perfection and grace, would unacceptably twitch, that is, sound or look impaired. Orchestras are hardly unique in their disdain for a disabled appearance.

Supercrips: Do Exceptions Prove the Rule?

What might seem to challenge my thesis – that WCM disables and impairs in ways other musics do not – are several PWDs among leading soloists and conductors. They include violinist Itzhak Perlman, percussionist Evelyn Glennie, conductors Jeffrey Tate and James DePriest, and vocalists Thomas Quasthoff and Andrea Bocelli.

Complex politics permit, even encourage, soloists and conductors with disabilities while rank-and-file musicians with disabilities remain so rare. It has long been possible for members of marginalized classes to reach the top of competitive fields like the arts and athletics while oppressed people of more typical abilities struggle for equality of employment and other basic rights. Fields requiring exceptional talent are less – or differently – discriminatory, at least partly because successful members of these groups serve established interests by appearing to provide evidence that hard work, ability, individual incentive and perseverance, rather than institutional reform, are all that are required to succeed.

In DS parlance, PWDs who "make it" against all odds are "Supercrips." ("Crip," short for "cripple," is a pejorative PWDs use similarly to the manner in which African-Americans use "nigger.") This in no way implies PWDs are contemptuous of success, only disdainful of such accomplishment being touted to rationalize an oppressive status quo as if it presented no serious obstacles that could not be overcome simply through elbow grease and grit. Supercrips make even better rags-to-riches narra-

tives of individual will than ethnic minorities or women, as it is easy to declare that their triumphs are over their own "handicaps," rather than systemic discrimination.

The careers and public personae of the WCM Supercrips noted above have differed, according to performing medium, impairment, and gender. Each could generate an entire article.

Violinist Itzhak Perlman may be as close to a household word as any WCM musician since Leonard Bernstein. His use of crutches, a result of childhood polio, is clearly no impediment to his playing. The only accommodations he requires to perform are that his accompanist or conductor carry his instrument to the stage and that he play seated.[33] It has been said that his disability has "forced the issue of accessibility to many stages and halls, a major benefit to others following in his footsteps."[34] Perlman's illustrious career has combined classical, crossover, and klezmer, and his public persona now only occasionally focuses on his disability. As likely to be portrayed as Israeli, Jew, serious eater, family man, or regular guy with a good sense of humor, he may be to WCM and disability what Bill Cosby is to television and race.

German baritone Thomas Quasthoff, whose mother took the drug thalidomide during pregnancy, is short-statured with his arms disproportionately much shorter and limited in function. His introduction to American audiences on the television news program *60 Minutes* focused on his disability. His condition remains a major topic of coverage. While his impairment has even less effect on his performance than Perlman's, with no instrument to carry (he, too, performs seated), his disability has profoundly affected his training and career.

Quasthoff endured significant discrimination in the course of his education and artistic development. He was initially placed in special schools wholly inappropriate to his exceptional intellectual gifts and subsequently refused admission to a German conservatory, ostensibly because his disability prevented him from learning piano, a ruling he describes as legal but of questionable morality.[35] At forty, his professional activities comprised recitals, appearances with orchestra, recordings, and teaching. Prior to achieving first-rank status, appearing in the best venues, with the finest orchestras under leading conductors, unlike his able-bodied peers, he had never been engaged to sing staged opera. Currently, he is preparing his first staged roles, beginning in 2003, in *Fidelio*, *Tristan und Isolde*, and *Parsifal*.

Quasthoff's first invitation to perform staged opera, from "well-intentioned" conductor Daniel Barenboim, was the role of *Rigoletto*, a deformed dwarf.[36] While Quasthoff declined this offer on purely vocal grounds,[37] sometimes citing a still-developing vocal maturity, sometimes an inappropriate, too high, tessitura, the latter was termed "bullshit" by Quasthoff's accompanist Justus Zeyen,[38] evidence that his refusal to be typecast is the real issue, as it has long been for African-American singers not wanting to be limited to *Otello* and *Porgy and Bess*. Despite opera's history of generously suspending disbelief to accommodate fine singers who do not at all look their parts by virtue of age, weight, race, or sex, a line seemed to be have been indelibly drawn at disability until Quasthoff's recent ascendancy to stardom. The barriers will likely long endure for singers with disabilities with anything less than Quasthoff's stellar gift.

Similarly, popular tenor Andrea Bocelli, totally blind, has only rarely sung staged opera, never in a major house, and to less than glowing reviews.[39] Some claim his vocal limitations, not his disability, are the reason, although press coverage indicates his blindness is indeed a concern, no matter how well he negotiates stage movement. Among the harshest critics of his singing is none other than Thomas Quasthoff.[40]

Virtually all press coverage of both singers discusses their disabilities with far greater frequency than with Perlman whose career and personal life are by now familiar. One reason for foregrounding Bocelli's and Quasthoff's disabilities may be that as singers their (impaired) bodies *are* their instru-

ments. Because of the importance of opera to singers' careers--my earlier observations about suspension of disbelief notwithstanding--at a very fundamental level, physical appearance is still bound to be more important than for an instrumentalist (at least for men), insofar as they are expected to look "good," which in a disabling culture means without noticeable impairment.[41]

For WCM female musicians, physical appearance is of great importance, regardless of performing medium. Much evidence supports this; and it is consistent with the values of the culture at large. One need only look to the protocols of concert attire.

With minimal variation, men, as soloists or in ensemble, appear in formal wear that is in essence a uniform. By contrast, women, particularly soloists and recitalists, are required to select from a much greater range of possibilities what fashion/sexual statement they make. It may appear that women in WCM have greater freedom to determine their sexual personae than men, but this obligation is time-consuming, expensive, and bears little relationship to the development of one's art other than distracting and detracting from it.

The epitome of this double standard may be witnessed, surprisingly, not among vocalists, but among female concert violinists. Press coverage of renowned violinist Ann-Sophie Mutter has long been replete with references to her trademark strapless evening gowns. She has always denied exploiting her much-admired good looks and claims she always performs in décolletage for purely musical reasons: either because she likes the violin on her skin[42] or because it helps her bowing.[43] Nude photos of Mutter – doubtless digital fakes – appear on pornographic websites.

Mutter's competition includes Lara St. John (who posed nude, covered only by her violin, on her self-produced, big-selling Bach CD),[44] Linda Brava (who appeared nude in *Playboy* magazine's April 1998 *Sex and Music* issue), and crossover specialists Vanessa Mae (who has performed Bach in a wet t-shirt) and Bond, an all-female string quartet

notorious for a nude group photo. In other media, the all-women's early music choir Mediaeval Baebes have released *Songs of the Flesh*, an album of photo erotica. The *Times of London* even reports an orchestra conductor who insists that the women of his ensemble "not wear underwear because it spoilt the line of their dresses."[45] Editorials justifying this sexual exploitation as means to the noble goal of drawing audiences to the classics are not uncommon.[46] In this very competitive field, women must vie for attention musically *and* sexually.

Even minus such obvious manifestations, sexualizing women performers in WCM is a given, in stark contrast to the super culture's stereotyping of PWDs, particularly women, as asexual, undesirable, and un-desiring.[47] This, of course, has much to do with body image. It is the appearance of disability which is thought to undermine desire.

The greater emphasis on women's appearance in WCM is borne out in that the only first-rank female soloist with a disability is Scottish percussionist Evelyn Glennie, who is deaf.[48] Much could be said of Glennie as a PWD and of her manipulation of her image as a deaf person. Here, it suffices to note that her disability is invisible and requires little obvious accommodation.[49] She is well-known for performing barefoot to enable her to better sense sonic vibration, although, unlike Mutter, there is no reason to doubt her sincerity regarding the rationale for her pedal exposure--overtly sexual only for foot fetishists. Playing shoeless, easily within the bounds of an acceptable female fashion statement, would seem far more peculiar for a formally attired man. Significantly, the "Photo Gallery" section of *The Official Evelyn Glennie Website* includes only passive photos, none in which she is performing (although some include some interesting-looking instruments).[50]

Alice G. Brandfonbrener, M. D., performing arts medicine specialist and editor of the journal *Medical Problems of Performing Artists,* reports two female patients who are exceptionally gifted musicians, a vocalist with cerebral palsy (whom she calls "beautiful") and a violinist with an am-

putated leg, visibly obvious impairments that have seriously disabled their careers.[51] Absent even one visibly impaired female soloist or conductor among WCM's top ranks, it appears that, as elsewhere, a woman's personal appearance counts for far more than a man's.[52]

(The violinist to whom Brandfonbrener refers is almost certainly her fellow Chicagoan Rachel Barton, who is enjoying a good, if not stellar, performing and recording career. Barton is unique in several ways. Fairly well established in her career while still able-bodied, the way she acquired her impairment – an accident involving a Metra/Union Pacific train,[53] which resulted in a controversial $30 million dollar settlement[54] -- contributed considerably to her notoriety, perhaps more in the worlds of personal injury law[55] and train transport[56] than in music. Thus, her disability has actually made news. Despite this, much of her press coverage ignores her disability and focuses on both her virtuosity and her interesting, widely respected crossover work, violin versions of heavy metal repertoire. Her disability is obviously more visible than Glennie's; she has used a wheelchair in performance at times. In concert and in publicity photos, she favors conventional long dresses. Once praised for being "no pushover in interviews, keeping to the subjects she wants to cover and politely but firmly declining others," she distanced herself from the soft porn exhibitionism of some of her colleagues and no mention was made of her disability.[57] Barton is occasionally active in disability causes, although one, Jerry Lewis's Muscular Dystrophy Association Telethon,[58] is widely despised by disability rights activists as condescending in its solicitation of pity. Obvious comparisons to Itzhak Perlman may conceal a commonality that is perhaps less apparent; that Barton denies/conceals neither her disability nor its irrelevance to her art.)

Beyond establishing the disabling nature of WCM musicking, determining precisely how, when, or where disabling occurs would require a database that does not yet exist. The very nature of WCM musicking as it is currently structured is disabling. Barriers to inclusion are sometimes harsh, arbitrary, and contrary to the spirit of reasonable accommodation and inclusion, as in the case of Thomas Quasthoff. Given the formidable abilities of Quasthoff, Perlman, and other WCM musicians with disabilities, and the outstanding contributions of PWDs in more accommodating musicking traditions,[59] the fear of what might be lost through inclusion could and should be allayed by understanding how much human potential goes untapped through oppressive and exclusive standards.

The disabling of (potential) WCM musicians is principally a reflection of societal norms and only partly a result of their amplification. The rate of unemployment among PWDs throughout the labor force vastly exceeds that of any other group. Seventy-four and six-tenths percent of PWDs are unemployed nationwide in 1999, according to the U.S. Census Bureau.[60] The high level of on-the-job performance of PWDs who obtain employment indicates that fear of inclusion is entirely unfounded and thoroughly wasteful. Disabled workers "have a better work ethic, are more flexible in their working hours, take less sick days, and stay longer at their jobs."[61] According to a 30-year Du Pont study, "The disabled had a 90% above-average job performance, with safety and attendance records far above the norm."[62] In an endeavor such as WCM, participation in which is regarded as a "talent" resulting from exclusion of PWDs appears even greater, with even extracurricular participation apparently discouraged from childhood.[63]

Canon Formation: Technology, Notation and Recording

While Western cultures are neither alone nor perhaps even exceptional in their oppression of the impaired,[64] the disabling nature of WCM is unique. While it is beyond the purview of this study to locate the typical moment of dissuasion from WCM participation in the lives of PWDs, it is easy to identify moments in music history that have contributed to WCM's disabling character.

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WCM's long reliance on sophisticated notation—"music" is often referenced as neither activity nor even sound but as ink on paper – creates difficulties for people with low/no vision who elsewhere might pursue musical vocations. This is an unintended if awful consequence, as notation's value for documentation and performance, especially by large ensembles, is indisputable. Still, the influence of complex notation on the ontology of WCM musicking and the development of musical values – aesthetic and otherwise – contributes to a system that disables with impunity.

The core of WCM's absolute commitment to intricate, fastidious notation is canon formation. This does not imply that other musics lack canons, evidenced even on radio stations that feature "classic rock" and even "alternative classics" (from the 1980s and 90s). Rather, the particular "what" and "how" of WCM canonization is uniquely – and literally – dehumanizing; thus intolerant of the "only human" condition of impairment.

Canons are everywhere, some might argue necessary. What may distinguish musical canons from others is the difficulty of defining, perhaps locating, "music." While "music" often references paper-and-ink attempts to store sonic intent in notated form, it is regarded elsewhere as action rather than object; hence Christopher Small's "musicking." Even were one to accept, as some influential people do, the premise that the only musical canon is comprised of the works of the "great composers" of WCM, the task would remain to determine what precisely is canonized: scores, actual performances, imagined performances, the composer's ideal performances?[65] The problem is manifest in the negotiability of even the most detailed musical notation, either inadequate – even the most recent scores usually say little or nothing about endless variations of timbre and vibrato – or like earlier scores – whose intentionally sketchy dynamics and tempi mandate interpretation. Even the most highly nuanced works of Boulez, with effusively serialized dynamics and articulations, in all matters other than pitch (for the most part) and instrumentation (with only minor exceptions), demand

interpretation rather than compliance. standardization of chant repertoire by the Catholic church, retained consistently at least in monastic – if not always also in public – performance since its inception. Smaller canonizations – that is, perpetuations of certain works as repertoire – occurred with the sacred compositions of Palestrina and Handel's *Messiah*. It should be no surprise that early canonizations were of sacred music. The canonic process in WCM (and elsewhere) is, in spirit if not always in nature, sacramental.[66]

Despite or irrespective of philosophizing as to what precisely constitutes a work of WCM, there is no doubt the "great composers"[67] and their works are referenced in reverent terms. That realizations of their works must cleave to "composer's intentions" is a veritable *idee fixe*, this is so no matter how impossible a composer's thinking may be to ascertain, how variable are performances for which such authenticity is claimed, or how entirely reasonable/desirable it would be to sanction such interpretation, as is expected, valued, and necessary in theatre and dance. These notations and performance traditions, with much larger interpretive roles for directors than music affords conductors, routinely mandate more forthright creativity than WCM currently allows.[68]

Canon propagation that discourages interpretation--that is, difference--both drives and is driven by technology. While the religious nature of WCM canonization and the technology that makes canonization possible may appeal to different temperaments, they are united, both as expressions of the desire to transcend normal human limits and as powers beyond normal human understanding. This melding of religion and technology has been both disabling and impairing.

Propagation of the WCM canon has relied on the technologies of notation, then printing and later also recording. Whatever effect these have had upon other musics, they have enabled and amplified WCM's preservationist impulse. I have often heard it argued that the desire for novelty long satisfied by hearing new works in live per-

formance (or learning them oneself, often at that wonder of Industrial Revolution technology, the piano), is now largely sated with new recordings of old works, especially those that are technologically innovative. Thus, science has helped transform Western art music into Western Classical Music, a museum, less than a living culture.

Printing enables the creation of definitive, sanctioned versions of compositions. This occurs only in the context of the preservationist impulse that had inspired the development of staff notation centuries earlier. Definitive WCM scores insist that certain notes--all of them and no others--be performed in certain rhythms and expressive nuances. (Other musics such as jazz use notation very differently.) The impact upon (potential) musicians with impairments can be exclusion. Unless one can perform precisely "the notes," one should not perform at all.

The difficulties for vision-impaired musicians were addressed earlier. For some mobility-impaired musicians, virtually the entire repertoire becomes inaccessible. The handful of commissioned piano works for left-hand only (the most important written for World War I-wounded Paul Wittgenstein) are exceptions that prove the rule.

Because the interpretive latitudes of jazz are far greater – notes are chosen and arranged with abandon – players with impaired hands like guitarist Django Reinhardt and pianist Horace Parlan have flourished by developing highly personal approaches to the entire repertoire. The difference between WCM's miniscule corpus of one-hand piano works[69] and jazz's adaptability for PWDs throughout its repertoire is that of an individualized (and quite limited) accommodation versus a splendidly effective Universal Design.

Technology, for both recording and dissemination, has had a major impact upon what and how music is made.[70] Equipment has much to say about instruments used and duration of performances. Works have been re-orchestrated minus troublesome instruments like snare drums; performances

of ragas, customarily lengthy, were limited to the duration of a cylinder or 78 rpm disk.

When recordings actually chronicled unedited performances, as predominated through the early 1960s, inevitable errors were tolerated and highly individualized interpretation flourished. The Romantic tradition in WCM performance – the individuality, if not always the nineteenth century mannerisms – persisted as long as technology could not challenge it. As sound editing grew more sophisticated, synthetic, technically perfect "performances" became possible. An aesthetic that values perfection above all became the norm, not only in recordings, where flawlessness is the editor's responsibility, but also, under the influence of recordings – the predominant mode of reception – in live performance. This places literally superhuman demands upon performers,[71] challenged, like John Henry, to perform like machines.

Where once the technical abilities of live performers dictated protocols of recording, the situation is now reversed. WCM (and some other) performers are now required to sound as much like digitally-edited recordings as possible. The ascendance of technology-as-aesthetic is also manifested in sports with performance-enhancing drugs and in femininity with cosmetic surgery. A *zeitgeist*'s impact may not be provable, but dissuading "flawed" PWDs from WCM performance, particularly in ensembles like orchestras whose protocols evoke bodily perfection, is consistent with trends in other endeavors.

Playing (and Writing) Hurt: Injuries and Indictments

It is hardly surprising that pressure to perform flawlessly has led to numerous injuries. A dedicated musician in any genre might overdo. Drummer Max Weinberg, formerly of Bruce Springsteen's E Street Band, now bandleader on *Late Night with Conan O'Brien* is a famous non-WCM case.[72] But there is evidence the demands of WCM make for a far greater likelihood of repetitive motion and other injuries than other musics.[73] The majority

of orchestral musicians in the United States[74] and internationally[75] have performance-induced upper-limb disorders.[76] Numbers are high for other WCM musicians as well. Twenty-nine percent of the Music Teachers National Association (6380 teachers, amateurs, and students) also have these disorders.[77] While percentages vary by instrument, most injured musicians are women.[78]

According to performing arts medicine consultant (and Minnesota Orchestra Associate Principal Cellist) Janet Horvath, length of season, number of services, and extensive repeated figuration in orchestral literature make for the preponderance of injuries among symphony musicians. Technical difficulties of WCM are addressed generically too. For example, by "violin" or "soprano," and rarely tailored to/by specific performer's idiosyncrasies, as is often the case in jazz and other musics whose texts are less set and whose performers are more autonomous than WCM's. The Western canon is rarely negotiable: one plays what is on the page. Some minimalist scores are so repetitive that, even sans extensive practice of difficult passages, rehearsal and performance may be painful and injurious.[79]

The walking wounded of WCM are generally not "disabled" per the Americans with Disabilities Act of 1990.[80] Injuries may heal with proper care (including rest) and may not inhibit the ADA's "major life activities" that are not construed to include virtuosic performance, even if it is one's livelihood.[81] Still, damage from overuse can be excruciatingly painful and devastate a career for which a musician has trained a lifetime. Repetitive stress injuries have seriously curtailed the performance activities of well-known pianists Leon Fleischer and Gary Graffman. WCM can be a very rough kind of play.

WCM disables people by discouraging the musical participation of people with impairments such as blindness/low vision for whom other musics provide opportunities. It transforms at least one common physical condition, left-handedness, from a normal variation into an impairment. Available data indicates that WCM impairs its practitioners through overuse to a greater degree than all other musics combined.[82]

It would be unfair not to disclose that a personal standpoint has fueled my obvious discontents with this civilization. Adding DS/disability rights to my repertoire of causes is motivated by my own condition[83] and long, arduous struggle for accommodation against "the system."

Willingness to "indict" is a typical and distinctive feature of ethnographies of WCM. Indeed, reviewing Kingsbury's *Music, Talent, and Performance: A Conservatory System*,[84] Ellen Koskoff asked, "How I would have felt had this book been written about some other more 'exotic' natives and not about 'my kind.' Would I have accepted this picture as 'the way it is there' (not knowing much about the place)? Or, would I be screaming bias?"

While Koskoff's questions are reasonable and necessary (Kingsbury can be nasty!), the answers are perhaps more complex than one might at first imagine. We need to know more about the standpoints of many/most authors. We probably don't scream bias anywhere near often enough. The ethnomusicologists who investigate WCM are more forthright about their standpoints than most. Bias cannot be addressed by elimination – impossible – only by revelation. Further, in the case of WCM systems such as conservatories, orchestras, and universities, these are complex cultures with intricate networks of power relations, and their own forms of otherness and oppression. The others and the oppressed are often those Nettl has identified as working in the margins of the curriculum, including ethnomusicologists. They also include the (literally) wounded. In that context, I offer a hearty *mea culpa* to the charge of bias, while simultaneously asserting that the conclusions reached here are based on a substantial foundation that includes, but is hardly limited to, participant observation.

Conclusion: Untapped Potentials

More important than any particular findings, an ethnomusicology of disability provides a pro-

vocative framework for investigating constructions of difference.[85] Further potential projects include representations of disability in musical fictions, for example, the near ubiquitousness of disabled subjects in recent films about WCM.[86] Besides asking, "Why are these films so made?" critical questions include, "Is disability plot-central or incidental?" and "Is – and of what – is disability symbolic?"

Another potential investigation would be disability acceptance in relation to race and class. WCM has always been associated with social prestige and economic power, especially of its patrons. Its meta-narratives of immortality (of its canon) and (technical and formal) perfection readily conflate with able bodies. Several American musics with strong proletarian and minority affinities – and frequent lyric references to disabling occupations and other potentially injurious habits – have significant representation of PWDs among their most prominent performers.[87]

For a model of musicking in spite of mobility impairments, one may look to soul music immortal Curtis Mayfield who, in spite of a freak stage accident which left him quadriplegic, was able, though with great difficulty, to continue composing, singing and recording[88] and to engage in disability rights activism.[89] His final album, *New World Order* (1996), for which the artist required a special harness to aid his singing, was a critical success.

Elsewhere, certain instruments – thus occupations – including koto and biwa[90] in Japan and bandura in Ukraine have been strongly associated with/reserved for PWDs, some of whom formed powerful guilds.[91] These successes provide important insights into alternative constructions of disability, some from distant times and places.

Ultimately, all the blues in the key of high theory offered as chronicles of oppression in DS and other area studies are worth little if they are not calls to action. It is good to remember the last words of labor leader Joe Hill: 'Don't mourn; organize!'

I have long thought WCM, nearly unique in its privileging of composition as distinct from performance (despite many of its best composers also being virtuosi), could lead the way to redefining what it means to be a musician by championing adaptive technology as a means of enabling people with severely impaired bodies to transcend physical limitations and allow their sonic imaginations to soar unencumbered. This hasn't happened. While it may not be possible to causally attribute this lack of outreach to WCM's demonstrated abhorrence of "flaws" in its music and musicians, there is an unfortunate consistency of values evident.

There is also a powerful alternative model in the Vancouver Adapted Music Society.[92] Founded by two musicians who became quadriplegic through accidents – one of them Sam Sullivan, a Vancouver City Councilman and Executive Director of five disability non-profits, including VAMS[93]-- the organization maintains recreational and professional studios, supports recording and performance projects, offers classes, workshops, private lessons and outreach, supports the band Spinal Chord, and has commissioned digital technologies that have enabled people with complex impairments to realize their creative potentials .[94] One such innovation is a "mini-modem-midi device [that] was perfected so that musicians who are immobile can now musically communicate with other musicians in real time from city to city over a telephone link to the digital technology."[95] Although the emphasis of its programs appears to be popular music (classes in "songwriting" are offered), as *musicking*, VAMS is something remarkably new.

The device described here is an example of Universal Design *par excellence*, whose broad application within and beyond the disability community is readily apparent. The initiative behind this remarkable invention (the creation of Vancouver-based non-disabled musician/technicians Bob Turner and Jeff Koftinoff) and VAMS itself was the self-determination of PWDs.

The impact of recent technologies upon WCM is not entirely negative. Fidelity and durability of

recordings has improved. Captioning devices invest vocal performances with heightened meaning. Composers have new resources for sound synthesis and desktop publication. Still, pressure to perform flawlessly, for which digital editing has surely been a major influence, has had much to do with the current pandemic of performance injuries. Mania for technical perfection is coupled with the ossification of the WCM canon. The recording industry – which has shifted audience interest from new repertoire to new format and packaging – is in great degree responsible. This has contributed to a culture of bored denial that resorts at times to the exploitation of nubile, (semi-)nude women performers, some whose lack of outstanding musical acumen is unlikely even to be noticed. It is hardly surprising a radically democratizing, technology-driven, concept such as adapted music originated in another genre.[96]

Ethnomusicology needs Disability Studies. Like music, disability is a universal human experience. It requires investigation not only as an inherently important and multivalent praxis but as a valuable window into both socialization and technology. Few if any human variants can tell us as much about ontologies of difference and equity. Much can be revealed about a musical system through observing both the status of PWDs within it and their self-determined strategies and tactics for inclusion.

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Endnotes

[1] See for example Mairian Corker and Sally French, eds., *Disability Discourse* (Buckingham: Open University Press, 1999), xi.

[2] The distinction between disability and impairment so critical to the social model of disability within DS is not common parlance, where disability and impairment are interchangeable terms. The reader is cautioned here that, in disability studies, disability and impairment are a distinction with a significant difference and that I use the two terms accordingly throughout this article.

[3] Thus, disability studies, grounded in the liberal arts, is neither medicine, rehabilitation, special education, physical, occupational, nor any other therapy. Not all practitioners of these professions are necessarily hostile to DS. Notably, the Department of Human Development and Disability at the University of Illinois-Chicago, arguably the nation's leading program, is affiliated with that school's departments of physical and occupational therapy.

[4] Nora Ellen Groce, *Everyone Here Spoke Sign Language: Hereditary Deafness on Martha's Vineyard*. (Cambridge: Harvard University Press, 1985).

[5] Ingrid Hofmann, a Deaf Ph.D. student in the University of Minnesota's Institute of Child Development, is comfortable with this characterization of who belongs in Deaf Culture, but notes that Deaf identity is hotly contested by the Deaf, with significant reticence about the wholesale categorization of, for example, hearing people fluent in sign language, late-deafened people, and hard of hearing people, as members of the community. Hearing members of Deaf families who are fluent in ASL are generally more accepted than professional interpreters, whose commitment to the community may be questioned. Ms. Hofmann also notes that the term "hearing impaired," not uncommon in DS discourse, is scorned by the Deaf community, which does not regard its auditory state as an impairment. The term Hearing is also sometimes capitalized in Deaf discourse when proffering respect, lower case when no respect is intended.

DS and Deaf Culture points of view regarding disability and deafness can differ significantly, though this is not always apparent in DS scholarship. See Mairian Corker, "Deaf Studies and Disability Studies: An Epistemic Conundrum," *Disability Studies Quarterly* 20(1) (2000): 2-10. Given that the social model that distinguishes between disability and impairment is not common parlance, where the terms are more or less synonymous, Deaf people unfamiliar with the social model are likely to reject the label "disabled," while acknowledging the complexities and challenges of life in a predominantly hearing world.

[6] In print, the capitalized Deaf refers to the culture, the lower-case deaf to the auditory state. While these terms are spoken homonyms, they are different symbols in British Sign Language, which British scholar Mairian Corker discusses in "New Disability Discourse, the Principle of Optimization and Social Change," in *Disability Discourse* (Buckingham, UK: Open University Press, 1999): 200. The distinction occurs but rarely in American Sign Language, whose sign for Deaf, a variant on "deaf," is not well-known.

[7] When I taught in Poland in 1999, I was surprised at the frequency with which television personalities, female and male, wore glasses. By contrast, when I showed a class a

video of my ensemble, Blended Cultures Orchestra, there was a large collective expression of shock that our vocalist was a woman of substantial girth. Upon learning later that one of Poland's leading jazz singers was also a large woman, I was informed that she "got away with it" by means of self-deprecation.

[8] The gerund form of "to music" that grounds music as activity rather than object, as used by Christopher Small in *Musicking: The Meanings of Performing and Listening* (Hanover, NH: Wesleyan University Press, 1998)

[9] I in no way exclude the eventuality that lessons of DS for ethnomusicology might apply to situations beyond disability and impairment. In particular, DS's use of medical, legal, and industrial relations sources--my own is a case in point--has broad implications.

[10] Post-mortem psychological (and medical) autopsies of Mozart are common and varied. It is important to note here that it is the perception of an impairment rather than impairment per se that disables a subject, a distinction noted in the Americans with Disabilities Act of 1990, Public Law 101-336, 104 Stat. 328 42 U.S.C. 12101-12213 (ADA). A July 29, 2001 Internet search for "personality disorders" and "Mozart" yielded 139 hits.

For a remarkably well-documented psychobiological case history of Mozart that relies on contemporaneous sources, see Benjamin Simkin, "Was PANDAS Associated with Mozart's Personality Idiosyncrasies?" *Medical Problems of Performing Artists* 14 (3) (1999): 113-116. Although the film and play *Amadeus* make no attempt at explicit diagnosis – and impairments are generally rendered rather than named in disability-themed films – they certainly characterize Mozart as a person whose social and life skills are seriously compromised.

[11] In the last two decades, most films about classical music have included prominent characters whose disabilities are central plot concerns. In fall 2001, I taught a course entitled *Beyond Silence: Classical Music, Disability, and Film*. Interestingly, the most honest renderings of disability tend to emerge from those films which make least claim upon a status of "non-fiction."

[12] I have three degrees in composition and have been a professor of music for 23 years. Besides my appointment at the University of Minnesota, I have been a guest lecturer and visiting artist/scholar in Europe, Asia, South America, Canada and throughout the United States. Dr. Shiraishi has degrees in composition, arts administration, and music therapy, and is an accomplished performer, teacher, and composer of taiko. Earlier in her career, she managed Greater Twin Cities Youth Symphonies, the largest organization of its kind, and was House Manager for Hancher Auditorium, the large performance hall of the University of Iowa and that state's premier performance space. We attended universities in Illinois, Iowa, Hawaii, and Minnesota.

Ideally, data on student musicians with disabilities will employ a large sample from a wide variety of institutions. As a means for demonstrating theoretical principles, using one's "clients" has many precedents, particularly in medical research, including that done on music-related injuries. While physicians keep more comprehensive records of their patients than are presented here, in our experience the presence of any music student with a disability is remarkable enough that what little information needs to be drawn from recollection can be remembered.

[13] I exclude here the numerous musicians with performance injuries (a subject treated later in this article) and clinical depression, the former well-documented, the latter, at least in my experience, a quite common occupational hazard. Conversations with students and colleagues suggest depression is often situational and induced through the stresses of a music career. There is of course no way to determine the number of cases of invisible disabilities unless they are identified. Performance injuries in music frequently go unmentioned for fear of reprisals. Other than depression, self-identification of students' disabilities has rarely occurred in my experience, although the recent and welcome movement towards including "disability statements" in syllabuses is intended to encourage students to self-identify (confidentially) to their instructors when they seek accommodation. Neither performance injuries nor situational depression are typically regarded as impairments that qualify for accommodation under the ADA.

[14] This by no means implies there have been no distinguished blind classical musicians. Foremost of these include composer-organists Francesco Landini, Louis Vierne, and Jean Langlais, and Spanish composer-pianist Joaquin Rodrigo. Louis Braille, inventor of the tactile writing system which bears his name, was an accomplished organist. Special mention should be made of the African-American pianist-composer, 'Blind' Tom Bethune (1849-1908), whose remarkable life is chronicled by Geneva Southall in *Blind Tom: The Post-Civil War Enslavement of a Black Musical Genius* (Minneapolis: Challenge Productions, 1979), *The Continuing Enslavement of Blind Tom, the Black Pianist-Composer* (Minneapolis: Challenge Productions, 1983), and *Blind Tom, the Black Pianist Composer (1849-1908): Continually Enslaved* (Lanham: Scarecrow Press, 1999).

[15] The Americans with Disabilities Act of 1990 states that an accommodation must be "reasonable," a modifier whose interpretation, in my experience, all too often functions as an escape clause and whose implementation is all too often to deny needed services.

[16] For a history of technological advances that originated as assistive technology for PWDs, see Steve Jacobs, *Fueling the Creation of New Electronic Curbcuts* (The Center for an Accessible Society, n.d.). http://www.accessiblesociety.org/topics/technology/eleccurbcut.htm. Of special interest for music, Jacobs notes that the long-playing 33 1/3 rpm

phonograph record was invented to assist the blind and the first acoustic sampling synthesizer keyboard, invented by Kurzweil, was inspired by a conversation he had with blind soul singer Stevie Wonder, who uses his Reading Machine.

[17] N.d., *Universal Instructional Design: What is UID?* (University of Massachusetts, 2000) http://www.umass.edu/ldss/universalinstructional design.html.

[18] As the result of the including in my syllabus a request for PWDs to identify themselves to the instructor (confidentially), one student identified himself as learning-disabled, though he refused accommodation, citing prior difficulties with campus disability service providers and a desire to avoid repetition of that experience. Complaints of this nature are common.

[19] My daughter Alyssa Lubet is the source, though not the author (anonymous), of this witticism.

[20] I speak only for myself as a lefty here. The Internet reveals many southpaws who consider themselves more oppressed than I. If discourse alone were the criterion--what with "sinister," "left-handed compliment," "out in left field," "gauche" and "right-minded"--left-handedness would be among the worst fates a body could endure.

[21] Often left-handed guitarists reverse the order of the strings, best accomplished with a reversed bridge and nut. Cutaways that allow easier access to the highest frets are also reversed, especially on electrics, where tone, volume, and pitch controls are also repositioned.

[22] The recent theory of National Cancer Institute geneticist Dr. Amar J. S. Klar is persuasive. His research indicates a single gene for right-handedness in 80% of the population. The remaining 20% lack the gene and are evenly split, apparently by environmental factors, between right- and left-handed, accounting for the 10% of the world that is left-handed. See David E. Rosenbaum, "On Left-Handedness, Its Causes and Costs," *The New York Times on the Web* (May 16, 2000), http://www.nytimes.com/learning/teachers/lessons/000516tuesday.html.

My wife and I are left-handed parents of two right-handed children. As unusual as I thought this, according to I. C. McManus and M. P. Bryden, "The Genetics of Handedness, Cerebral Dominance and Lateralization," *Handbook of Neuropsychology, Volume 6: Developmental Neuropsychology*, I. Rapin & S. J. Segalowitz, eds. (Amsterdam: Elsevier Science, 1992): 115-144, left-handed parents have a 73.9% chance of producing a right-handed child, consistent, within an acceptable margin of error, with Klar's theory.

[23] I am indebted to my University of Minnesota colleague violinist Mark Bjork for this information.

[24] Not all left-handers are as tolerant of the right-handed majority as I, perhaps owing to their personal histories. See, for example, E. Stephen Mack, *Left-Hander: Living in the Mirror* (1995), http://www.emf.net/~estephen/facts/lefthand.html.

[25] Bruno Nettl, *Heartland Excursions: Ethnomusicological Reflections on Schools of Music* (Urbana: University of Illinois Press, 1995).

[26] Henry Kingsbury, *Music, Talent, and Performance: A Conservatory Cultural System* (Philadelphia: Temple University Press, 2001).

[27] Christopher Small, *Musicking: The Meanings of Performing and Listening* (Hanover: Wesleyan University Press, 1998).

[28] My colleague Jeffrey Van, classical guitar instructor at the University of Minnesota for over three decades, has told me of numerous left-handed students, but no more than three who chose to play left-handed, an apparent difference from the worlds of vernacular music. As a lefty who plays right-handed, when presented with the opportunity as an undergraduate to study classical guitar, I chose not to, having decided after many years of playing steel strings, that I would never be able to master its formidable right hand technique.

[29] Jeff Tod Titon, general ed., *Worlds of Music*, 3rd ed. (New York: Schirmer Books, 1996).

[30] Elizabeth May, ed. *Musics of Many Cultures* (Berkeley: University of California Press, 1980).

[31] Otherness and selfness are of course subjective and constructed, but a perusal of the journal *Ethnomusicology* and of the bibliographies featured in each issue will indicate that white scholars tend to opt for ethnic difference in their selection of subjects, while scholars of color explore musics to which they can claim ethnic connection. I include as connected, for example, African-Americans who study Africa and the Caribbean, but would view as an "other" relation a WASP Balkan specialist, for whom I suspect cultural difference trumps similarity of skin pigment.

[32] Pun intended, Beatles' drummer Ringo Starr is also left-handed. While, unlike McCartney, his sinistrality had no effect on the stage layout of the band, Ringo has been quoted as saying it did contribute to his unique and in my opinion vastly underrated playing.

[33] These accommodations are roughly analogous to disabled golfer Casey Martin's need for a cart. Martin's legal battle with the Professional Golfer's Association (PGA) over an interpretation of the *Americans with Disabilities Act of 1990* required a Supreme Court decision. The court ruled in favor of Martin's right to use a cart, but public opinion remains greatly divided. Those who oppose Martin's right to use a cart claim walking the course is intrinsic to the sport. Given Perlman's total acceptance in WCM, it seems ascending the podium, violin in hand, is not. See *PGA Tour, Inc. v. Martin* (FindLaw: Laws - Cases, Codes and Regs: 2001), http://caselaw.lp.findlaw.com/scripts/getcase.pl?court=US&vol=000&invol=00-24#section1.

[34] Alice Brandfonbrener, "Artists with Disabilities," *Medical Problems of Performing Artists* 15 (2) (2000): 1-2.

[35] Elizabeth Gleick and Paul Moor, "Triumph of the Spirit," *Time* 149 (26) (1997), http://www.time.com/time/magazine/1997/int/970630/amusi.triumph_of_th.html.

[36] Norman Lebrecht, "Thomas Quasthoff - A wonderfully vocal minority." "The Lebrecht Weekly," in *La Scena*

Musicale. 18 October, 2000, http://www.musicweb.uk.net/lebrecht.html.

[37] Gleick and Moor.

[38] Janos Gereben, "Thomas Quasthoff confirms Opera plans," *GOpera.com* by Margo Briessinck (23 June, 2000), http://www.gopera.com/quasthoff/articles/opera_on_stage.html.

[39] Ching Chang, "Verdi's *Ballo* Around the Bend," Rev., *San Francisco Classical Voice* (31 October, 1999), http://www.sfcv.org/arts_revs/ballo_11_2_99.html. Stryker, Mark. "Bocelli at MOT: An Uneven Debut," Rev., *Detroit Free Press* (30 October, 1999), http://altavista.com/cgi-bin/. Tommasini, Anthony. "Bocelli Seeks Legitimacy (And Bucks) In '*Bohême*,'" *The New York Times* (3 December, 2000): 29.

[40] Lebrecht.

[41] This may also explain why blind popular and jazz musicians generally wear dark glasses in public, while this is extremely uncommon among other blind people. Classical/crossover tenor Andrea Bocelli does not wear dark glasses.

[42] Dalya Alberge, "Cover Up, Conductor Tells Fat Fiddlers," *The Times* (London: August 23, 2000), pub6.ezboard.com/fressonance3general.showMessage?topicID=19.topic.

[43] Richard Morrision, "So What Is the Bottom Line, Mr. Blobby?" *The Times* (London: August 23, 2000), pub6.ezboard.com/fressonance3general.showMessage?topicID=19.topic. It is impossible to take this statement seriously. Were there basis to it, there would long ago have been a revolution in concert attire for both women and men.

[44] In remarks akin to Mutter's, if even more far-fetched, St. John claimed her nude pose was not intended as sexual, only to show intimacy with the instrument; that nothing stood between her and her violin. John Marks,"Selling 'Jailbait' Bach," *U. S. News Online* (11 November, 1996), http://www.usnews.com/usnews/issue/11musi.htm.

[45] Alberge.

[46] James McQuillen, "Babes con Brio," Rev., Eroica Trio, Lewis & Clark College, *Willamette Week* (5 February, 1999), http://www.wweek.com/html/cultfeature021099.html. "Fortissimo & Louder: Super Chick Fiddler," Rev. of *Four Seasons* by Antonio Vivaldi, performed by Anne-Sophie Mutter, *Best Classical CD* (Volume IV, n. d.), www.bestclassicalcd.com/Archives/Volume_4/fort.html.

[47] That this stereotype is far from true is borne out in the *National Study of Women with Physical Disabilities: Sexual Functioning* (Houston: Department of Physical Medicine and Rehabilitation, Center for Research on Women with Disabilities, Baylor College of Medicine, 1999), http://www.bcm.tmc.edu/crowd/national_study/SEXFUNC.htm.

[48] On *The Official Evelyn Glennie Website* (n.d., http://www.evelyn.co.uk/), in essays written by her husband/manager Greg Malcangi, Glennie denies being disabled or even truly deaf, and even the very notion of deafness is challenged. She has been active in philanthropic activities that promote an invasive assistive technology, the cochlear implant, mostly virulently opposed by the Deaf community. She also offers scholarships in music to children the USA with hearing loss. The Deaf community regard themselves as an oppressed cultural minority, rather than as PWDs, a position that differs radically from Glennie's. An important field within Universal Design is Web Accessibility. In this regard, the Glennie site does not conform to industry standards. See *MIT Disability Resources: Universal Design and Web Accessibility*, http://web.mit.edu/ada/waccess.html. For "Bobby," the standard downloadable tool that tests the accessibility of web sites for PWDs, see *CAST Bobby* (Peabody, MA: Center for Applied Special Technology, 2001), www.cast.org/bobby/.

[49] Glennie obviously has enough useful residual hearing, that is, hearing that remains after the illness that caused her hearing loss, to perform extremely challenging percussion repertoire in recital and with orchestra. She speech reads extremely well and speaks with perfect clarity, although enough of her hearing has been lost that she is, for example, unable to make full use of a standard telephone.

[50] *The Official Evelyn Glennie Web Site.*

[51] Alice Brandfonbrener, "MTNA Music Medicine Survey Part 2: The Teachers," *American Music Teacher* 39 (3) (1989-9): 20-3, 61. Alice Brandfonbrener, "Preliminary findings from the MTNA Music Medicine Survey," *American Music Teacher* 39 (1) (1989): 37-41.

[52] Ibid.. I read Brandfonbrener's editorial only after completing the first draft of this article. It provides an analysis of the issue of WCM superstars with disabilities remarkably similar to mine, even choosing Perlman, Quasthoff, and Glennie as her three test cases. Interestingly, she directly contrasts Quasthoff, as disabled by his appearance (Brandfonbrener was at the time unaware that Quasthoff had finally been engaged to perform staged opera), to Glennie, who is not. She does not treat gender as an issue, though she provides important evidence for it.

[53] Aaron M. Renn, Untitled, *The Weekly Breakdown 2 (4)* (1999), http://www.urbanophile.com/breakdown/archive/vol2/wb2-04.html.

[54] Emily Gottlieb, "Reading Between the Headlines - The Media and Jury Verdicts," *Research*, Volume 2 (The Center for Justice and Democracy, Minnesota Consumer Alliance: 2 January, 2001), http://www.mnconsumeralliance.org/mca_research.htm.

[55] Ibid.

[56] Bentley (no first name given), "Commuter Crew Not At Fault, Railroad Official Testifies," *Today's Headlines* (International Brotherhood of Locomotive Engineers: 10 February, 1999), http://www.ble.org/pr/news/headline0210a.html.

[57] Lawrence Johnson, "An Interview with Rachel Barton," *Fanfare Magazine* (September-October 1997): 1-5, http://www.rachelbarton.com/noframes/articles/art0997.htm.

[58] Jim Brown, "First Worldwide Telethon Sets $52 Million Pledge Record," *MDA News* (7 September 1998), http:

//www.mdusa.org/news/980906webcast.html.

[59] It is difficult to imagine African-American popular music without Ray Charles or Stevie Wonder or jazz without Art Tatum or Rahsaan Roland Kirk. An Internet search for "+blues +blind -"blind pig"' (blind pig is an important blues recording label) on July 9, 2001 (Google) yielded 799 "hits."

[60] *Statistical Abstract of the United States: 2000,* 120th edition (Washington, DC, U.S. Census Bureau: 2000): 415.

[61] Karen Gair, "Good for Business," *SEEK* jobs database and employment advice (2000), http://www.seek.com.au/editorial/0-8-7_disabilities.htm.

[62] N.d., "*Equal to the Task: 1981 Du Pont Survey of Employment of the Handicapped*" (Wilmington: Du Pont, 1982). "*Equal to the Task II: 1990 Du Pont Survey of Employment of the Handicapped*" (Wilmington: Du Pont, 1991?).

[63] In the five years my wife, Dr. Iris Shiraishi, worked for/managed Greater Twin Cities Youth Symphonies, which at the time had eight orchestras, elementary through high school, and was the largest organization of its kind, we observed only two students with disabilities. Both had mobility impairments affecting their arms. One of the eight conductors was a PWD, also mobility-impaired, one of only three professional classical musicians with physical (other than performance injuries) or sensory disabilities we have known personally.

[64] For a perspective on disability in Chinese culture, see Emma Stone, "Modern Slogan, Ancient Script: Impairment and Disability in the Chinese Language," in *Disability Discourse*, Mairian Corker and Sally French, eds. (Buckingham: Open University Press): 136-147.

[65] Benjamin Boretz, "Nelson Goodman's *Languages of Art* from a Musical Point of View," in *Perspectives on Contemporary Music Theory*, ed. Boretz and Edward T. Cone (New York: W. W. Norton & Company, 1972): 31-44.

[66] Carnatic (South Indian) classical music regards as (literally) a saint its greatest composer, Sri Tyagaraja, noting his profound devotion to Lord Rama as his musical inspiration. Nonetheless, his compositions, while revered, are not/cannot in practice (owing to less notational nuance and performance practice that encourages improvisation and interpretation) be objectively preserved in the manner of WCM.

[67] Austrian theorist Heinrich Schenker and disciples like Edward Aldwell and Karl Schachter speak often and unabashedly of a group of almost entirely Germanic (Chopin and Scarlatti, the ethnic exceptions, are so noted by Schenker) eighteenth and nineteenth century composers as the "great composers"; that is, the ones whose works conform to Schenker's theories. See, for example, Edward Aldwell and Carl Schachter, *Harmony and Voice Leading*, 2nd ed. (Fort Worth: Harcourt Brace Jovanovich, 1989).

[68] The history of WCM may be viewed in large degree as progressively delegating greater responsibilities for musical choices to composers (mostly through enhancements to notation) at the expense of wide interpretive, even improvisational, latitudes that were not only required of performers but hallmarks of their individual greatness. Efforts to revitalize improvisational performance practice in WCM, beginning in the late 1950s with Luca Foss's Improvisation Chamber Ensemble and continuing most prominently in the work of Terry Riley, have been all but abandoned in recent years, even by Foss and Riley themselves. (African-American composer Alvin Singleton, whose connections to the jazz world are strong, is a notable exception.) Interestingly, some performers in the historical performance movement, among them forte pianist Malcom Bilson, have begun to add their own embellishments to performances of works from the Classical period, not in the interest of creativity per se, but because it is an authentic performance practice.

[69] Two of the five works Wittgenstein commissioned, concertos by Ravel and Prokofiev, have attained standard repertoire status for able-bodied as well as hand-impaired pianists. Noted American composer George Perle has recently written a left-hand work for Leon Fleisher. There are no standard works for right hand only, though pieces were composed for pianist Lionel Nowak. See Donald L Patterson, *One Handed: A Guide to Piano Music for One Hand.* (Westport, CT: Greenwood Press, 1999).

[70] Simon Frith, "The Industrialization of Music," in *Music for Pleasure* (New York: Routledge, 1988): 11-23.

[71] I recall three telling anecdotes. The first was a Minnesota Public Radio interview in the early 1980s with conductor Sir Neville Marriner, then Music Director of the Minnesota Orchestra. He stated that he regarded his concerts as rehearsals for his (numerous) recordings and noted he eschewed certain types of rubato (rhythmic liberties) because of difficulties they created for the audio editor.

The second anecdote concerns a PBS documentary on the 1990 Tchaikowsky Competition in piano. A mandatory work in the preliminaries was Prelude and Fugue in D minor from Book Two of J. S. Bach's *Well-Tempered Clavier*. The video showed segments of about ten different performances of the fugue by an equal number of pianists, spliced together to form a single "performance." As different as the artists looked (I suspect this was the point), the technically flawless performances were so remarkably similar as to sound like a seamless, though not particularly interesting, whole.

Finally, I note my first digitally edited recording, in 1997, of my 1980 piano work, *Shabbat Shalom*. This 13-minute recording consists of over 100 digital "splices." While a wonderful rendition, pianist Jeffrey Jacob has never before or since played the entire work without pause, from beginning to end; that is, he has never "performed" it, even privately. While it is reasonable to record WCM this way, since that session, I have pondered the proper role of digital editing in improvised music, a question that inhibits my

willingness to record that facet of my *ouevre*.

[72] L. Tabor, "Rock Drummer Max Weinberg's battle with Hand Injuries," *International Musician* 85 (11) (1987): 7, 28-29. Max Weinberg, "Back to practicing and playing after tendonitis," *Journal of Hand Therapy,* 5, (1992): 120.

[73] The exception is hearing loss, often (and hardly surprisingly) reported by/about rock musicians (and their audiences). See Kris Chesky and Miriam Henoch, "Instrument-Specific Reports of Hearing Loss: Differences between Classical and Nonclassical Musicians," *Medical Problems of Performing Artists* 15 (1) (2000): 35-38.

[74] M. Fishbein, S. E. Middlestadt, V. Ottai, S. Straus & A. Ellis, "Medical Problems Among ICSOM Musicians: Overview of a National Survey," *Medical Problems of Performing Artists* 3 (1) (1988): 1-8.

[75] Ian James," Survey of Orchestras," in *Medical Problems of the Orchestra Musician*, Raoul Tubiana and Peter C. Amadio, eds. (London: Martin Dunitz, 2000): 195-202.

[76] Similarly, Yeung *et al.* report a 64% incidence of playing-related musculoskeletal problems among professional orchestral musicians in Hong Kong. Ella Yeung, Winnie Chan, Florence Pan, Phoebe Sau, Maggie Tsui, Belinda Yu, and Christine Zaza, "A Survey of Playing-related Musculoskeletal Problems Among Professional Orchestral Musicians in Hong Kong," *Medical Problems of Performing Artists* 14 (1) (1999): 43-46.

[77] Brandfonbrener, 1988-89 and 1989.

[78] Raoul Tubiana, "Upper Limb Disorders in Musicians," *Maitrise Orthopedique* 100 (2001), www.maitrise-orthop.com/corpusmaitri/orthopaedic/mo69_limb_disorders/index.shtml. See also William Dawson, "Upper Extremity Overuse in Instrumentalists," *Medical Problems of Performing Artists* 16 (2) (2001): 66-70, for a statistically rich examination of the author's own musician patients. Additional, if less clinical, evidence that the majority of performance-injured musicians are from WCM includes a review of the performing arts medical and related scholarly literature (in music, rather than medical, publications) and popular, self-help books and periodicals. My examination of bibliographic sources indicates the vast majority of publications directed to musicians in a particular genre are for WCM. Notably, the four *Playing (Less) Hurt* conferences dealing with performance injuries, held in the late 1980s and early 1990s and coordinated by Janet Horvath, Associate Principal Cellist, Minnesota Orchestra, and performing arts medicine consultant, were overwhelmingly attended by WCM musicians.

[79] Many years ago, I was involved in rehearsals for the premiere of one of my compositions which, while not literally repetitious, involved many similar figurations. At the same time, the players, from a major orchestra, were rehearsing a work by a prominent "'Minimalist" composer. There were numerous complaints about how painful it was to play his piece, especially late in the season. In that context, they declared my piece "impossible," likening it to the orchestra piece to whose performance they objected. In part, as a result of the negative reaction of the orchestra to playing this work, the music director (and the orchestra's marketing staff) openly retreated from the adventurous, largely contemporary programming of his first season. The ensemble refused to play my piece and I was forced to reschedule my premiere and an entire evening of my work. Later, I engaged different players from another major orchestra during a summer hiatus. There was no suggestion my work was even particularly difficult, let alone impossible, and no mention of pain. The piece has enjoyed many successful performances since.

[80] Americans with Disabilities Act of 1990.

[81] Because repetitive motion injuries are extremely common among the industrial labor force as well, it may be that economics are a reason their status as disabilities is so fiercely resisted.

[82] It is possible that musics other than WCM have underreported data on performance injuries. Certain categories of WCM musicians, such as those in major symphony orchestras, are among the best-paid and may have superior access to medical care. As previously stated, WCM musicians are also by far the most studied category in the performing arts medical literature.

[83] Although it may seem an unfair provocation not to discuss the precise nature of my impairment/disability here-- having disclosed that it exists-- one of the protocols of DS is that claiming a disability identity is a public social/political statement. One's particular impairment is anatomical, intimate, and thus private, unless it is critical to one's argument. It is not here, nor are the details of my battles with human service bureaucracies. For a comprehensive exploration of the politics of this and related discursive and disclosure matters, see Simi Linton, *Claiming Disability: Knowledge and Identity* (New York: New York University Press, 1998).

This "need to know" basis for determining whether to disclose highly personal anatomical matters is mirrored in the transgender community, whose lives make perhaps the most powerful case for a distinction between gender and sex.

[84] Ellen Koskoff, rev. of "Music, Talent, and Performance," by Henry Kingsbury. *Ethnomusicology* 34 (2) (1990): 314.

[85] The Australian *Lawlink* has published an excellent exegesis of legal constructions of difference and discrimination in which disability is considered at length and the perspective is international. Report 92 (1999), "Review of the Anti-Discrimination Act 1977 (NSW)," *Lawlink NSW, 3,* http://www.lawlink.nsw.gov.au/lrc.nsf/pages/r92chp.

[86] Including *Amadeus, Immortal Beloved, Shine, Hillary and Jackie, The Red Violin, Mr. Holland's Opus, Beyond Silence, The Piano*, and *Thirty-Two Short Films About Glenn Gould.*

[87] In jazz, Art Tatum, Rahsaan Roland Kirk, Marcus Roberts, Django Reinhardt, George Shearing, Lenny Tristano, Horace Parlan, Wingy Manone, Diane Schuur, Michel Petrucciani, Louis Armstrong, Quincy Jones, and

Charles Mingus (the latter three only late in their careers). In African-American popular music, Stevie Wonder, Ray Charles, and, late in their careers Teddy Pendergast, and Curtis Mayfield. In blues, Lemon Jefferson, Sonny Terry, Willie McTell, Gary Davis, and numerous others. In country and Southern folk music, Mel Tillis, Vic Chesnutt, and Doc Watson. In Latin pop, Jose Feliciano.

[88] N.A., "Excite Music: Curtis Mayfield Biography," *At Home Corporation* (2001): http://music.excite.com/artist/biography/15625.

[89] N.A., University of Georgia Columns, "Diversity Conference Planned," (19 May 1997): http//www.uga.edu/column/051997/digest.html.

[90] See M. Miles, "Blind People Handling Their Own Fate," except from "Disability on a Different Model: Glimpses of an Asian Heritage," originally appearing in *Disability and Society* 15 (2000): 603-618, http://www.independentliving.org/LibArt/mmiles1.html. Miles writes of blind Japanese lutenists, by which he refers to the biwa, but not koto, which is a plucked zither, and not only to Japan, but also, to a lesser extent, China. In this article, he investigates a range of occupations through which the blind in these countries have at times maintained considerable autonomy and even power.

[91] Ibid.: 1.

[92] *VAMS Homepage*, http://www.reachdisability.org/vams/vams_homepage.htm.

[93] N.A., *Rehabilitation Management 2001 - Accommodation the Right Fit*, conference announcement, (27-28 April 2001) (Vancouver, Canada: Simon Fraser University, 2001): 2.

[94] Delia Mallette, "Programmer Fulfills Prophecy," *The Gazette*, (Grand Forks: 15 November 1995): 1-B. www.jdkoftinoff.com/gaz1.html. N.A., "Bob Turner: Partnerships in Progress" (n.d.), http://www.turnercom.com/primal/turbio.html.

[95] Ibid.

[96] It would be unfair and dishonest to ignore music therapy programs, most of which are located in conventional, WCM-based schools of music. Still, these entail a radically different curriculum from all other majors, occupy a similarly marginal position to ethnomusicology and jazz, and arguably privilege art musics in general and WCM in particular far less (if at all) than other courses of musical study in higher education. Music therapists often work with clients with disabilities and who sometimes use adaptive technologies. VAMS includes therapy as one of its stated objectives. An important distinction is that music therapy applies music to extra-musical, often didactic, ends, while VAMS and other organizations of musicians with disabilities primarily foreground musicking as an expressive practice of inherent worth.

Essays And Creative Works

Will the Next Generation Please Step Forward?
A Legacy for the Next Generation of Troublemakers

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Abstract: The author reflects on how several mentors, including the late Dr. David Pfeiffer, shaped her awareness of the Disability Rights Movement, her own identity, and the need for the next generation to carry forth the Movement.

Key Words: mentor, David Pfeiffer, Disability Rights Movement

The recent death of David Pfeiffer made me reflect on the legacy that is left behind by people like David, who lived and breathed the Disability Rights Movement of the 1970s and carried the Movement forward to this day. As a thirty-something who, until I attended UC Berkeley in the 1990s, had no concept that people like me would not have gone to college at all if it had not have been for people like David, this reflection does not come easily. It is very easy for my generation to sit back in our armchairs and enjoy the luxury of a semi-social existence without sticking our necks out and questioning why "semi" isn't good enough. Learning about the Disability Rights Movement, learning about my place in the world as a human being, came from meeting people who, like David, will someday be legacies. These people taught me to recognize when I was being humiliated, trampled on or left out in the cold, and not to take it. To quote my favorite line from Simi Linton's *Claiming Disability* (1998), borrowed from Crosby, Stills and Nash, I learned to "let my freak flag fly" and to prosper well under it. The challenge for my generation is to take the flag forward onto the next battleground.

My first introduction to the Disability Rights Movement came from my mentor in Berkeley, Susan O'Hara, who somehow still manages to live there. In days long past, Susan was a history teacher at a Catholic school in Illinois. Her sister came out to Berkeley in the 1970s and brought back tales of the amazing electric wheelchairs that the wild Californians were using. When Susan arrived at Berkeley, her "dorm" was a ward at the University hospital. Expecting to be greeted by a bunch of sick people, instead she was greeted with a paper cup of Scotch. After that, the story about "all the fun they had" grows quite vague.

When I arrived at UC Berkeley, Susan was the Director of the Disabled Student's Program. She formed a student advisory board. I am sure the University administration, to have approved such a measure, had images of the lot of us parked around the table spilling cups of tea (those darn blind students) and discussing the joys of student support services. Instead, the group became a war band aimed at people who rode their bicycles on campus. People who rode bicycles on campus at high speed or parked them along handrails were endangering the lives of the blind, deaf, mobile-y slow and distracted, and we vowed to bring them all down. We posted flyers. We wrote letters to the editor. We met with the Chancellor. We cheered when the Vice-Chancellor nearly incurred a head injury after being hit by a bicycle on campus. We smeared Vaseline on the empty seats of unsuspecting cyclists. We even spent our lunch hours actually counting the number of bicycles that passed by Dwinelle Hall for a week and submitted a report to the Campus Police. My point is not to trash people who ride bicycles, but to say that somehow an advisory group turned into an advocacy group under Susan's tutelage. She didn't just nod her head and say, "Are you being served?" She told us her stories. She encouraged us to address things that we saw as wrong. And we thrived under her example.

Susan also introduced me to the *Disability Rag*. The first issue that I read had an article by Rob Kocur called, "The Thorn In Our Side" (December, 1995), in which the author takes the perspective of a Red Neck who offers, among other priceless observations, a "final solution" for getting rid of that "mutant army of welfare riffraff". Among Kocur's suggestions are to send everyone with a disability to Montana, where they could "breed to their heart's content with each other" and allow paying visitors to "intermingle with these special people." I still can't read through the article without laughing until I cry. But what I recognized when I first read it was that there are people who really do think like that. Many people regard people with disabilities as troublemakers who want more than they deserve and who are best kept with their own kind. Realizing that made me understand how far people with disabilities have come, and what a long, long way we have to go.

I had another mentor at Berkeley named Sandy Muir. Sandy is very nice, despite being a Republican. Sandy taught Political Science and he also taught me that I should expect normal things from myself despite the fact that I am normally-challenged. I remember when I went to Sandy to ask his advice about which major I should choose for my undergraduate degree. "I am not sure if I want to be an elementary school teacher, a lawyer, a journalist, an English Professor, or a genetic counselor," I moaned. "Well," said Sandy, "I think two of the best majors that will prepare you for Law School or just about anything are History and English. You would like the History program here because all of the students are required to write an undergraduate Thesis and none of the other majors require that." Besides the fact that I have Sandy to thank for helping me to choose English as my major, he also constantly steered me towards thinking of personal success as an option defined both me and by my possibilities. He said that I could be a "big fish in a small pond" or a "small fish in a big pond" but that my choices were mine to make.

My choice brought me to Hawaii and to another mentor in David Pfeiffer. When I took a job with the Center on Disability Studies (CDS) I heard stories about David. They were very conflicting. He was the mythic editor of the *Disability Studies Quarterly*. He was a sweet old guy who was

nice to everybody.   He was the blaster of often en-raged and caustic emails sent to the CDS list-serve in reaction to things like the description of anyone with a disability as "inspirational". I often found myself turning to David when I needed a reality check or advice about negotiating life among the Normals. Because we shared the experience of having a disability, somehow my concerns, large or small, were safe with David. I worked with him on his plans to start a new journal and to bring a disability pride library to the University of Hawaii. I was looking forward to learning so much under his tutelage.

About a year ago, David and Steve Brown and Lillian Gonzales Brown had lunch at my apartment. Lillian was quite upset over an incident at a recent Disability and Diversity Studies Institute where she had made a soapbox speech about people without disabilities using the accessible bathroom stall. It turns out the person who had incited her speech told Lillian after the fact that she had a bad back. Lillian said that a number of people had told her the speech was "out of line" and "lacked Aloha" and Lillian was tending towards believing them. David listened very carefully and very quietly and then suddenly he roared, with the hint of Texas in his voice that still lingered, "BULL-SHIT." Those words still ring in my ear every time I find myself starting to believe that somehow my expectations of fairness and equality are wrong.

When David died, I thought, "Oh no, who will edit the new journal? Who will bring the library to Hawaii, who will push the University for better access, who will nail people when they say goofy, stupid things? " – I am sure David would have said, "*You* will."

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Kocur, R. (November – December, 1995). The thorn in our side. *The Disability Rag and Resource*, 23-28.

Linton, S. (1998). *Claiming disability: Knowledge and identity.* NY: New York University Press.

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Bibliographies And Resources

Still Celebrating Disability Culture: A Peek at the Annotated, Disability Culture Bibliography

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Abstract: An update of the 2nd edition of my self-published annotated bibliography about disability culture.

Key Words: bibliography, disability culture, disability history

I've been compiling bibliographies for as long as I can remember. When I first became interested in disability culture I knew I'd want to create a bibliography.

Over the years I've developed two different bibliographies. One is a non-annotated version. It currently contains 2529 citations entered into more than twenty computer database categories. I published an early version of this bibliography in *Investigating a Culture of Disability.*

As the non-annotated bibliography grew and publication did not seem imminent, I started an annotated bibliography. I've self-published two versions, both called, *A Celebration of Diversity: An Annotated Bibliography about Disability Culture.*

I've been adding to the 2nd edition, since its 2002 publication.

While we prepared this journal issue, I offered to share bibliography entries that have not been previously published. All are included below, excluding the ones in the review section of this issue. Not all entries are from new publications. The reason for this is I've added entries as I've read or reviewed them. This bibliography therefore includes both recently published and released materials as well as classics.

References

Brown, Steven E., *A Celebration of Diversity: An Annotated Bibliography about Disability Culture* (Las Cruces, NM: Institute on Disability Culture, 2000).

Brown, Steven E., *A Celebration of Diversity: An Annotated Bibliography about Disability Culture, 2nd ed.* (Las Cruces, NM: Institute on Disability Culture, 2002).

Brown, Steven E., *Investigating a Culture Of Disability: Final Report* (Las Cruces, NM: Institute on Disability Culture, 1994).

Update To An Annotated Bibliography About Disability Culture

I. Books: Non-Fiction

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

An excellent addition to the growing literature. This gives a good overview of the development of the disability rights movement, particularly in the U.S. and U.K. Would be a good choice for an introductory graduate course, especially for students who have not studied disability issues previously.

Bogdan, Robert, *Freak Show: Presenting Human Oddities for Amusement and Profit* (Chicago, U. of Chicago, 1988).

A detailed account of freak shows from the mid-nineteenth to mid-twentieth centuries. Who was a freak, why, and how they were presented. All placed in the context of the late twentieth century disability rights movement.

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

In this collection, many previously published essays (and some new ones) explore this journey through autobiographical essays, scholarly analysis, profiles, and critiques of how disability is perceived and impacted in all aspects life

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

Another excellent history in the series NYU Press is putting out. Burch does an admirable job of showing that cultural Deafness continued during a period when oralism seemed dominant. One of the best parts of the books is Burch's ability to place Deafness issues in the context of overall American social issues. Because of that I wish she'd included more about the oppression of other languages during the same time that oralism seemed to be dominating ASL.

Darnell, Lila Ridings, *The Ghost Behind the Wheelchair* (1stBooks, 2002).

This book is billed as the first maternal account of living with a child who's had a Spinal Cord Injury (SCI). The author says she wrote the book because she could find no guides for parents in similar situations when her son became injured. The attraction of this book is that it takes the reader into the panicky, crazy situation of learning a child has been injured and may or may not survive, and if they do survive they will be a high level quadriplegic. It's a mile-a-minute ride in discovering what this kind of

life is like. The book is not as good at describing the years following rehabilitation, but that's not the primary focus.

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

Davis, who's a literary critic, does something very few of us do—he moves all of our positions forward in his discussions about disability identity, and how critical analysis of writings from novels to Supreme Court decisions impact those of us with disabilities.

Fleischer, Doris Zames and Frieda Zames, *The Disability Rights Movement: From Charity to Confrontation* (Philadelphia: Temple, 2001).

Two sisters, one of whom had polio as a child, throw themselves into the daunting task of documenting the disability rights movement. This is an ambitious, frustrating, and fascinating book. The authors, who had roles in many of the activities they describe, attempt an overview of all aspects of the disability rights movement, from the beginnings of rehabilitation to parent groups in the mid-20th century to the Americans with Disabilities Act and beyond. While the overview is excellent, it's also a clarion call to future researchers to analyze each section of each chapter and move forward to develop books about each of these subjects. It's hard to be too critical of this attempt to place the disability rights movement in the context of our times, but there are problems. One is that the sisters are from the New York and their Eastern bias clearly shows. Not only in their subject matter and their knowledge of it, which is often more detailed than for other parts of the country, but also in their descriptions of the rest of the country, especially California. Perhaps because I know that part of our history better than I do eastern events I caught

lots of mistakes in the descriptions of the Berkeley CIL's history and in the story of Ed Roberts. There are some gaps in details, which better editing might have removed. For example, at one point, the authors announce the first CIL anywhere developed in 1971, but nowhere do they say where or what this CIL is. More frustrating, however, than editorial or factual mistakes is the tendency to take first-person accounts without any critical analysis. To use Ed as an example, comments he made in his mid-50s might differ from those of his early twenties and both are examples not only of factual recounting, but also of public relations, at which Ed excelled. A good biography of Ed and a good history of CIL would dig deeper than the authors did in this book. Exposing our inconsistencies, foibles, and conflicts will only demonstrate that we are like every other movement, not any better or worse. Having said that, perhaps the Eastern history is less accurate than it appears to me, because I don't know it. Since I don't have the background to analyze their descriptions critically I found the events of the eastern part of the country fascinating as is much of the rest of this book. I know of no other book like this that has tried to summarize legislation, education, transportation, veterans issues, independent living, assistive technology, street actions, and much more. While I found gaps, mistakes, and omissions, this is by far the best start at an overview of U.S. disability rights history that we have had. The book belongs in every disability studies library and in every disability rights organization's toolkit of information.

Gartner, Alan and Tom Joe, eds., *Images of the Disabled, Disabling Images* (New York: Praeger, 1987).

I finally got around to reading this collection, which I've been hearing about for years. It's an interesting combination of essays about media, services, technology, and politics, from Harlan Hahn and Paul Longmore to Robert Funk and the editors. All the essays contain historical value, but the ones I found most pertinent still were about media and literature. Politics has changed, tech-

nology has advanced; attitudes seem to have moved forward much more slowly and this is reflected in discussions about literature and stereotypes.

Gottlieb, Daniel H., *Voices of Conflict: Voices of Healing: A Collection of Articles By a Much-Loved Philadelphia Inquirer Columnist* (San Jose, iUniverse, 2001).

A practicing psychologist who became a quadriplegic and continued to practice, write, and host a radio show. These columns of gentle advice hold inspiration for all of us.

Johnson, Mary, *Make Them Go Away: Clint Eastwood, Christopher Reeve and The Case Against Disability Rights* (Louisville, KY: Advocado, 2003).

An excellent book, that goes into great detail about why people say they mean no harm to "the handicapped," yet go ahead and discriminate anyway. Johnson presents cogent arguments and backs them up with many facts. Indeed, my biggest concern about this book is that people will only focus on the first part, where the case against disability rights is made; not the second where Johnson, long time editor of the groundbreaking disability rights magazine, the *Ragged Edge*, makes the case for disability rights.

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

This is the book I wish had been available when I started reading about disability history in the United States. Longmore does a wonderful job of weaving personal experience and academic investigation in elegant prose. From his first essay, an introduction to the first edition of Disability Rights Advocates' *Disability Watch*, in which Long-

more explains why there is a need to observe—and change—disability policy to his culminating essay, why he did burn his book, there is a wealth of U.S. social history, disability history, and plain good history. His groundbreaking essays on Randolph Bourne and the League of the Physically Handicapped of the 1930s are here as well as other influential writings. Longmore, unlike most historians, recognizes how the past—and present—affect not only him, but his peers—and maybe, most importantly does something about it, not on the streets necessarily, but in the academy. This book belongs in every disability studies program in the country, but more crucially, it belongs in every library. Read it!

Lusseyran, Jacques, *And There was Light: Autobiography of Jacques Lusseyran, Blind Hero of the French Resistance* (New York: Parabola, 1998, first published in 1963).

An autobiography with a difference: a blind man who can see, literally—maybe? and was indeed a hero in the French Resistance. How he dealt with blindness and life in World War II.

Medoff, Mark, *Children of a Lesser God* (New York: DRAMATISTS PLAY SERVICE, 1980).

Like many people, I saw the movie when it first came out. Years later I had an opportunity to meet Mark Medoff and to become friendly with him. After he agreed to write testimonials for a couple of my manuscripts I decided I should read the play, (that I had never seen) which I had heard differed greatly from the movie. I got a copy from the library recently and sat down with it. An eye-opening experience. A great play, especially considering its publication date. Medoff evokes paternalism, rebellion, stubbornness, pride, helplessness, culture, competition and cooperation, among other emotions. If I ever get a chance to see the play performed I will.

Priestley, Mark, *Disability: A Life Course Approach* (Cambridge, UK: Polity, 2003).

Another excellent contribution from the folks at the Centre for Disability Studies at the University of Leeds. In this book, Priestly discusses many familiar issues, but treats them from a new perspective, the life course. In doing so, he analyzes, for example, how eugenics has had an impact from conception to death, and how recreation affects people from their earliest years to their last ones. A good introduction to another way of thinking about disability studies and disability issues.

Stiker, Henri-Jacques, *A History of Disability* (Ann Arbor, Michigan, 1999, originally published in French in 1982).

Stiker has become well-known in the U. S. recently. In this book he uses a variety of diverse disciplines to come to conclusions about disability from ancient times to the present. Many of his arguments were revolutionary when first published, but are less so now, as disability rights has progressed and as other scholars also use a variety of disciplines to analyze the idea of disability.

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

When I began this book, I felt unsure about Titchkosky's goals. By the time I finished I was ready to recommend it to future graduate seminars. Titchkosky has done something new, at least to me. She's analyzed, in detail, aspects of her daily life, living with disability, and interacting with the world, and explored how her experiences living with her own dyslexia, her partner's blindness, and perceptions about –and by—both of them, have the ability to influence everyone's internal and external environments. For example, in her conclusion, she takes the horrid unemployment figures for people with disabilities, that we have all known about for years, and analyzes how these figures can

be used to prove multiple paradigms: the need for disability rights; the need for rehabilitation; the need to have social programs; the need to eliminate social programs, and so on. She then suggests that we explore why these figures fit multiple paradigms and learn from them. Most importantly, she explores how disability can teach all of us more about ourselves and our world, no matter how much we think we already know.

II. Books: Fiction

Elton, Ben, *Gridlock* (London: Time Warner, 1991).

Elton is a humorist with kind of a preachy message in this book about the horrendous effects of cars on all of our lives. What gets it into this bibliography is that at least two of the major characters in the book have disabilities and Elton's portrayals of us are pretty funny indeed, even though to an American audience some of his words will feel most outdated—and maybe even, politically incorrect.

III. Books: Poetry

Brown, Steven E., *Love Into Forever: A Tribute to Martyrs, Heroes, Friends, and Colleagues* (Las Cruces, NM: Institute on Disability Culture, 2002).

A tribute to colleagues and friends who have passed on or who we thought would no longer be here.

IV. Articles: Journals, Magazines And Encyclopedias

Blaser, Art, "Answers Ten Objections to Disability Identity Politics," *Mouth: The Voice of the Disability Nation*, XIII (1), (May-June 2002), 18-21.

Why disability identity politics developed, why disability identity politics are still needed, and responses to some objections raised about them.

Bowers, Rick, "Celebrating Disability Through the Arts: Jesuit Brother Discovers Life's Mission in the Theater," *In Motion*, 12 (2) (March/April 2002), 12-13, 15, -16.

The story of the founder of The National Theatre Workshop of the Handicapped, Jesuit Brother Rick Curry, who founded the organization in the late 1970s in New York City.

Byzek, Josie, "Dianne Piastro," *New Mobility: Life on Wheels*, 13 (102), (March 2002), 45-49,

About a woman with MS who has paved the way for columnists with disabilities and opened many other avenues. See also, "Victoria Williams: Coping on the Road," *New Mobility: Life on Wheels*, 13 (103), (April 2002), 52-53, a profile of the singer who has MS.

Dobbs, Jean, "Vic Chesnutt: Raw Revelation," *New Mobility: Life on Wheels*, 13 (103), (April 2002), 44-51.

A profile of the somber singer/songwriter who became a quadriplegic at the age of 18.

Drill, Herb, "Art & Ability," *New Mobility: Life on Wheels*, 14 (122) (November 2003), 20-22.

Good review of the Bryn Mawr Rehabilitation Hospital Art Program.

Gilmer, Tim, "Teddy Pendergrass: Teddy Bear Returns," New Mobility: Life on Wheels, 13 (103), April 2002, 36-42.

An excellent profile of the sensual crooner who became a quadriplegic in 1982 and how he has rebuilt his life.

Snow, Kathie, "Kid Renounces Therapies, Survives," *Mouth: Voice of the Disability Nation*, 12, (6) (March-April 2002), 24-31.

How a Mom listened to her son and doesn't regret it one bit.

V. Music

Leidy, Peter, *Greetings from Human Serviceland* and *More Songs for People Like You and Me* (Available for $10.00 from Peter Leidy, 610 Miller Ave., Madison, WI 53704, pleidy@optionsmadison.com).

These two CDs are the first I know of that look at the human services bureaucracy related to people with disabilities from a humorous perception. Leidy has a penchant for stealing other people's tunes and adding his own, often ingenious, lyrics. I laughed out loud on first hearing some of these songs. Others make you want to cry and still others to shout in anger at the world's injustices.

Academic Programs in Disability Studies

Steven J. Taylor and Rachael Zubal-Ruggieri
Center on Human Policy
Syracuse University

The following section contains a listing of Disability Studies programs in North American Academic Institutions. The title "Disability Studies" has become popular and is sometimes used to refer to programs in clinical or instructional fields. The programs in this listing meet the following criteria: (1) the sponsoring university offers a four-year undergraduate degree or Master's or doctoral degrees; (2) the programs offer a formal academic program,

including a degree, concentration, specialization, minor, major, or certificate in Disability Studies; (3) the programs include disability course work in non-clinical and non-instructional fields (e.g., the Humanities, Social Sciences, Literature, Law, Policy Studies, or the Visual or Performing Arts); and (4) information describing the programs can be found in written form or on a university web site. This listing does not include research or training centers that do not offer formal academic programs.

Academic Institution: College of Staten Island,
The City University of New York
Program: Minor in Disability Studies, Interdisciplinary Program
Academic Unit: Department of Sociology, Anthropology, and Social Work
Address: Psychology/Sociology, Anthropology, and Social Work Building (4S)
Room 436
2800 Victory Boulevard
Staten Island, NY 10314
Contact: David Goode, Ph.D.
Phone/TTY: (718) 982-3757
E-mail: GOODE@postbox.csi.cuny.edu
WWW: http://www.csi.cuny.edu/catalog/undergraduate/programs/disabilitystudies.html
Comment: This minor may be taken in combination with any baccalaureate degree.

Academic Institution: Gallaudet University
Program: Master's of Arts in Deaf Studies
Cultural Studies Concentration
Deaf History Concentration
Academic Unit: Department of ASL and Deaf Studies
Address: Hall Memorial Building, Room E-111
800 Florida Avenue, NE
Washington, DC 20002-3695
Contact: M.J. Bienvenu, Department Chair
Phone/TTY: (202) 651-5814 - v/tty
E-mail: Martina.Bienvenu@gallaudet.edu
WWW: http://depts.gallaudet.edu/Deaf.Studies/
Comment: Disability Studies is incorporated into History and other courses.

Academic Institution: Ohio State University
Program: Undergraduate Minor in Disability Studies
Academic Unit: Arts & Sciences (Interdisciplinary)
Address: c/o Department of English
421 Denney Hall
164 West 17th Avenue
Columbus, OH 43210
Contact: Brenda Brueggemann, Associate Professor
Phone/TTY: (614) 292-6065 x 7395 (v/tty y) (office)
E-Mail: brueggemann.1@osu.edu
WWW: http://ada.osu.edu/DisabilityStudies.htm

Academic Institution: Pacific University
Program: Disability Studies in the Humanities and Social Sciences (Minor)
Academic Unit: College of Arts & Sciences
Address: Disability Studies/Humanities
2043 College Way
Forest Grove, OR 96116
Contact: Dr. Tim Thompson
Phone: (503) 352-2868
Email: thompsot@pacificu.edu
Web Address: http://www.pacificu.edu/admissions/undergrad/academic/factsheets.cfm?action=disability

Academic Institution: Ryerson University
Program: Bachelor's of Arts in Disability Studies
Academic Unit: School of Disability Studies
Address: Ryerson University
350 Victoria Street
Toronto, ON M5B 2K3 CANADA
Contact: Melanie Panitch, Director
Phone/TTY: (416) 979-5000 (ext. 6128)
E-Mail: mpanitch@ryerson.ca
WWW: http://www.ryerson.ca/ds/
Comment: Course-work can be taken via two-week on-site courses and distance education.

Academic Institution: State University of New York (SUNY) Stony Brook
Program: Disabilities Studies Concentration, Bachelor of Science in Health Science
Academic Unit: School of Health Technology & Management
Address: HSC – SHTM, L2-439
Stony Brook, NY 11794-8201
Contact: Pamela Block, Ph.D., Clinical Associate Professor
Phone/TTY: (631) 444-3197
E-Mail: pblock@notes.cc.sunysb.edu
WWW: http://www.hsc.stonybrook.edu/sohtm/sohtm_bshs_index.cfm
Comment: This concentration will offered starting January 2004.

Academic Institution: Suffolk University
Program: Disability Studies Concentration, Master of Public Administration
Academic Unit: Sawyer School of Management
Address: 8 Ashburton Place
Boston, MA 02108-2770
Contact: Richard Beinecke, Chairperson
Phone/TTY: (617) 573-8062
E-Mail: rbeineck@suffolk.edu
WWW: http://209.240.148.229/pad_mpa_disability.htm

Academic Institution: Syracuse University
Programs: Graduate (Master's and Ph.D.) Concentration in Disability Studies
Graduate Certificate of Advanced Study (CAS) Program in Disability Studies
Joint Degree Program in Law (J.D.) and Education (Master's and CAS in Disability Studies)
Academic Unit: Cultural Foundations of Education, School of Education
Address: Center on Human Policy
Syracuse University
805 South Crouse Avenue
Syracuse NY 13244-2280
Contact: Steven J. Taylor, Ph. D., Professor and Coordinator of Disability Studies
Phone/TTY: (315) 443-3851; TTY (315) 4 43-4355
E-Mail: staylo01@syr.edu
WWW: http://thechp.syr.edu/disstud.htm
Comment: The CAS in Disability Studies in available to students matriculated in any graduate program at Syracuse University as well as persons who are not otherwise enrolled in a university program. For information on the Joint Degree Program and Law and Education, contact Professor Arlene Kanter, 446 College of Law, Syracuse University 13244 (kantera@syr.edu or 315-443-4582).

Academic Institution: Teachers College, Columbia University
Program: Master of Arts in dis/Ability Studies in Education (DSE)
Academic Unit: Department of Curriculum and Teaching
Address: Box 31
525 West 120th Street
New York, NY 10027
Contact: D. Kim Reid, Ph.D., Program Coordinator
Phone: (212) 678-3038
TTY: (212) 678-3853
E-mail: dkr10@columbia.edu
WWW: http://www.tc.columbia.edu/catalog/pdf/09CURRIC.PDF (see page 10 of this document)
Comments: This program will start as of July 1, 2004, pending approval by the New York State Department of Education.

Academic Institution: Temple University
Program: Graduate Certificate in Disability Studies
Academic Unit: Department of Occupational Therapy
College of Allied Health Professions
Address: 3307 North Broad Street
Philadelphia, PA 19140
Contact: Moya Kinnealey, Ph.D., OTR/L, Chair
Phone/TTY: (215) 707-4813
E-Mail: otcahp@temple.edu
WWW: http://www.temple.edu/OT/cert_disability_study.htm

Academic Institution: Temple University
Program: Graduate Certificate in Disability
Studies
Academic Unit: College of Education
Address: Institute on Disabilities
Room 423 Ritter Annex
1301 Cecil B. Moore Avenue
Philadelphia, PA 19122
Contact: Mike Dorn, Ph.D., Coordinator of
Disability Studies
Phone/TTY: (215) 204-3373; TTY (215) 204-
1356
E-Mail: mdorn@temple.edu
WWW: http://disabilities.temple.edu/programs/ds
Comments: Graduate Certificate is currently
in the final stages of approval at the University
President and Board of Trustees (August 2003).

Academic Institution: Washington State University
Program: Undergraduate Minor in Disability
Studies
Academic Unit: Department of Speech an d
Hearing Sciences
Address: P.O. Box 642420
Pullman, WA 99164-1035
Contact: Dr. Gail D. Chermak, Professor and
Chair
Phone/TTY: (509) 335-4526
E-Mail: chermak@wsu.edu
WWW: www.libarts.wsu.edu/speechhearing/
academics/minor.html

Academic Institution: University of California at Berkeley
Program: Concentration in Disability Studies in
Undergraduate
   Major in American Studies
Academic Unit: American Studies
Address: Office of Undergraduate and
Interdisciplinary Studies 301 Campbell Hall
Berkeley, CA 94720-2922
Contact: Marianne Callum, Student Affairs
Officer
Phone/TTY: (510) 642-9320 or (510) 642-0108

For TTY/TDD access, call (510) 642-9900
E-Mail: mcallum@socrates.berkeley.edu
WWW: http://ls.berkeley.edu/dept/as/forms/AS_
HANDBOOK_12-2002.pdf
and see page 16 of this handbook for information
on the concentration on Disability Studies.

Academic Institution: University of Delaware
Program: Undergraduate Interdisciplinary Minor
in Disabilities Studies
Academic Unit: The College of Human Services,
Education and Public Policy
Address: The Center for Disabilities Studies
166 Graham Hall
Academy Street
Newark, DE 19716-7355
Contact: Dr. Carol R. Denson, Associate Professor
Phone/TTY: (302) 831-6974; TTY (302) 831-
4689
E-Mail: crdenson@udel.edu
WWW: http://udcatalog.udel.edu/humanservices/
undergrad/CHEPUgPDF/CHEPMinor.pdf

Academic Institution: University of Hawaii at Manoa
Programs: Disability and Diversity Studies
Doctoral Leadership Program
Culture and Disability Studies Masters Training
Certificate Program
Disability Studies Minor within Liberal Studies
Bachelors Degree Program
Academic Unit: Center on Disability Studies
Address: 1776 University Ave., UA 4-6
Honolulu, HI 96822
Contact: Norma Jean Stodden
Phone/TTY: (808) 956-4454
E-Mail: NJ.Stodden@cds.hawaii.edu
WWW: http://www.cds.hawaii.edu/cds_core_
programs/index.html

Academic Institution: University of Illinois at Chicago
Program: Interdisciplinary Ph.D. Program in
Disability Studies
Address: Disability, Health, and Social Policy
Building

1640 West Roosevelt Road, Room 207 (MC628)
Chicago IL 60608-6904
Contacts: David T. Mitchell, Ph.D., Director
of Graduate Studies, Michelle Jarman, Program
Coordinator, PhD in Disability Studies
Phone/TTY: (312) 996-1508; TTY (312) 996-4664
E-Mail: dmitchel@uic.edu; mjarman@uic.edu
WWW: http://www.ahs.uic.edu/ahs/php

Academic Institution: University of Illinois at Chicago
Program: Master of Science in Disability and
Human Development
Address: Department of Disability and Human
Development
Suite 436 IIDD
1640 W. Roosevelt Road
Chicago, IL 60608
Phone/TTY: (312) 4 13-1647; TTY (312) 413-0453
E-Mail: DHD@uic.edu
WWW: http://www.uic.edu/depts/idhd/
msindhd.htm

Academic Institution: University of Maine
Programs: Undergraduate Disability Studies
Core Curriculum Graduate Interdisciplinary
Concentration in Disability Studies Academic
Unit: Center for Community Inclusion
Address: 5717 Corbett Hall, Room 114
Orono, ME 04469-5717
Contact: Elizabeth DePoy
Phone/TTY: (207) 581-1084 or (800) 203-6957
E-Mail: ccimail@umit.maine.edu
WWW: http://www.ume.maine.edu/cci/learning/
ids.htm

Academic Institution: University of Manitoba
Program: Interdisciplinary Master's in Disability
Studies Academic Unit: Education
Address: Room 128 Education Building
Winnipeg, MB R3T 2N2 CANADA
Contact: Tanis Woodland
Phone/TTY: (204) 474-7017
E-Mail: disability_studies@umanitoba.ca

WWW: http://www.umanitoba.ca/disability_
studies

Academic Institution: University of Pittsburgh
Program: Graduate Disability Studies Certificate
Program Academic Unit: School of Health and
Rehabilitation Services
Address: 6051 Forbes Tower
Pittsburgh, PA 15260
Contact: Dr. Miriam Hertz
Phone/TTY: (412) 383-6653
E-Mail: mhertz+@pitt.edu
WWW: www.shrs.pitt.edu/SHRSnews/headlines/
disability_studies.htm

Academic Institution: University of Toledo
Program: Undergraduate Interdisciplinary Minor
in Disability Studies
Master of Liberal Studies Program (MLS),
Concentration in Disability Studies (DST)
Academic Unit: College of Arts & Sciences
Address: Disability Studies Program
University Hall 2100, Mail Stop 920
2801 W. Bancroft
Toledo, OH 43606-3390
Contact: Patricia A. Murphy, Program Director
Phone/TTY: (419) 530-7244
E-Mail: pmurphy@utnet.utoledo.edu
WWW: http://www.dstprg.utoledo.edu/
Comment: An interdisciplinary major in
Disability Studies has been proposed.

Academic Institution: University of Wisconsin-Madison
Program: Interdisciplinary Cluster
Academic Unit: College of Letters And Science
Address: South Hall
1055 Bascom Mall
Madison, WI 53706
Contact: Marsha Mailick Seltzer, Ph.D.
Phone/TTY: (608) 263-5940
E-Mail: mseltzer@waisman.wisc.edu
WWW: http://wiscinfo.doit.wisc.edu/cluster/view_
proposal_single.asp?id=50
Comment: The University of Wisconsin-Madison
does not yet have a formal academic program in

Disability Studies. However, the university has made a commitment t o the development of a program through a Cluster Hiring Initiative to fill multiple tenure track positions in Disability Studies.

Academic Institution: York University
Program: Master of Arts in Critical Disability Studies
Academic Unit: Faculty of Graduate Studies
Address: 283 York Lanes
4700 Keele Street
Toronto, ON M3J 1P3 CANADA
Contact: Marcia H. Rioux, Professor and Director of the Graduate Programme
Phone/TTY: (416) 736-5157
WWW: http://www.yorku.ca/grads/cal/disa.htm

Book, Art And Film Reviews

Book Review

TITLE: *Movie Stars and Sensuous Scars: Essays on the Journey from Disability Shame to Disability Pride*

AUTHOR: Steven E. Brown

PUBLISHER: iUniverse, Inc. People with Disabilities

COST: $17.95 US

REVIEWER: Tanis Doe tdoe@uvic.ca

History buffs or disabled people interested in learning more about their community history will be interested in this book. Students of disability studies will also benefit from the mixed stories of individual and political, autobiographical and biographical, local and national narratives. While this very accessible, readable set of stories will be appealing to many readers, those who have a more advanced conception of disability studies may find that the book lacks a new level of analysis. However, it adds significantly to what we know about Ed and Zona Roberts and their role in disability history. It shares personal and intimate tales of dealing with disability and the organizations that serve people with disabilities. The intimate stories are the most enticing. For example, when Steven Brown's partner Lillian cannot move temporarily, they both wait. He writes, "This dissonance impacts every arena of our lives. Sometimes, more often as we age, sexual contact presents difficulties. Which is unfortunate because Lillian is one of the sexiest people I know and easily the most compelling, desirable lover I've had." The book will not scare off novice disability scholars. From the beginning through the end there are short and medium length stories that vary from describing the author's experience with disability to his essays on social commentary and legal progress. He brings together many issues in his discussion of the progress of the

disability rights model and the growth of disability culture. Students and history buffs will enjoy the details and discussion. There are a few chapters that address disability issues in other countries and that tie back to the ADA or the Independent Living movement in the US. It is reasonably priced and a positive contribution to the history of the disability rights movement and disability culture in the United States of America.

Book Review

TITLE: *Disability and Culture: Universalism and Diversity (ICIDH-2 Series)*

EDITORS: T. Bedirhan Ustun, Somnath Chatterji, Jerome E. Bickenbach, Robert T. Trotter II, Robin Room, Jurgen Rehm, Shekhar Saxena

PUBLISHER: Hogrefe & Huber Publishers, Seattle. Published on behalf of the World Health Organization, 2001. ISBN 0-88937-239-X. Library of Congress Catalog Card Number 00-105123.

COST: $44.50 US

REVIEWER: Jean L. Johnson, DrPH Center on Disability Studies University of Hawai`i at Manoa

Overview

As advertised by the publisher, this book presents the background, results, and conclusions of a cross-cultural applicability study of the revised version of the WHO's International Classification of Functioning and Disability (ICIDH-2). In the opening chapter, the authors address the criticisms leveled at the ICIDH 1980—that it was too medical and did not include social models of disability. Although the revised ICIDH-2 supposedly addressed this issue, synthesizing the medical and social models, ICIDH-2 remains largely a medical

model for understanding disability. Moreover, the authors' protests against the medical model to the contrary, Disability and Culture: Universalism and Diversity follows the medical model in discussing disabilities.

The authors state that, "disability is not an intrinsic or defining feature of a subset of human beings…, but is a universal condition of humanity itself." They further state that "it is inappropriate and scientifically inaccurate to characterize disability… in inherently negative and deprecatory terms." However, the authors did not always follow their own counsel—throughout the book the authors use the term "wheelchair-bound" to refer to persons who use wheelchairs.

Following the three introductory chapters, detailing the background, objectives, and applicability of the cross-cultural applicability research study, fifteen chapters describe the research process in specific countries, including both developed and developing third-world countries across Asia, the Middle East, Africa, and Europe. The authors intended that the research instrument would test the cultural relativity of the disability construct, and the psychometric requirements for the development of cross-cultural instruments. And while the research plan was ambitious, the book failed to convince this reader that a universalism approach is possible, given the diversity of populations. The inadequacy of "representative spokespersons" (often the most westernized of the population) to speak for the diversity of disabilities within any culture remains a troubling research methodology.

Targeted Audience

The publisher aimed the book toward public health professionals, health policy planners, social scientists, including cross-cultural psychologists, physicians and others involved in programs for the disabled. The publisher also considered the book as appropriate for higher level and undergraduate students. Considering the book's lack of "people-first language"—e.g., the authors refer to "disabled

people" instead of "persons with disabilities"—and the stigmatizing language used by the publisher and authors (e.g., "wheelchair-bound"), hopefully these targeted individuals will not be reached.

Appropriate Audience

Ironically, the audience targeted by the publisher did not include persons with disabilities themselves. That oversight, however, may be fortunate, since this reader was told that several persons with disabilities described themselves as "screaming after reading the first three pages." Thus, from the standpoint of at least some persons with disabilities, this book has no appropriate audience.

Summary

Given the limitations of the research methodology, it is doubtful that this book contributes significantly to existing knowledge. As nighttime reading, this book would lead to early slumber. Only those willing to laboriously explore the topic will find the book of interest. Selling as a paperback for $44.50 US, it is not considered worth the price.

Monograph Review

TITLE: *Celebrating Disability Arts*
[Available free of charge from www.artscouncil.org.uk, in print and a variety of alternative formats].

PUBLISHER: Arts Council England

COST: No Cost

REVIEWER: Steven E. Brown

Celebrating Disability Arts is an exciting document. In the introduction, Maria Engle, England's Minister for Disabled People, states:

Our dynamic and creative arts scene is something this country can be proud of. It is timely then, in the European Year of Disabled People, that we celebrate the quality and vibrancy of disability arts. This publication from Arts Council England seeks to do that – to raise the profile of disabled arts practitioners, to leave a legacy and to mark the achievements of the past four decades.

About a dozen artists and art groups are among those discussed and profiled in this brief (about 30 oversized pages) monograph, that celebrates thirty years of developing disability arts by companies and individuals. Most of those profiled I have not encountered previously, like Minika Green, a singer with a mobility disability; Maria Oshodi, a writer-performer who's blind and helped create the first performing arts company in the United Kingdom, Extant, managed by blind arts professionals; and Heart 'n Soul, a musical theater group and more, including DJs, tutors and a technical crew, all of whom have learning disabilities. Descriptions of these artists and the others described would be skewed in any brief review, because almost all these performers are engaged in multiple artistic and activist mediums. So it comes as no surprise that one of the artists is Johnny Crescendo, a rock and rolling musician with a mobility disability who's been in the United States many times. He helped created DAN, the Direct Action Network, modeled on the U.S.'s ADAPT.

What makes this document so appealing is its combination of text, written by Allan Sutherland, exploring the disability arts movement, both historically and contemporaneously; written and pictorial profiles of artists; and the vibrancy of the coalition of disability arts in the United Kingdom that's clearly represented in this document.

In the mid-1980s, Anthony Tusler, of California, in the U.S., assembled a show that celebrated disability and the arts and published a booklet about it called *Disability and the Arts²: An Exhibit Confronting Our Attitudes and Experiences* (Rohnert Park, CA: Sonoma State University Office

for Students with Disabilities, 1985). That was a groundbreaking document. The first of its kind that I know about in the U.S. This publication is similar. It will clearly alert anyone who is unaware of the disability arts scene in the U. K. just how active it actually is. For those of us who have known about its existence, but not who all the players are, this is a wonderful find and will complement any library, be a useful class tool, and a fun read.

Review: Music

TITLE: *Angryfish, Eight Men Called No, and Barbed Wire and Pot-Holes,* (Available from www.angryfish.co.uk).

REVIEWER: Steven E. Brown

Robin Surgeoner, aka, the Angryfish, is an English activist who likes to rock'n'roll. His short play CD, Eight Men Called No and the full-length Barbed Wire and Pot-Holes, are meant to be played loud. Barbed is also the story of a man's awakening from being a person with a disability to being a member of an oppressed group and learning what he can do to change the world for the better. It's the first complete story CD I'm aware of by a person with a disability about the disability experience. Lyrics from one song, "Free Our People," are included below. Check it out.

There are people - everywhere
Living their lives without a care
There are people everywhere - everywhere
Living their lives without a choice

CHORUS
I hear you asking - if this is really true
Surely we all have the right to do what we want to do
Please don't be surprised - how could you realize
It's sometimes hard to see the truth before your eyes

Basement Billy ain't got a view

His rooms got windows, but he ain't got a clue - That the drugs they claim are helping - helping him to survive
Have really shut his mind down and are killing him alive

CHORUS

Freaky Freddy's got his hands inside his pants
Do you think he chose this and composed his scary rants
Or the scarring down his cheeks from endless acid tears
Or could it be that he has been locked away for countless endless tears

They might have been beaten - if lucky only raped
If you're here celebrate cause you've escaped
You have the power to destroy their ivory steeples
You have the power to join in and FREE OUR PEOPLE

Correspondence

Letters to the Editors and brief commentary are included in this section and can be addressed to Dr. Megan Conway, Associate Editor, Review of Disability Studies, Center on Disability Studies, 1776 University Avenue, UA 4-6, Honolulu, HI 96822, U.S.A. or emailed to submissions_rds@cds.hawaii.edu.

Announcements

**20th Annual Pacific Rim
Conference on Disabilities:
Promises to Keep, Futures to Seek
March 29, 2004 - March 30, 2004
Honolulu, HI**
http://www.pacrim.hawaii.edu/

Since the first Pacific Rim (Pac Rim) Conference in 1985, the scope and size of this premier event has grown to include participants from the

U.S. Mainland, Alaska, Pacific Islands Nations, Japan, Australia, the Philippines and numerous other countries. Persons with disabilities, family members, researchers, and service providers join policymakers and nationally recognized speakers in the field of disabilities to share resources for communities to fully accept and support persons with disabilities. This year's theme, "Promises to Keep, Futures to Seek", reflects on the promises and goals made and the opportunities created for persons with disabilities. Sponsored by the Center on Disability Studies at the University of Hawai'i in Manoa and various community partners.

RDS Information

Information for Advertisers

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Dimensions for a half page are 7 x 4 inches at a cost of $300. Dimensions for a full page are 7 x 8 inches at a cost of $500.

Discounts:
10% discount for 3, 4 or 5 insertions
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10% publishers discount
10% discount for first time advertisers
Please note: Only one type of discount will be applied to each booking. Combinations of discounts are not accepted.

Copy Dates (subject to change)

RDS is published four times a year and runs approximately 100 pages.

Issue	Published	Date Copy Due
1	January	December 1 of the previous year
2	April	March 1
3	July	June 1
4	October	September 1

Terms And Conditions

1. All advertisements submitted are subject to editorial approval. We reserve the right to refuse or to remove advertisements at our discretion.

2. A confirmation of your order will be supplied upon acceptance.

3. We cannot make any guarantees as to publication dates. While we will make every effort to ensure that your advertisement will be published, the Review of Disability Studies may run ahead or behind schedule.

4. All advertisements are accepted on a space available basis. On rare occasions it may not be possible to accommodate a particular advertisement. Should this be the case, a refund or substitute issue will be offered.

5. No liability is accepted by the Center on Disability Studies or the University of Hawaii for the content of any advertisements or quality of any products, materials, or services advertised.

6. The Center on Disability Studies and the University of Hawaii do not accept any liability for loss or damage arising from the use of any products or materials purchased as a result of advertisement publication.

7. Invoices for all advertisements must be settled within 30 days of receipt from the date as postmarked.

8. All advertisement prices are subject to sales tax, general equity tax, value added tax, or any similar tax if chargeable and at the current rate.

9. Prices are correct at the time of publication. The Center on Disability Studies, at the University of Hawaii at Manoa, reserves the right to increase advertisement rates at any time.

About the Center On Disability Studies

The mission of the Center on Disability Studies (CDS), at the University of Hawaii at Manoa, is to support the quality of life, community integration, and self- determination of all persons accomplished through training, service, research, demonstration, evaluation, and dissemination activities in Hawai`i, the Pacific Region, and the mainland United States.

The Center on Disability Studies is the umbrella for some 25 funded projects. It originated as the Hawaii University Affiliated Program (UAP) funded by the Administration on Developmental Disabilities of the U.S. Department of Health and Human Services. It was established in 1988 as part of a network of over 60 UAP's in the United States. It is now a University Center for Excellence in Disability Education, Research, and Service.

Although core funding for the Center is provided by the Administration on Developmental Disabilities, other federal and state funds are provided by the Maternal and Child Health Bureau of the U.S. Department of Education, various other programs in the U.S. Department of Education, the University of Hawaii, and the State Planning Council on Developmental Disabilities.

The activities of the Center for Disability Studies extend throughout the state of Hawaii, the mainland United States, and the Pacific region with funded projects in several initiative areas including intercultural relations and disability, mental health, special health needs, Pacific outreach, employment, and school and community inclusion.

The Center provides a structure and process to support and maintain internal professional development, collegiality, and cooperation, reflecting an organizational commitment to excellence. Center activities reflect a commitment to best practice and interdisciplinary cooperation within an academic, community, and family context. Activities are culturally sensitive and demonstrate honor and respect for individual differences in behavior, attitudes, beliefs, and interpersonal styles.

Submissions and Subscriptions

Information about submissions can be found on the inside cover of the journal. A subscription form is included at the back of the journal.

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For questions please email rds@cds.hawaii.edu or phone 808-956-5688