Disability Studies Quarterly ISSN 1041-5718

Fall 1995

Volume 15 No. 4

Publishers: Suffolk University and Brandeis University

Financial assistance was provided by the National Institute of Disability and Rehabilitation Research, U.S. Department of Education, and other assistance was provided by the American Foundation for the Blind. This assistance is gratefully appreciated.

Issue Theme: Disability Culture
Guest Editor for this issue: Steven Brown, Institute on Disability Culture

Editor's Preface

This issue marks the second one of my term as editor. I am thankful for all of the encouragement which many persons have given me. I also extend my appreciation to the guest editor of the Summer issue and to the guest editor of this Fall issue. In addition, on behalf of the DSQ Steering Committee I thank all of you who have paid your subscriptions and made donations.

Plans continue to advance for finding a permanent home for DSQ. We are grateful for financial assistance from the National Institute on Disability and Rehabilitation Research and for other assistance from the American Foundation for the Blind. This assistance along with that from the publishers and from you the subscribers guarantees that DSQ will be published through the end of volume 16 (1996).

The Winter 1996 issue will be a generic one continuing Irv's tradition. At present it is anticipated that the Spring 1996 issue

will have the theme of ethnicity and disability with Elaine Makas as guest editor. Other planned issues are: developmental disabilities (Summer 1996) with Phil Ferguson as guest editor, the new economics of disabilities (Fall 1996) with Corinne Kirchner as guest editor, a generic issue (Winter 1997), and disability history (Spring 1997) with Paul Longmore as guest editor.

A table of contents will be found at the end of this issue.

Focus

Disability Culture: Here and Now

Steven E. Brown, Ph.D.

Two years ago, at the Society for Disability Studies (SDS) Annual Conference in Seattle, I approached Irv Zola about guest editing an issue of the Disability Studies Quarterly on Disability Culture. Irv, as gracious and enthusiastic as ever, said "great, when can you do it?" I fumbled for a minute, as I thought about the changes in my life, and said not for at least a year. He suggested I get back to him. A year later, at the SDS Annual Conference in Rockville, I did just that. He again asked me when I could be ready to assume a guest editorship and I replied in about a year. He said, "great, you do the fall issue of 1995." And, here we are, unfortunately, without Irv, who believed and encouraged me, as he did with so many others.

I am pleased to say that David Pfeiffer has been just as supportive and that the response to this issue has been overwhelming. About six months ago I realized that I would have to turn people down who wanted to contribute because there was getting to be too much information. Who would have thought five years ago that an issue about Disability Culture would be filled to overflowing?

Eight articles and a poem, contributed by nine people, have been submitted for this issue. Each author has vital arguments, debates, or information to offer the discussion on the no-longer merely emerging, but vibrant existing Disability Culture. Although as many readers know, I have been studying this field for several years, and the Institute on Disability Culture, which Lillian Gonzales Brown and I founded, has published the report to the National Institute on Disability Rehabilitation and Research (NIDRR) which resulted from a Switzer fellowship, Investigating a Culture of Disability: Final Report, my submissions to this issue are limited to this introduction, a bibliography, and a poem.

The authors of the articles submitted for publication represent academic disciplines as diverse, and alike, as anthropology, history, and psychology. They range from people who have been in academic positions, policy making, and art. Carol Gill, perhaps the pre-eminent proponent of Disability Culture during the past decade, explores her thoughts in a provocative essay. At the other end of the spectrum, Gene Chelberg, a student a few years ago, combined with doctor of education Sue Kroeger to discuss the discovery of Disability Culture from the perspective of

disabled students. Karen Hirsch and Jerry Hirsch, historians, discuss the need to listen to people with disabilities in our research and how historians have generally failed even to consider this approach in the past. Graduate history student Ruth Brannon offers a compelling discussion of the evolution of the concept of Disability Culture, set against the background of many SDS meetings. Anthropologist Ed Eames discusses the use of hearing dogs and what it means in light of the concept of Disability Culture. Finally, Elias Katz, who has been doing this work longer than any of the rest of us, discusses the establishment of the National Institute of Art and Disabilities and how it has impacted individuals with developmental disabilities and spawned many replicas.

There is no one viewpoint expressed in this issue. I hope it will serve as a forum for continued discussion of the issue. I also believe, as an advocate of both the existence and importance of a cross-disability Culture of Disability, that this is a field which is about to mushroom onto the landscape of the disabled and non-disabled publics. But, I also believe that it is never enough to describe Disability Culture in academic terms. The impact of the culture comes across most dramatically in its artistic outlets. For that reason, the final contribution to this issue is my poem, "Martyrs," which, unfortunately but inevitably, keeps getting longer.

(The Institute on Disability Culture is located at 2260 Sunrise Point Rd., Las Cruces, NM 88011. A publications list is available from the author.)

Current Research

The Use of the Concept of Disability Culture: A Historian's View

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Introduction

This paper is an exploration of the evolution of the concept of disability culture. (1) Disability scholars have publicly debated the existence of disability culture in recent years. For some, the term serves as a theoretical framework for evaluating the shared experiences of persons with disabilities. For others, disability culture is a misnomer because the disability experience does not meet some academic criteria of culture. In addition, there is a growing artistic expression of disability culture in literature, film, and live performance.

The relationship of culture consciousness to rights movements will be explored in this paper. Part of the agenda building process of the disability rights movement has been an appeal to cultural concepts to foster group identify, to build coalitions among differing disability groups, and to aid the search for empowerment. This appeal to culture has not gone unchallenged by some scholars of disability issues. These scholars, trained in

traditional academic disciplines, have resisted or been slow to adopt what they consider to be a nontraditional application of the term culture to describe disability group membership.

In some respects the emergence of a discourse on disability culture reflects a self-conscious examination of culture concepts by individuals who are themselves persons with physical and/or mental disabilities and who are cognizant of their role in the formation of a new analytical construct. Many of the academicians involved in this discourse are social scientists whose writings appear in both academic and nonacademic materials. Their debate has often centered on whether there is a disability culture or whether one needs to be created for political reasons. It may be too early to put disability culture into an historical perspective because of the newness of the concept even within the disability community. Yet, Black history, women's history, and the history of the gay rights movement have cultural as well as political aspects and may provide a possible contextual framework that helps place disability culture within a wider intellectual and cultural framework.

Background: The Disability Rights Movement

Scholars of American civil rights movements increasingly recognize the emergence of a disability rights movement. This rights movement has evolved over the last 40 years and has national leadership and a political agenda. (2) A definitive history of this evolution has not yet been written, although there are histories of various aspects of deaf culture as well as of services for both persons with deafness and persons with vision impairments. One recent attempt at writing a history of disability rights was made by Joseph Shapiro, a Washington based journalist, in his 1993 publication, No Pity: People with Disabilities Forging a New Civil Rights Movement. (3) Among the factors that Shapiro and others identify as contributing to the growth of the disability rights movement is the increase in the numbers of persons with disabilities attributable to improved medical success in treating disabling conditions of both traumatic and chronic origins. (4)

Equally important is the influence of other rights movements. People with disabilities, especially those on college campuses, were often involved in anti-Vietnam era protests. Some were involved in Black civil rights causes, and many of the women were influenced by the feminist movement of the 1970s. (5) Disability rights leaders speak of their realization that the rights embedded in these other movements could and should be expanded to their rights as persons with disabilities. (6)

Although no one event has been singled out as the defining moment of the beginning of an active disability rights movement, the efforts of a group of disabled students at the University of California, Berkeley in the early 1960s have been identified as providing a

model for other young people with disabilities. With Ed Roberts leadership, a group of students convinced the university to admit them and agreed to accept space in the university infirmary as living quarters for disabled students. These students eventually established their own disability student center. Known as the Rolling Quads, this group eventually moved their activities off campus and obtained funding from the Berkeley City Council to establish the Berkeley Center for Independent Living which became a model for hundreds of independent living centers that eventually came into being. (7)

Around the country, other persons with disabilities were organizing around rights issues. For instance, in 1971, Judy Heumann formed a group called Disabled in Action to advocate for disability rights in New York. Soon there were chapters in a number of other states. (8)

The Rehabilitation Act of 1973 is also a pivotal moment in the evolution of a rights movement for persons with disabilities. (9) Section 504 of this Act, modeled on civil rights legislation of 1964, forbade discrimination on the basis of disability by any program or institution receiving federal funding. This legislation helped turn disability advocates into activists when months went by and no federal regulations were issued to implement the provisions. Around the country, advocates organized demonstrations and sit-ins to force the regulations to be issued. In interviews with disability rights leaders, many remember these demonstrations as being pivotal in their realization that there was a disability rights movement. (10)

The growing public presence of people with disabilities led to a White House Conference on Handicapped Individuals in 1977. This Conference brought attention to disability issues and to the lack of adequate civil rights protection for persons with disabilities. (11) In 1986, the National Council on Disability published Towards Independence, a Congressionally mandated examination of the status of persons with disability in the U.S. This monograph contained a series of recommendations including one that called for a civil rights law that guaranteed equal protection for persons with disabilities. The Council took the initiative to draft such a bill and persuaded Senator Lowell Weicker to introduce it to Congress in 1988.

Influenced by his long association with Evan Kemp and Justin Dart, prominent Republicans with disabilities, George Bush promised to support the rights of persons with disabilities if elected in 1988. Bush kept this promise by supporting the passage of the Americans with Disabilities Act (ADA) in 1990 despite conservative Republican concern that the law would negatively affect business. The ADA is to date the greatest achievement of the political activists of the disability rights movement. It established requirements for access in a wide variety of public accommodations, state and local government, and communication systems. (12) Passage of ADA was accomplished through a coalition of

disability advocacy organizations who worked together with sympathetic Congressional leadership and luke warm White House support.

Disability Culture: Evolution of a Concept

The emerging disability rights movement provided the critical framework in which disability culture emerges. (13) One of the first public discussion of disability culture (14) occurred at a conference of the Association on Handicapped Student Service Programs in Post-Secondary Education. At this meeting, both David Pfeiffer and Andrea Schein addressed the issue, "Is there a disability culture?" Pfeiffer and Schein held up the concept of disability culture to academic standards to answer the question asked by their title. Pfeiffer (15) used anthropology as the critical discipline to apply to disability culture and concluded that disability culture met the basic anthropological definition of culture: there are artifacts, art, literature and language, political, economic, and social networks, and finally coping mechanisms like support systems. (16)

Schein's presentation incorporated both sociological and anthropological standards in defining disability culture. She argued that persons with disabilities conform to the requirements of minority group status when sociological frameworks are applied. Further, she concluded that disability meets the criteria for culture as espoused by anthropology, including requirements for concepts, beliefs, values, rules and public values, and routines. (17) For Schein, the term disability itself satisfied the concept requirements. She identified common beliefs such as "Disability does not mean inability." Shared values included independent living models as opposed to medical models for living lives with disability. (18) Disabled people have implicit rules of conduct in Schein's analysis because they believe that persons with disabilities should run their own lives. Finally, Schein concluded that persons with disability have shared routines in their common efforts to deal with accessibility barriers in the dominant culture.

These speeches were not reported in detail in disability publications, yet they are known to students of disability culture. (19) Two years later, this topic was again introduced in a public forum, within the pages of the Disability Rag. In a 1987 cover article, the editor, Mary Johnson, reported on Carol Gill's presentation to the West Los Angles Chapter of the California Association of the Physically Handicapped. (20) Johnson reported that Gill argued for the creation of a disability culture because of a belief that only a cultural perspective is necessary to motivate both people with disabilities and the larger public to be sympathetic to the disability rights movement. The argument further built upon an analysis of how negative images of disability characterize public perception of persons with disability and concludes that, "a cultural statement can

take that negative image....turn it around, and put strength and power and style where tragedy and dependency have been." (21)

In this speech, Gill identified the barriers to formation of disability culture, including problem of defining members of the culture because "we are different people," have "different backgrounds," "are not used to cooperating," "have been physically isolated from others with disability," and are "separated by time and place" from others with disability. Still, Gill found incentives to creating disability culture. The disability experience "brings persons with disabilities together," and a disability culture movement could "foster pride." Most importantly, "through our culture, we can recruit people." Increasing awareness of disability rights by carving our a disability culture will "increase our numbers and our power, and that will feed our cultural movement even more."

Gill also introduced the concept of disability subculture when she argued, "we are disability foster children....we have been raised in families in the 'majority culture' - nondisabled - and have accepted the majority culture as our own." As evidence of an emerging disability culture, Gill pointed out the increasing use of terms such as "disabled and proud." The theme of pride was repeated throughout this article. Pride in disability will let people with dis-abilities, "stop apologizing for being physically different." Like other minority groups, especially Blacks, persons with disabilities can, according to Gill, use culture consciousness to express their differences and their pride in these differences. Gill concluded, "If we neglect the cultural aspects of our movement, we will fail." Gill developed a paradigm that identified four main attributes of disability culture, including (a) fortification, providing strength to face oppression, (b) communication of shared values, (c) creating unity and recognizing community, and (d) serving as a tool to recruit outsiders to a movement.

Although Mary Johnson's introduction of Carol Gill to the pages of the Disability Rag produced no immediate response as measured by letters to the editor, over the next few years other Rag contributors referenced Gill's work in articles on disability culture. In the 1987 May/June issue, Karen Hirsch identified additional attributes of the disability culture experience in her article, "Studying Culture." She discussed the importance of shared experiences in establishing culture and group identity. Hirsch advocated "cultural activism" and justified this call to action by arguing that traditional study of culture, social history, and folklore have ignored disability issues. Hirsch also introduced another theme of disability culture advocates: knowledge of disability issues can inform American understanding of its overall culture and enlarge the scope of historical inquiry into the experience of being American. Hirsch seemed to develop this argument as an additional justification for the development of the concept of

disability culture. (22)

Disability culture was further explored in "The Bargain." (23) The bargain is, in the author's view, the understanding that "disabled people...have to become like nondisabled 'normal' people...in order to be essentially ok." The argument contrasted majority culture values with their impact on the minority, in this case disability culture. Much of the argument in this article drew on previous work of a leading disability studies scholar, Harlan Hahn.

Hahn attributed to "aesthetic anxiety" the fear that the dominant culture expresses when faced with physical conditions or characteristics that are disturbing. (24) Hahn connected the cultural dimension with the political by arguing that persons with disabilities will become powerful only when they accept the concept that disability is beautiful. In Hahn's view, finding self-esteem as a person with disability is possible only through a conscious repudiation of the majority culture view of beauty. (25)

In a more recent article in the Disability Studies Quarterly, Hahn explored the limitation of current theoretical constructs for assessing "the political implications of corporeal differences." Hahn found that "the major impetus for social and political change in the second half of the twentieth century has emerged from groups defined by embodied attributes such as race or ethnicity, gender, age, and disability. They "transform devalued characteristics into positive sources of identity." (26)

In many ways, Carol Gill's activist view of disability culture has been profoundly influenced by the work of both Harlan Hahn and Paul Longmore. (27) Hahn, in a series of publications, explored the application of "a minority group model" to disability issues. This model appears to provide the theoretical framework for Gill and others developing theories of disability culture. In this model, Hahn emphasized the importance of sociopolitical interactions between the individual and the environment, making labeling and self identification critical components of the interaction. (28)

Paul Longmore also influenced Carol Gill's thinking. Longmore, a historian with a special interest in media, is skeptical that there is such a thing as disability culture. (29) However, his discussion of how popular media portray persons with disabilities influenced Gill and other proponents of disability culture. Longmore's theme is that traditional media use disability as a "melodramatic plot device," portraying persons with disabilities solely in terms of their coping skills towards disability, often depicted in negative ways.

In Longmore's analysis, dramatists seldom, if ever, explored the impact of societal handicaps on the lives of disabled persons. As a result, persons with disabilities feel "indignation and impotence" when faced with media depictions of disability. Longmore used concepts of powerlessness to underscore his point about the impact of popular culture on the

daily lives of persons with disabilities. In one article, he concluded, "The aim of the disability rights movement is to empower them [disabled persons] to organize their anger toward social change. (30)

Gill's contribution to the discussion of disability culture incorporates both Hahn and Longmore's ideas into a definition of the bi-cultural aspects of the disability experience because persons with disabilities experience discrimination, segregation, and social devaluation like other minority groups and because disabled persons must live with dominant culture stereotypes that are negative towards disabilities. (31)

She expands the argument to reflect Hahn's work even further in her most recent writing in the Rag when she describes the marginalized status assigned by society to people who are different enough from majority cultural standards to be judged abnormal or defective in mind or body. In Gill's perception of an ideal world, disability would be accepted as a cultural experience that enriches human existence. (32)

Disability Culture--The Academic Debate

The academic debate over the concept of disability culture has largely been carried out within the membership of the Society for Disability Studies. This society, established in 1983 by Irving Zola, a Brandeis medical sociologist and a person with a disability, has several hundred members and sponsors an annual conference. In recent years, disability scholars have argued about disability culture in panel sessions at this conference. Steve Brown, a historian and disability activist, discussed the disagreements in his work on disability culture. (33)

In 1991, two graduate students presented papers on disability culture and received the Society's emerging scholar award. Brown recalls that there was considerable criticism, however, of the papers, particularly by SDS anthropologists who did not agree that the disability experience met the definition of culture. Culture was a topic at the SDS meetings in Seattle in 1993 at a panel, co-chaired by Brown, convened to re-examine the basis for disability studies and concluded that disability studies would be incomplete without a study of the "new Renaissance," namely, disability culture. In another panel at the same meeting, Simi Linton, from the Hunter College Project on Disability Curriculum, co-chaired a discussion that concluded that disability studies should recognize the cultural aspects of disability. (34)

Culture continued to be a topic at the 1994 Society meeting in Rockville, MD. Disability historian Richard Scotch chaired a panel on "Disabled Community and Disability Culture: What Are They and Who Cares?" This panel concluded that there was not a disability culture although there was recognition that disability could be discussed in terms of marginal groups and subculture. Steve Brown was in the audience for this panel and concluded, "Those of us in the audience representing the daily work of exploring disability

culture concluded that the panelists had not rejected the notion of disability culture as we perceived it so much as they had not understood it." (35) Brown's comments are better understood in the context of his self-avowed adoption of disability culture as his life's work. (36)

In the spring of 1994, the Disability Studies Quarterly's issue was devoted to an evaluation of the current status of disability studies as a field of endeavor. A number of prominent disability scholars contributed to this issue and several addressed the centrality of disability culture. Kate Seelman, currently director of the National Institute of Disability and Rehabilitation Research, discussed "Future Scenarios for Disability Studies" (37) and concluded that "increasingly, disability is recognized as a distinct cultural phenomenon which has become a subject of inquiry, i.e., disability studies." Simi Linton, head of the Disability Studies Project at Hunter College in New York, (38) described the influence of disability studies models in shifting the mode of discourse about disability from a medical/treatment model to one that embraces a "social/cultural/political paradigm." (39) Linton has compared the emergence of disability culture consciousness to that of gay culture and thinks that disability culture serves a similar group identity building purpose. (40)

The academic discourse on disability culture has expanded beyond the Society for Disability Studies. In 1990, Marilynn Phillips reported on a study of the disability experience in America. (41) A key finding of her analysis of oral narratives about the lives of a group of people with disabilities was her informants belief that majority culture perceptions of deviance and normalcy defined their experiences as persons with disabilities. More recently, Paul Higgins explored the social transformation of human variation in terms of cultural depictions of disability and concludes that, "Understanding disability can help us to understand those of us who are not disabled." (42)

The debate on disability culture is ongoing; there is not yet academic consensus on its meaning and validity. Jessica Scheer, a medical anthropologist critical of claims that there is a disability culture because the concept does not meet technical anthropological definitions of culture, continues the debate in another recent article. She asserted that, "in the analytic sense, culture is the total body of broadly shared tradition transmitted from generation to generation." (43) Because people with disabilities, especially acquired disabilities, are likely to have grown up with no knowledge of disability, Scheer contended that disability is not a cultural experience. On the other hand, Scheer supported Hahn's concept of minority group status as a useful tool in the search for social integration of persons with disabilities. (44)

Conclusions

The historical relevance of disability culture is still

unfolding. In this paper, some of the theoretical aspects of the term have been explored. Unlike cultural labels like the culture of delinquency, coined by observers to categorize events from a distant viewpoint, disability culture as a concept has been created by members of the disability studies and disability advocacy communities. These individuals are themselves persons with disabilities and their use of the term is influenced by their own personal experiences.

That this effort is debated by traditional scholars within the disability community reflects a conflict between ideologies, e.g., disability advocacy and disability consciousness raising on one side and membership in traditional academic circles on the other. This aspect of the evolution of disability culture concepts may be little more than a footnote eventually although it represents a struggle for legitimacy at the present time. Tracking the continued use and development of the disability culture construct is both an opportunity and a challenge for future historians of disability social history.

Footnotes

1. The term culture in this paper is used when the sources use the term without critical analysis of whether their use of the term is appropriate.

2. See David Rothman, The Discovery of the Asylum: Social Order and Disorder in the New Republic; Gerald Grob, Mental Institutions in America: Social Policy to 1875; Theda Skocpol, Protecting Soldiers and Mothers for scholarly interpretation of how 19th-century reform movements aided persons with disabilities and provided a springboard for continued demand for first services and then rights in the 20th century.

3. Joseph Shapiro. No Pity, pp. 41-73.

4. Ibid., p.76. Richard Scotch. From Good Will to Civil Rights: Transforming Federal Disability Policy, pp. 6-7.

5. Stephen Percy. Disability, Civil Rights, and Public Policy, p. 102. James Charlton. Monthly Review, July 1994, pp. 77-87. Interviews with Arlene Mayerson (March 31 and April 24, 1994), Patrishia Wright (March 10 and May 4, 1994), and Mary Lou Breslin (March 29 and April 4, 1994) by author. These informants have been disability rights activists for many years and were instrumental in passage of the Americans with Disabilities Act.

6. Interviews by author with Patrisha Wright, Mary Lou Breslin, and Arlene Mayerson during 1994. Each of these women, founders of the Disability Rights Education Defense Fund, were involved in both the anti-Vietnam and then the women's rights movement for years. In the interviews, each one discussed their growing realization that the rights they were working for as women were very relevant to their own experiences as persons with disabilities. They each turned their attention from other movement activities to issues related to disability. In interviews with other disability leaders, Justin Dart, for instance, similar transference is described. Dart, President Bush's Chair of the Committee on

Employment of Persons with Disabilities, was a leading Texas proponent of civil rights for Blacks and, in interviews with the Sylvia Danovitch of the Equal Opportunity Commission, recounts his growing realization that, as a person with a disability, he did not have the rights he was advocating for Afro-Americans (Danovitch interview with Justin Dart, September 1993).

7. Shapiro. Op. Cit., pp.47-51. Roberts died suddenly in March 1995 and was widely eulogized as a founder of the disability rights movement. His role in making Berkeley, both the university and the town, a model for disability access was chronicled in the PBS series, "Americans on the Move."

8. Richard Scotch. From Goodwill to Civil Rights, p. 36.

9. Richard Scotch. Op. Cit., pp. 3-5.

10. Shapiro, Op. Cit., p. 45. Jim Weisman. Interview by Gerben DeJong, Ruth Brannon, and Karin Behe, November 16, 1993. Linda Toms Barker. Interview by author, October 22, 1995. In this interview, Barker, a leading disability rights advocate from California, responded to a question about whether she thinks there is a disability culture by responding that everyone who was involved in the sit-ins of the federal building in San Francisco over 504 thinks there is a culture and that shared experience is the basis of it.

11. Scotch, Op Cit., p. 164.

12. Jane West. Federal Implementation of the Americans with Disabilities Act, 1991-1994, pp. 17-31.

13. The relationship between rights movements and culture of another group; namely, homosexuals can serve as a comparison to what is happening in disability culture. One excellent analysis of the relationship within gay history is John D'Emilio's Sexual Politics, Sexual Communities. D'Emilio's work, however, emphasizes how the growth of an urban, homosexual culture influenced the development of a rights movement. This relationship on the surface appears to differ from the disability movement where the rights movement seems to have sparked an awareness of the existence of a culture.

14. There is an extensive literature on the history of the deaf community and the concept of deaf culture. Much of this history focuses on the schism between the oralists, who favor teaching spoken language to persons with hearing impairments, and people who advocate using sign language as the primary communication mechanism. Use of sign language, particularly American sign language, reflects an emphasis on communication within the deaf community and to a great extent exclusion of persons outside this community. To a large extent, the American deaf community has been separate from the disability rights movement although the deaf community was actively involved in the coalition that help obtain passage of the Americans with Disabilities Act. I have chosen not to incorporate the literature on deaf culture at this stage of the paper.

15. David Pfeiffer. "Is there a Culture of Disability?" Proceedings of the 1984 AHSSPPE

Conference. July 30-August 2, 1984.

16. Interview with David Pfeiffer, March 16, 1995. Pfeiffer does not recall being asked to speak on this topic. He remembers that there were beginning to be discussions about disability culture among disability studies colleagues and he felt that it was time to address the issue in a public forum.

17. Schein used a paradigm for identifying culture that originated with Ward H. Goodenough in "Culture, Language and Society," 1981.

18. The medical model as contrasted to the model of independent living is an organizing paradigm in disability studies. One excellent analysis of this conceptual issue is Irving Zola's Socio-Medical Inquiries: Recollections, Reflections, and Reconsiderations.

19. Steve Brown also discusses these presentations in Investigating a Culture of Disability, p 84.

20. Carol Gill as quoted in Mary Johnson's "Emotion and Pride: The Search for a Disability Culture," Disability Rag. January/February 1987, pp. 1-10.

21. Carol Gill in Mary Johnson, Op. Cit., p. 3.

22. Karen Hirsch. "Studying Culture," p. 3.

23. Mary Johnson. "The Bargain." The Disability Rag. May/June, 1989, p. 5.

24. See, "Forging a Queer Identity," in George Chauncey, Gay New York, pp. 101-111, for a discussion of how homosexual identity was forged in relation to predominant societal images of sexual abnormality and how some homosexuals reacted to "fairies," men with distinctly feminine attributes, in ways that reflected the dominate societal view of abnormal sexual behavior.

25. Harlan Hahn. "Can Disability Be Beautiful?" p. 9. See also, Hahn, "The Minority Group Model of Disability: Implications for Medical Sociology." Research in the Sociology of Health Care. Vol. 11, 1994, pp. 3-24.

26. Harlan Hahn. "Towards a Politics of the Body--Theory and Disability." Disability Studies Quarterly. Spring, 1992, Vol. 12, No. 2, p. 23.

27. Interview with Carol Gill, by author, March 11, 1995.

28. The most recent Hahn exposition of this subject can be found in "The Political Implications of Disability, Definitions, and Data." The Journal of Disability Policy Studies. Vol. 4, No. 2, 1993, p. 42-28.

29. Discussion with author, February 2, 1995. In this conversation, Longmore wondered if the term disability culture was anything more than a political shibboleth.

30. Paul Longmore. "Talking Back to the Media." p. 1. See also Longmore, "Screening Stereotypes & Images of Disabled People in Television and Motion Pictures."

31. Carol Gill. "What the Doctors Didn't Want to Know." The Disability Rag. May/June, 1992, pp. 11-13.

32. Carol Gill, "Continuum Retort--Part II," p. 4.

33. Steve Brown. Investigating A Culture of Disability, p. 77.

34. Ibid.

35. Ibid., p. 78. Carol

Gill recalls being in the audience for this discussion and remembers that the "whole back eight rows" of people were seething at the conclusions of the panelists and that there was a lot of animosity from the floor and ongoing debates in hall ways following the session.

36. Steve Brown, Interview with author, March 22, 1995.

37. Kate Seelman, "Future Scenarios for Disability Studies." Disability Studies Quarterly. Spring 1994, Vol. 14, No. 2, pp. 20-23.

38. This project has collected curricula of hundreds of disability studies courses. Its avowed purpose is one of curriculum transformation in support of the growth of disability studies.

39. Simi Linton, quoted in Simi Litvak's "Disability Studies vs. Disability Policy Studies." Disability Studies Quarterly. Ibid., p. 23.

40. Interview with author, March 11, 1995.

41. Marilynn Phillips. "Damaged Goods: Oral Narratives of the Experience of Disability in American Culture." Social Science and Medicine. Vol. 30, No. 8, 1990, pp. 849-857.

42. Paul Higgins. Making Disability, p. 13.

43. Jessica Scheer. "Culture and Disability: An Anthropological Point of View." in Human Diversity: Perspectives on People in Context. Edison J. Trickett, Roderick J. Watts, and Dina Birman, editors, Jossey Bass, 1994, p. 247.

44. Op. Cit., p. 250.

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A Psychological View of Disability Culture

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As I am not an anthropologist, sociologist or historian, I make no claim to understanding culture from any of those perspectives. As a psychologist, however, I have become interested in the impact of culture on the emotional well-being of individuals. Moreover, my interest is deepened by my own minority group membership (Disabled people).

My former work as a clinical psychologist spanned sixteen years and hundreds of clients ranging in age from adolescence through end-of-life, both with disabilities and without. Having conducted my doctoral research on identity development, I was often concerned with the pressures and rewards of minority group identity in my clients. Particularly, I was impressed by the way cultural affiliation mediated the effects of social devaluation in persons from the African American, Latino, Asian, non-Christian, and gay communities.

In the mid 1980's, I accepted an invitation to attend shabbat at a Jewish temple recognized for its efforts to integrate people with disabilities into its activities. It turned out to be a great opportunity for an "outsider" like me to learn more about Jewish cultural expression. The evening left an indelible mark. I saw how re-telling history and folklore, explaining symbols, sharing rituals, teaching customs to children, and how eating, laughing, weeping, embracing, and singing together united and fortified a diverse minority community in the space of three hours!

That year, I also attended an incredible disability community event in Southern California: the mournful yet triumphant commemoration of the annihilation of more than two hundred thousand Disabled people in Hitler's Germany. A Deaf survivor of the holocaust recounted the horror and destruction of her people. We (Deaf, physically and cognitively Disabled participants) lit candles, told the story, viewed the photos, cried together and proclaimed to each other "Never again!" It was the first official Disabled people's cultural event I had ever attended.

Also that year, I began to present publicly my thoughts about disability culture. I addressed a chapter meeting of the California Association of the Physically Handicapped (CAPH). Using a family model to describe our orphan-like dependence on an arrogant, rejecting able-centric parent culture, I suggested to the twenty-some assembled members that we could oppose our social devaluation through developing a strong disability community-family and elaborating a proud disability culture. To my amazement, the majority of my audience broke into tears. They spontaneously took turns describing their ideal of a disability culture and how it would heal them.

A few months later, I did

the cover featured interview with Disability Rag on the benefits of focusing on disability culture. It failed to generate much direct reader response, but Disabled people across the country still pull that issue out of their briefcases and wheelchair bags to show me that they've kept it.

THE FUNCTIONS OF A DISABILITY CULTURE: From the time of the CAPH speech, I have focused on four major functions served by the development of a disability culture.

1) Fortification - The definition and expression of our value as a community charges us up and enriches our lives, giving us energy and endurance against oppression.

2) Unification - As we hear ad nauseam, people with disabilities are a heterogeneous community encompassing different ages, races, genders, socio-economic statuses, etc. The expression of our beliefs and heritage in cultural activities, however, brings us together, encourages mutual support and underscores our common values.

3) Communication - Our developing art, language, symbols, and rituals help us articulate to the world and signal to each other who we are as a distinct people.

4) Recruitment - The expression of our culture is a positive and defiant conversion of our social marginalization into a celebration of our distinctness. It encourages people with disabilities (particularly new and young Disabled persons) to "come out" as part of the community, allowing them finally to integrate their disabilities into their individual identities and offering them a sense of group "belonging."

CORE VALUES. I have been constructing a list of the core values of the disability culture - the values that undergird our political struggles, that are reflected in our art, conversations, goals and behaviors. They include:

1) An acceptance of human differences (e.g., physical, functional, racial, intellectual, economic/class).

2) A matter-of-fact orientation toward helping; an acceptance of human vulnerability and interdependence as part of life.

3) A tolerance for lack of resolution, for dealing with the unpredictable and living with unknowns or less-than-desired outcomes.

4) Disability humor--the ability to laugh at the oppressor and our own situations, to find something absurdly hilarious in almost anything, however dire.

5) Skill in managing multiple problems, systems, technology and assistants.

6) A sophisticated future orientation; an ability to construct complex plans taking into account multiple contingencies and realistically anticipated obstacles.

7) A carefully honed capacity for closure in interpersonal communication; the ability to read others' attitudes and conflicts in order to sort out, fill in the gaps and grasp the latent meaning in contradictory social messages.

8) A flexible, adaptive approach to tasks; a creativity stimulated by both limited resources and experience with untraditional modes of

operating.

DISABILITY CULTURE - WHAT IS IT? It is not simply the shared experience of oppression. If that were all our culture was, I would agree with those who doubt the probability of a disability culture. The elements of our culture include, certainly, our longstanding social oppression, but also our emerging art and humor, our piecing together of our history, our evolving language and symbols, our remarkably unified worldview, beliefs and values, and our strategies for surviving and thriving. I use the word "remarkable" because I find that the most compelling evidence of a disability culture is the vitality and universality of these elements despite generations of crushing poverty, social isolation, lack of education, silencing, imposed immobility, and relentless instruction in hating ourselves and each other.

Our culture has been submerged by the profundity of our oppression and the forces that have divided us from each other. But any time disabled people have been able to come together, culture has flourished - in hospital wards, in special schools, at charity camps, during sit-ins, during creative workshops, in peer-support groups, in the hotel corridors of disability conferences, in jail. Furthermore, these scattered spurts of cultural development bear a significant resemblance to each other. For example, a Disabled woman in the southern states described the themes of her childhood play with other Disabled girls in an orthopedic hospital. She recalled the creativity, cooperation, and multi-level humor satirizing the nondisabled culture that she and her playmates employed to cope with their marginalization and to promote group spirit. Her story was remarkably similar to that of a Disabled friend from Scandinavia. At SDS in 1994, Larry Voss and I quoted interview responses from Disabled adult participants in our education study. Afterward, we were swamped by members of the audience from across the U.S. and from Japan and Canada who said their experiences and interpretations of those experiences had been virtually identical to our interviewees. The disability rights and independent living movements have accelerated the transmission of our culture. As I travel around the country or speak by phone to Disabled persons overseas, I am struck by the common usage and understanding of such terms as "AB," "supercrip," "overcoming," "medical model," and such concepts as crip time, normalization, and passing. Our emotional reactions and beliefs regarding issues such as eugenic abortion, nursing homes, community access, entitlement to accommodation, media images and "special" anything are becoming universal. This is due, I believe, not only to our exchange of more information, but also to our transmission of values about life with a disability.

Maybe "culture" is not the proper term for a set of elements deriving from a mixture of: 1) inherent differences; 2) societal treatment; and 3) transmitted facts, interpretations, and preferences. But

what better term is there for that collection of common views and expressions that increasingly characterize Disabled people everywhere? What else do you call that familiar, comfortable rhythm of shared meanings that Disabled people, even strangers, fall into when they meet? That wide-ranging compatibility is difficult to convey to those outside of our community, however sensitive they may be to disability rights issues. (Maybe that is one reason that some of our most aware non-disabled allies and Disabled persons who are fighting hard to "make it" in the majority culture oppose the notion of disability culture.) Several Disabled individuals I know have independently referred to that in-sync feeling (when in the company of other Disabled persons) as "coming home."

I have also noticed that once we began to attach to these common elements the label "culture," Disabled people of all kinds began to rally behind it with a fervor I have rarely seen. In less than a decade, "disability culture" has become a popular term among our people whether activist or not, young or old, scholarly or under-educated. I detect an underlying assertion in this embrace of the term that goes something like, "Yes, we have learned something important about life from being Disabled that makes us unique yet affirms our common humanity. We refuse any longer to hide our differences. Rather, we will explore, develop and celebrate our distinctness and offer its lessons to the world."

Tenets of Disability Discovery

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In August of 1993, 65 disabled students representing 37 colleges/universities throughout the United States, Canada, and Great Britain met in Minneapolis for what would be a life-changing event, "Disabled and Proud: the 1993 National Gathering of College Student Leaders with Disabilities." The purpose of the gathering was to advance a new generation of leaders by promoting positive images of people with disabilities, creating strategies for individual and community empowerment, establishing meaningful linkages with disabled people of achievement, exploring the development of a national association of students with disabilities, and promoting disability pride.

In the few years leading up to "Disabled and Proud," students, staff, and faculty at the University of Minnesota began talking and thinking about disability in new ways. In particular, staff at Disability Services (DS) began to question the notion that disability resides in the individual, with the implication that it is up to individuals with disabilities to "overcome their challenges" in order to gain access to the academic environment. New questions emerged from these conversations: Is there a distinct disability experience? Do people with disabilities have

a sense of connection to a disability community? Do disabled students desire to be a part of a disability community? Should DS be playing a more significant role in the life-long development of students with disabilities?

To help answer the above questions about the experience of college students with disabilities, the DS office supported a research project which had focus groups of disabled students. The objective of the project was to explore perspectives of disabled students regarding campus and disability community. The findings of the project suggested that disabled students were isolated from and anxious to connect with other disabled students to broaden their understanding of the disability experience (Litsheim, 1993).

Within a few months of the final analysis of the research, DS staff, the researcher, and a few students met to discuss the all important question, "Now what?" The students decided, with the support of DS, to work toward the creation of a student center to be housed in the student union. The students were adamant that this center would be a place where disabled students could gather to draw strength from their shared experiences and become a more vibrant part of the larger University community. It was mutually agreed that the center's focus would be on the social, political, communal, and cultural aspects of disability.

Just one year later the students opened the Disabled Student Cultural Center (DSCC) in the heart of the campus student union. The mission of the DSCC was to foster and develop disability community, culture, and pride at the University of Minnesota. In preparing for the opening of the center, members of the DSCC contacted national leaders in the Disability Community. One national leader encouraged the students and staff at the University to host a national conference for college students with disabilities.

As a result, the DSCC, DS, and other campus units collaborated to host the first national gathering of college student leaders with disabilities. The program was designed to allow for exploration and interaction of participants and speakers around the themes of disability history, culture, identity, and leadership. To ensure that the lives of disabled students were reflected through the conference, all speakers, facilitators, and performers were disabled.

The conference was highly successful and University staff are still hearing about the positive impact that the conference had on the personal and professional lives of participants.

The following statements (adapted) emerged from the conference as overarching themes and challenges for the disability community. As we work to celebrate disability and present ourselves to the nondisabled world, these tenets remain integral to our efforts to build a strong disability community.

1. The American obsession with hyper-individualism and our distorted sense of independence thwart the development of

community. We in the Disability Cultural Movement are redefining what it means to be whole, interdependent members of the human community.

2. The medical and moral models of disability are still alive and well in our society, institutions, and families. We must continue to embrace the socio-political definition of disability and our right to disability culture.

3. We must continue to stress the importance of building cross-disability community. We need to subvert the old disability hierarchies and come together in appreciation of our shared experiences as well as our unique differences.

4. We must be inclusive of our brothers and sisters with hidden disabilities and supportive of their efforts to identify with the broader disability community.

5. We must work toward ending our isolation as individuals with disabilities by fostering global disability community networks.

6. We must challenge the prejudice and bigotry which exists within the disability rights movement and build multi-cultural coalitions incorporating other social justice agendas into the disability rights movement.

7. We must build our disability community to satisfy our universal longing to be let in, or we will be left begging to be let into the majority culture at the risk of losing our identity.

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Self-Defining Narratives: Disability Identity in the Postmodern Era

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(This article was first published in Spanish translation, "La Identidad de la Discapidad en la Era Post-Moderna," in Historia y Fuente Oral, Al Margin, No. 13, 1995, 7-14, University of Barcelona, Barcelona, Spain.)

For many years Jerry Lewis, self designated "father and provider," starred in his most self aggrandizing show, the Labor Day Muscular Dystrophy Telethon, without any opposition or challenge from his "kids." Today, some of "Jerry's kids" call themselves "Jerry's orphans." What has changed? What has become more important than all that money?

The answer is: Telethons effectively help create and perpetuate representations of people with disabilities that have become totally unacceptable to most disabled adults, totally incompatible with the identities that they are working to construct for themselves. Suffering, cute, and helpless children are the most effective props for a telethon. Adults with disabilities have discovered that these images tend to linger in the minds of teachers, employers, and other "gate keepers." Competent,

articulate, and determined adults with disabilities often find that their abilities are not acknowledged, their contributions not appreciated, their points of view not even recognized.

In their effort to begin to construct a strong and positive self image for themselves, people with disabilities have turned to each other for support and community. Some people with disabilities have discovered that although they live with different kinds and degrees of disabling conditions, they often have many goals in common, they share similar experiences in their interactions with employers, service providers, the general public.

A shared group identity among people with various kinds of disabilities is emerging in the United States as well as internationally. Members of this disability community are promoting the idea that they have the right to participate in shaping both the services provided for individuals with disabilities and the public images projected about disability experiences and conditions. Self defining narratives are seen as important tools in the process of political empowerment and in the effort to re-define the cultural meaning of disability in the postmodern era.

Oral history interviews are useful in exploring the different kinds of disability identities that can be found among disabled people from a variety of backgrounds. When given a chance to talk about their lives, most people have disability stories to tell, but historians, so far, have not used this information in their work. (1)

Postmodern conditions have made it possible for a variety of oppressed classes to challenge the definitions of their groups that arose with modernity. Colonization is a phenomenon that is rooted in the modern world view - colonized people needed to be conquered and educated by the colonizers to become part of the modern world. While the powerful colonizers viewed themselves as benefactors for the people they oppressed as they brought them missionaries and medical care providers, they saw the native inhabitants of the colonies as perpetually incapable of self government.

The medical model of diagnosis, treatment, and cure that characterizes modern medicine, gives great authority to the medical and "helping" professionals while relegating the recipients of medical care to the "sick role" and similar states of disfranchisement. (2) Only gradually have colonized people all over the world started the struggle to free themselves from the rule(s) of the people who governed them and from the definitions of who they were that the colonizers imposed on them.

If people with disabilities are the "colonized" people, and the "helping professionals" are the colonizers, the struggle of the oppressed to free themselves from their colonizers often takes place within institutions that the colonizers established: residential institutions, group homes, nursing homes, special education, and vocational rehabilitation. These institutions, run by "helping

professionals," are currently being challenged by articulate disability activists who question their value and the validity of their established traditions.

In the wake of the American civil rights movement increasing numbers of oppressed groups are claiming their right to define who they are and what terms should be used to describe them. While individuals with disabilities are still seen as generally incapable of exercising self government and wielding sovereign authority over wealth and power in the modern world, the medical model and its paternalistic implications that were imposed upon people with disabilities by the helping professions, are being rejected and replaced by a minority group model. (3)

Integrated community living, personal friendship ties with families and neighbors, contacts with disabled peers, and access to information and support from the disability community - these experiences often contribute significantly more to the quality of life for a person with a disability than do "services" provided by professionals. There is a growing dissatisfaction among disabled people with the "services" they have received for so long from professionals who are trained, paid, and given the power to "serve" them. People with disabilities are using legal and political means to gain control over service delivery programs, educational institutions, and public policy developments. The "natives" are rebelling against the colonizers and taking power and control away from them.

The medical model of disability, while useful and effective for the medical treatment of a disabling condition, usually helps perpetuate stigmatizing cultural conceptions of disability when applied to such other aspects of a disabled person's life as educational, professional, social, economic, recreational, and civic activities and interests. Under the medical model, a disability remains a problem that is located solely in the person rather than in the interaction between the person and the environment. Also under this model and mode of thinking a life with limited experiences seems to be the "natural" consequence for a person with a significant disability.

Until recently, most people with disabilities have had few opportunities to view their lives as rich and full of options, and for many this situation remains unchanged. A polio survivor in the American Midwest laments that he "feels sad [about] the last eleven years [that] I've been here [in the nursing home]. I have more freedom than I used to [have] when I lived with my parents and my brother. I do more, but I still feel like I was cheated out of a normal life, I mean, yeah, I have a life, yes, but I wanted what I would have [had] if I hadn't gotten crippled." (4) This polio survivor believes that it is only his disability that has limited his life. He does not see the attitudes and barriers in his environment as the most limiting agents.

The minority group model tends to locate the limitations associated with a disability in

the built environment - such as physical barriers - and/or in the social environment - such as limiting stereotypes and expectations. It was only recently that disability scholars and advocates started working on this way of defining their group and their experiences. (5) As they create spaces in which they can share their stories, disabled activists are shaping both individual and common group narratives of disability experiences that make for a shared but not a fixed identity. The language used in these narratives reveals the shift from the medical to the minority group model. In the process of telling their stories disabled individuals are dismantling essentialist notions about the "handicapped" imposed upon them by the helping professions and the larger culture. (6)

What many people with disabilities are asking for is a community of peers and a disability identity that is voluntary and constructed by themselves, not one that is prescribed from the outside by others. People with disabilities have begun to signal to each other that a positive disability identity and a sense of belonging to a cross categorical disability community can represent a wealth of healthy, sustaining, and enriching life experiences that in turn can cancel out many of the negative aspects of living with a disability.

Most people have disability related experiences in their lives - and these experiences are often central to their life stories. Oral history projects that were designed to document the lives of such groups as mill workers and Southern tenant farmers, provide examples of how people have disability stories to tell and how historians so far have been ill prepared to make use of these stories or even pay attention to them. Textile mill workers that were interviewed as recently as the early 1980s, had many disability stories to tell, but the interviewers did not pay attention to these stories, did not ask follow-up questions, and had no conceptual framework for analyzing or even including this information in their theoretical treatment of the Southern textile mill villages. (7)

Disability issues, it seems, have been ignored, if not avoided by historians. The idea of disability as a stigma, a "handicap," has developed over a long time in the history of Western culture. Any social and cultural history that does not at least consider the perspective of disability history is incomplete at best, probably skewed and inaccurate in some instances. As post-modern disability activists set out to change the social and cultural meaning of living with a disability, they need to know the history that they must build on, they need to understand the cultural forces, the deeply imbedded ideological values that govern the meanings ascribed to a different shape of the body, a different way of communicating or walking or dealing with stress.

Medical diagnosis as well as other categories used by the helping professionals tend to emphasize differences - differences among disabled people and differences between

having and not having a disability. In order to overcome the stigmatizing valuation of disabilities, it is important to focus on the similarities and the shared experiences. People with disabilities have had few opportunities to develop a sense of group identity and to find strength and support in their community. With the backing of federal legislation, people with disabilities in the United States are currently developing new institutions where they are free to govern themselves, provide services for each other, and create cultural expressions of their experiences. So far, these institutions have little power, money, or prestige, but they harbor people with powerful ideas and invaluable insights. They are community institutions where disabled people have a chance to develop new models for the services they need.

These institutions are called "Centers for Independent Living." The name derives from one of the first such centers, established in Berkeley, California, in the early seventies, and it does not refer to housing for people with disabilities. Instead, the name "Center for Independent Living" describes an office where disabled activists are working to increase general community access until it becomes possible for people with significant disabilities to live and function independently in that community. (8)

By now there are hundreds of Centers for Independent Living throughout the United States and each state has a federal mandate to develop a network of such centers covering the entire state. In many states people with disabilities are pushing to reach this goal. In other states the "Independent Living Movement" has not been as successful. A few Independent Living Centers have also been established in other countries around the world. Because of these centers, as well as other efforts at cross disability organizing, there is a growing sense of a national, and even an international, disability community where ideas about group and individual identities are shared and widely communicated. The "colonizers" have little access to power in these organizations and the "natives" get a chance to develop their skills at self rule and service delivery.

The disability community is promoting a new image of people with disabilities - an image of competent, mature adults with a variety of complex and rich life experiences. In contrast, many media images of disability experiences are still being influenced by the medical model, serving the purposes of telethons, and boosting the self images of the helping professionals. A few films, such as "My Left Foot," have attempted to display a new disability image, a person who is able to grow up and take charge of his life and his relationships.

One of the problems with "My Left Foot" is that the film superimposes a contemporary postmodern disability identity perspective on a person who lived before this kind of disability identity had evolved. Christy Brown, strong and gifted, lived his life in ways that mirrored the cultural

contexts and religious traditions of his time and surroundings.

Here are some issues that must be clarified through a serious study and writing about disability history. Early disability activists and demonstrators, such as the polio survivors demonstrating against the Works Progress Administration in New York City during the mid and late 1930s because they were denied relief work, had not adopted the kind of inclusive disability identity that is currently emerging in the disability community. They did not, for example, have the vision to include people using wheelchairs in their organization and their cause. (9)

People with significant differences in physical, sensory, and mental functions can be found throughout history, but the idea of "a person with a disability" has only recently taken on its current layers of meaning. The postmodern condition with its civil rights legacy and advanced technology has made it possible for increasing numbers of people to regard their disability as the basis for a self defining, chosen identity. In everyday life able bodied people are still seen as the essential definition of being human, providing the only acceptable norm for how to move, communicate, live. The theoretical foundation for a postmodern disability identity is a decentering of these norms and values, an acknowledgment that moving, communicating, living, can be accomplished in a number of different ways.

Disability activists need an academic community that will begin the work of "unearthing" disability history so they can better understand the cultural forces that shape and maintain the barriers they have to struggle with in their efforts to improve community accessibility. (10) Compliance with such legislative measures as the Americans with Disability Act, a comprehensive public law providing civil rights protection for Americans with disabilities, will only be accomplished through hard work coupled with historically and culturally informed decisions. Oral history interviews with disabled community members could also help build a positive sense of an inclusive disability community where the idea that disability is stigmatizing is rejected by the whole group. Disability history could help people with different disabilities accept each other across medical categories, work together to break down barriers, and affirm a shared sense of human value and dignity.

End Notes

1. Some notable exceptions are historians Paul K. Longmore, John S. Schuchman, and David Gerber. See for example, Paul K. Longmore, "Uncovering the Hidden History of People with Disabilities," Reviews in American History 15 (September 1988): 355-64, John S. Schuchman, "Silent Movies and the Deaf Community," Journal of Popular Culture 17 (Spring 1984): 58-78, and David Gerber, "Anger and Affability: The Rise and Representation of a Repertory of Self-Presentation Skills in a World War II Disabled Veteran," Journal of

Social History 27 (Fall, 1993): 5-28.

2. For a discussion of the medical model, see Gerben DeJong, "Defining and Implementing the Independent Living Concept," in Independent Living for Physically Disabled People, ed. Nancy M. Crewe and Irving K. Zola (San Francisco: Jossey-Bass Publishers, 1987), 15-18. The idea of the "sick role" was first developed by Talcott Parsons in The Social System (Glencoe: The Free Press, 1951).

3. Harlan Hahn, "Civil Rights for Disabled Americans: The Foundation of a Political Agenda," in Images of the Disabled, Disabling Images, ed. Alan Gartner and Tom Joe (New York: Praeger Publishers, 1987), 181-203.

4. Robert Pine (name changed), Interview by Jena Jetmore, February 22, 1993, Kirksville, Missouri.

5. Sylvia Danovitz, "Collective Identity and Power: The Disability Rights Movement," paper presented at the International Conference on Oral History, New York, NY, 1994.

6. Karen Hirsch, "Culture and Disability: The Role of Oral History," Oral History Review, forthcoming.

7. Jacquelyn Dowd Hall, James Leloudis, Robert Korstad, Mary Murphy, Lu Ann Jones, Christopher B. Daly, Like a Family: The Making of a Southern Cotton Mill World (Chapel Hill, North Carolina: The University of North Carolina Press, 1987).

8. The story of how the first Center for Independent Living was started in Berkeley, California, shows the struggle of disabled people to free themselves from the heavy handed control that the medical establishment had over their lives. See, for example, "How IL Got Rolling," and "How It's Spozed To Be," Interviews with Ed Roberts, This Brain Has A Mouth: The National Magazine of People with Brains, (July/August 1992). For other stories about how people with disabilities have had to struggle to free themselves from dominance by others see The Disability Rag, (September 1985), especially Lynn Williamson, as told to Cass Irvin, "Breaking Free," 13-17, and Steven E. Brown, "The Stories of Real Centers, The Walkout," 39-40.

9. Paul Longmore and David Goldberger, "Jobs, Not Tin Cups: New York City's League of the Physically Handicapped and the Definition of Disability Identity," paper presented at the Oral History Association Annual Meeting, Cleveland, OH, 1992.

10. This idea is expressed by Paul Longmore in his article "Uncovering The Hidden History of People with Disabilities," Reviews in American History (September 1987): 355-64.

Deaf Unity and Hearing Dogs: An Outsider's Perspective

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As a guide dog user and co-author of a book dealing with guide dog training programs (Eames and Eames 1994), I am involved in blindness-related issues as both insider and outsider. However, as a blind

anthropologist I have recently become interested in the issue of deaf culture as an outsider. It is my belief that the negative attitudes held by many culturally deaf people toward the partnership between deaf persons and hearing dogs represent some of the cross currents that work against unity within the deaf and hard-of-hearing community. As in most social systems, internal factionalism and fragmentation mitigate against the growth and continuity of the culture. Furthermore such dissension blunts efforts toward a unified disability rights movement.

Among people with physical and sensory disabilities in the United States, the deaf and hard-of-hearing community has the greatest potential for continuing the development of a unique subculture. Blind and physically disabled Americans do not have the building blocks of cultural distinctiveness, such as a unique language and a dedicated university. Despite these potentially unifying forces, the amount of disunity within the deaf and hard-of-hearing community is disturbing.

My goal is not to catalogue the ideological problems and historical process dividing the deaf community, but to focus on the issue of hearing dogs as a potential element of further fragmentation.

The presence of a hearing dog, clearly identified by leash, collar and cape, proclaims to the world that the human partner is deaf or hard-of-hearing. Such identification runs counter to the deep-seated value in the community of being inconspicuous. Those of us who are blind or physically disabled do not have this option. Thus, partnership with a guide or service dog does not set us any further apart than the white cane, wheelchair or crutches.

Hearing Dogs

With less than two decades of recognition through the establishment of the first training program in the United States, these canine assistants perform a variety of alerting or signaling functions for their human partners. Among the sounds alerted to are smoke alarms, telephones, door knocks, baby cries, name calls and other household sounds such as whistling kettles, washing machines, dryers, microwaves, etc. Dogs are trained to alert by making physical contact with the human partner and moving toward the source of the sound.

More than 20 programs currently train dogs to work with deaf and hard-of-hearing individuals. Other hearing dogs are trained by their human partners or by professional dog trainers. Based upon incomplete figures, we would estimate a total population of 2,500 working teams. The vast majority of these canine assistants are partnered with hard-of-hearing rather than congenitally deaf individuals.

Paul Ogden, a culturally deaf Professor of Deaf Education at California State University, Fresno, has written a book about his life with his hearing dog Chelsea (Ogden 1992). In his account, Paul does not deal with the issue of the antipathy toward Chelsea and other hearing dogs by members of the deaf community. However, he has informed me that much of the negativism toward hearing dogs by some deaf people is based

upon the view that, to them, the dog symbolizes dependence and helplessness rather than independence and self-sufficiency. Several other hard-of-hearing informants partnered with hearing dogs have made similar observations. It is worth noting that similar views are still heard about guide dogs in the blind community.

A Peculiar Case of Access Denial

In January 1991 when Randy Moering arrived at Gallaudet University with his hearing dog Kim, they found a community that was not very receptive to the presence of a hearing dog. Despite a deaf president and a shift in power toward a deaf administration, the team found itself excluded from many parts of the campus. Because of Kim, Randy was denied access to a dormitory room and denied help in securing off-campus housing. When Randy appealed to fellow deaf students, he was appalled by their lack of support of his right to have Kim with him. They were no better informed than the general public about the assistive functions performed by hearing dogs.

Matters came to a head when members of the administration asked the college security force to deny the team access to the student activities center. After being shown a copy of the Washington, D.C., law by Randy, security personnel refused to deny him entry to the building.

Disgusted with these attempts to deny his rights, Randy filed a complaint against the university with the Washington, D.C., office of civil rights. Under threat of legal action and adverse publicity, university officials changed their position and agreed to remove their opposition to Kim's presence on campus.

What's the Problem?

How can we explain the negative value placed on hearing dogs displayed by the power elite and a majority of the student body at Gallaudet? As an outsider I believe the anti-hearing dog position is based on the nature of deafness as an invisible disability and the desire of many members of the community to appear nondisabled. Thus, walking along with a dog wearing a cape proclaiming his/her status as hearing dog proclaims the disability status of the human partner.

It is worth noting that the same assertion can be made about sign language, the heart of deaf culture and deaf pride. Even today many parents of deaf children insist on raising them as oralists or speech readers, rather than as signers. These parents want their children to be as "normal" as possible and not draw attention to themselves. Frequently when these youngsters discover sign language and deaf culture they resent the early isolation imposed on them by their parents. Many members of the culturally deaf community see these efforts by parents of deaf children as destructive of the deaf culture movement. Yet it is many of these same critics of parents denying deaf culture access to their children who oppose their peers opting for partnership with hearing dogs. The dissonance between these two positions is rarely recognized.

I believe that hearing dogs, like sign language, can become a source of deaf pride if

the pervasive striving for "normality" can be set aside. Independence has been a central theme in the disability rights movement and hearing dogs provide greater independence for those deaf and hard-of-hearing individuals choosing this option. When these canine assistants are accepted as symbolic representations of independence by the deaf community rather than stigmatizing objects, they can serve as a source of pride and solidarity rather than divisiveness and derision.

If we can move in this direction, then we can look forward to a time when the figure of hearing dogs would be expanded way beyond the current estimate of 2,500.

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An Innovative Rehabilitation Facility: The Creative Art Center for People with Disabilities

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Over the past 25 years, there has emerged an innovative rehabilitation facility, the art center for people with disabilities, which taps a long-neglected yet essential aspect of human functioning: *creative self expression*. Such centers not only offer an alternative for people with disabilities who do not fit into existing facilities and programs, but some may be the program of choice to meet their needs (Katz 1993).

An art center for people with disabilities may be defined as "a full-time supportive and stimulating environment without pressure, threat or competitiveness in which creative work in painting, sculpture, printmaking, creative crafts, etc., is carried on in a studio setting by people with mental, physical or social disabilities" (Ludins-Katz & Katz, 1990a, p. 14).

At the present time there are at least 26 art centers for people with disabilities, including two in Canada. Fifteen centers are located in California (Katz, 1991b). Many groups in the United States and other countries are developing art centers for people with disabilities.

There are differences among these art centers. Some include only visual arts - painting, sculpture, printmaking, crafts, while others provide music, dance, and theater arts experiences as well. Some serve as many as 100 artists with disabilities daily, while others limit themselves to no more than 20 or 25 persons at any one time. Some centers maintain an "open studio" space while others prefer smaller classrooms with specialized instructional areas. Some are free-standing, independent agencies, others are components of larger organizations. Despite these differences there are many commonalities.

Each art center provides an environment in which creative self-expression in the arts by persons with disabilities is encouraged and supported. Participants enjoy working in this environment. They often create works of art prized by art critics and collectors (MacGregor, 1992). Their art is appreciated and purchased. They receive part or all of the payment for their art. Individuals who engage in these art centers derive great satisfaction from showing their work to others. They grow in self-esteem. Those around them often begin to see them in a different light: as productive, creative, expressive people, rather than unproductive, lacking creativity, and unable to communicate inner feelings or thoughts (Ludins-Katz & Katz, 1987; 1990a, p. 14).

The staff that facilitates the creative expression is composed of practicing artists who are sensitive to the creativity in themselves and in the individuals they work with. They must not only be creative people themselves, but they must be able to bring out the creativity that lies dormant in the participants. They subscribe to the concept that "creative self-expression in the arts is the outward expression in an art form of what one feels internally. . . . Creativity lies within the individual and must be expressed for well-being and growth" (Ludins-Katz & Katz, 1990a, p. 3). As caring, dedicated persons, NIAD artist-teachers are essential components of the art center's psychological environment.

To illustrate the operation of an art center for people with disabilities, we describe a typical work day of George, an artist in the National Institute of Art and Disabilities (NIAD) (1), a visual arts center for people with disabilities.

George (2) "uses public transportation and has learned to make two changes from his home to the studio. He arrives at 9:30 am and signs in. He writes unintelligibly, but the staff has learned to recognize his signature. He hangs up his coat, puts his lunch box away, and puts on his smock.

"The art teachers have been there for an hour and have prepared art supplies, consisting of tempera paints, water colors, colored pens, sculpture and printing materials. These are placed on different tables around the room. Papers of all sizes and colors are stored in easily accessible open cabinets.

"The work George does is determined by his own desire. He may be stimulated by the materials he sees in front of him or by images he saw on the way to the studio or by a dream or a vision. He may have an idea for new work or he may be continuing an unfinished one. He makes his own decision as to where he wishes to work. There is no seat assigned to him. This morning he chooses to work on an unfinished painting.

"He cannot immediately find his picture. An art teacher helps him go through a small stack of unfinished work. He picks out his painting, looks around the room and sees a friend next to whom he would like to work. He goes to the table and places his paper on it. He walks around the room, finds the colors and brushes he

needs, and places them on the table in front of him. He is now ready for work.

"George works intently, stopping in mid-morning for a juice break. The teachers occasionally stop to talk with him. They offer suggestions but do not demand that he comply with them. George will make his own decision as to whether he wishes to carry out their suggestions or if he wishes to proceed in his own way. A little before lunch, he is finished with his painting. He asks a teacher to look at it and discuss it with him. The teacher makes suggestions and George decides to make some minor changes. When he is finished to his own satisfaction, he places the painting on the drying rack. Since he cannot write, the teacher helps him sign his name and the date.

"He decides to go to the clay table. He places clay on a bat and now it is the beginning of the lunch hour. He takes his lunch box and goes to the area where the other artists are gathering for lunch. Coffee and juice are available. He brings only a skimpy sandwich. A staff member makes a mental note of his lunch and will bring it up later during a staff case discussion of George and his work.

"George finishes his lunch in 15 minutes and decides to look at art books and art magazines. Since he does not have a clean-up assignment on this day, when the other artists are finished with lunch he goes to the nearby park and plays kick ball with them and some staff members until the end of the lunch hour.

"He returns to the clay table and starts modeling a head. He has trouble adhering the nose to the form he has built. He approaches a teacher and points out his problem. The teacher gets a piece of moist clay and shows him how to score and use slip to make connections. George practices this and when he has mastered the technique under the teachers guidance he returns to his sculpture and applies the knowledge he has gained. He is dissatisfied with the first results and starts again. The teacher comes by a little later to see how he is doing and shows him how to improve his technique.

"A volunteer becomes interested in what George is doing. She takes a piece of moist clay and sits next to him. They share their discoveries.

"A teacher walks by, stops to speak to George, who proudly displays what he has learned. He continues working on the head. A few minutes before 3:30 pm it is clean-up time. George puts wet cloths on the herd and places it where the unfinished clay work is kept. Tomorrow he will be able to continue. He cleans the table where he has worked and puts away his tools. He hangs up his smock, says good-bye and leaves for the day.

"This picture of George shows a self-sufficient, interested person able to care for himself, to make decisions, to travel independently. He is able to ask for and take assistance and criticism in an appropriate manner and is completely involved in his work. He is able to work independently as an artist.

"This was not always the case. When he first came to the center after many years of institutionalization he could not travel independently. He could not pronounce his name distinctly. Unless he was explicitly told where to go and what to do, he stood in a corner and rocked. Although he still has many areas of difficulty, he is now a happy, dependable man and a promising artist. What caused this great change?

"Although he is a man with great talents in many different fields of the visual arts, his talent did not show immediately. His first paintings were childish and without imagination, like the drawings in a coloring book. Very likely he had spent many hours coloring pictures while in the institution. His subject matter was pumpkins, four-leaf clovers, Mickey Mouse and Bugs Bunny drawings. Gradually the work changed. Hills, mountains, buildings seen en route to the center and people he knew began to appear in his pictures. Less time was spent rocking in the corners and more time absorbed in his work. He no longer had to be told where to go and what to do.

"In his work, new developments started. He began to model with clay - at the beginning a primitive head, followed by astounding portraits of people in the center. He discovered black and white drawing and spent much time designing pages for calendars and publications. An artist came to demonstrate weaving. George took to this immediately. He designed a hanging rug and was able to complete it with meticulous craftsmanship. It was sold, and he received 50% of the sale price.

"During this period of development he began to talk, very hesitantly and slowly, not always correctly, but he was able to make himself understood. Rocking almost totally disappeared since there was no longer any time or need for it.

"The staff, after much discussion and concern, decided he could be trained to travel to the studio by himself. He was encouraged to paint pictures of the restaurant where he would have to get off the bus, to draw the bus with its correct number, to draw the time on the clock when he had to leave home in the morning. Despite misgivings and mistakes, he finally learned. Now he travels by public transportation not only to the studio, but to many other places.

"What has happened to George is not unique. Many students go through a similar growth process and become capable artists and are recognized as such. Through creative experiences in art they learn to care for themselves, to travel, to speak more fluently, to become proud of their accomplishments. Their behavior reflects these changes. They earn money from the sale of their art work. They are contributing members of society and society is enriched by their efforts" (Ludins-Katz & Katz, 1990a, pp. 25-27).

The above typical day of the artist in the NIAD visual arts center would be incomplete without a description of the exhibitions program. Once the artist has completed a work it is treated with respect and

care. In the studio, many works are on display including paintings, prints, ceramics, and crafts. One large wall is devoted to showing at least one example of current work of each artist. This is a favorite place for the artists to show their work to visitors. After each work is completed it is signed by the artist, dated, and placed in the artist's portfolio. In this way it is possible to go through a portfolio and see the changes which take place over time. Many works are created of high artistic quality, worthy of being hung in galleries and art museums. Indeed, their power, freshness, and vitality have been recognized by the National Endowment for the Arts (Katz, 1991), state arts councils, and art critics. With the growing interest in "outsider art," "naive artists," "art brut," and "folk art" many of the artists in art centers for people with disabilities have achieved greater visibility in the art world and their works are sought and purchased by many collectors.

An important function of the center is to show the art work as widely as possible. In some centers, an art gallery is on the premises. Here the work of "professional" artists is hung side by side with the art of artists with disabilities. In other instances, the art is exhibited and sold in shopping centers, department stores, restaurants, government buildings, and universities. One center has developed a program for selling art work to corporations as a part of their decor. The key to success in exhibitions and sales lies in the professional approach provided by trained and experienced staff.

Summary

There is a growing interest in improving the quality of life through creative experiences in the arts for people with disabilities (Clements, 1994; Cook, 1992; Edelson, 1991; Katz, 1993; Ludins-Katz & Katz, 1987; Ludins-Katz & Katz, 1990; Peterson & Foley, 1992; Rodriguez, 1984). The art center for people with disabilities is a recently developed innovative rehabilitation facility providing an environment which promotes freedom to create. This environment enhances the self-image of the participant as a productive person, since each person can achieve success at whatever their level of functioning. This facility offers an alternative for many persons with disabilities who do not fit in existing vocational and employment-oriented programs, and for some the opportunity to express oneself creatively in the arts may be a program of choice.

1. NIAD was founded in 1984 by Florence Ludins-Katz, M.A. (1912-1990), an artist and art educator, and Elias Katz, Ph.D., a clinical/community psychologist. They had previously founded and co-directed three art centers for people with disabilities and had consulted with many groups interested in establishing similar centers (Allen & Allen, 1988).

2. "George" is a composite of several NIAD artists.

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Bibliography

A Celebration of Diversity: An Introductory, Annotated Bibliography About Disability Culture

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The idea of celebrating disability, a condition historically viewed from tragedy to deviance to incompetence, remains mostly unbelievable to a society guided by precepts of medical practice which convey the belief that the only positive solution to disability is repair or cure. The most popular current-day view of disability is molded by what many disabled people consider the scourge of the late twentieth century - telethons.

Telethons have generated great controversy for the past decade or so. Entertainer Jerry Lewis has become one focal point of this conflict. Several years ago Lewis spent some time in a wheelchair to see what it was like. He wrote about his experiences in Parade. His comments were so disparaging that two advocates with Muscular Dystrophy formed a group called "Jerry's Orphans" to sponsor annual Labor Day demonstrations to protest Lewis' demeaning approach to disability.

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

"Four major telethons - Easter Seals, the Arthritis Foundation, United Cerebral Palsy, and the M.D.A. - are the single most powerful cultural mechanism defining the public identities of people with disabilities in our society today, mainly because they reach so many people. The telethon sponsors claim that, collectively, they have a combined audience of 250 million people. That's the equivalent of the population of this country. The message of telethons is that whatever condition people with disabilities have, that condition has essentially spoiled their lives, and the only way to correct that is to cure them. The message of the disability-rights movement is that it's possible to be a whole person with a disability." (Bennets, 1993, 92)

The final two sentences of Longmore's analysis form a precise description of the models of charity and celebration of disability that have emerged in the late twentieth century. Several scholars have endeavored to explore these models through the development of paradigm charts, such as my own "The Chart: Disability Rights/Culture/Pride Paradigm."

Perhaps the simplest way to describe disability culture is to exclaim pride in the condition of disability. Dianne B. Piastro is a middle-aged woman with a disability. She was once a nondisabled adult. Her experiences in becoming disabled from Multiple Sclerosis created a desire to write. Since the mid-1980's Piastro has published a syndicated newspaper column called "Living with a Disability." In a July 18, 1993,

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

Some of those individuals who have recognized value in the experience of disability have been posing questions about the culture of disability for much of the past decade. The first recorded work exploring this issue occurred at the 1984 Conference of the Association on Handicapped Student Service Programs in Post-Secondary Education (AHSSPPE, recently changed to Association on Higher Education and Disability or AHEAD). The presenters, David Pfeiffer of Suffolk University and Andrea Schein of the University of Massachusetts-Boston, each asked "Is There a Culture of Disability?" Their affirmative responses were published in the Association's Proceedings.

In the decade since Pfeiffer and Schein first posed the question about the existence of a disability culture, answers began slowly, then escalated. For most of the 1980s the question was rarely pondered. When it was raised it most often came in the form of tentative queries or explorations in little-known disability-oriented magazines or in thundering nos from the halls of academia.

The discussion about a culture of disability has changed considerably in the 1990s. A plethora of activity has emerged in literature, art, history, music, movies, and other arenas. Two national bodies have recently recognized disability culture activities for the first time. The National Institute on Disability and Rehabilitation Research (NIDRR) funded my 1993-1994 fellowship proposal to conduct research about disability culture. The National Endowment for the Arts recognized another leading proponent of the culture, Cheryl Marie Wade, with an Arts Solo Theatre Artist's Fellowship in 1994.

As the number artists, writers, scholars, and advocates of disability culture grow, so too does the need for an exploration of what is already available. The mushrooming examples seem endless.

The field of disability writing is not an easy one to assess or to access. Books about the subject of disability, and disability culture, are to be found in diverse sections of libraries and bookstores. In the past year, I have taken to wandering into new bookstores and inquiring about a disability section. A few have such a beast, but what one finds in it ranges from self-help books to autobiographies to disability-specific stories to a conglomeration of other topics. Any of these subjects might be found in other sections as well.

To further complicate matters, some of the best information about disability and disability culture is found in neither books nor journals, but in newsletters, brochures, fliers, and other kinds of media that are difficult to locate in any systemic way. The result of this miscellany of materials has been an attempt on my part to read, view, hear, and locate all I could. But in this process, I

have overlooked journal articles, missed books, and certainly missed much of what is out there to be found about disability culture. This would apply to movies, music, and media as well.

The most complete bibliography published thus far is in my manuscript resulting from the NIDRR fellowship, Investigating a Culture of Disability: Final Report. It includes a total of more than 250 citations, including 65 books, 24 anthology articles, 99 magazine and journal articles, 20 newspaper and newsletter articles, 11 unpublished manuscripts, 50 films, 5 musical entries, and 8 cultural artifacts, including comics, calendars, and a poster. Yet, this too is only a selected bibliography highlighting the most important of the present 737 citations entered into twenty-one computer database categories of "Books: Non-Fiction," "Books: Fiction," "Fiction: Short Stories," "Books: Photography," "Books: Poetry," "Poetry: Tapes," "Poems," "Books: For Children," "Articles from Anthologies," "Journal, Magazine and Newspaper Articles: Non-Fiction," "Newspapers, Newsletters," "Monographs," "Unpublished Works," "Letters," "Films," "Videos," "Radio," "Music: Tapes," "Music: Songs," "Comics," and "Cultural Artifacts: Calendars, Catalog, and Posters," as of this writing.

The annotated, disability culture bibliography which follows is an introductory, idiosyncratic effort reflecting my own personal tastes, biases, and knowledge.

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Berkowitz, Edward D., Disabled Policy: America's Programs for the Handicapped (Cambridge: Cambridge University Press, 1987). A look at the beginnings of twentieth-century disability programs. The author argues there is in reality no policy, which has been costly for America and Americans with disabilities. The history of Worker's Compensation and Social Security is explored in detail.

Bowe, Frank, Changing the Rules (Silver Spring, MD: TJ Publishers, 1986). An autobiographical examination of the early years of one of the United States' most influential policy advocates with a disability, particularly riveting in discussing Bowe's pre-adolescent years coping with deafness. See also, Handicapping America: Barriers to Disabled People (New York: Harper & Row, 1978), an exploration of how society handicaps its members with disabilities, and Rehabilitating America: Toward Independence for Disabled and Elderly People (New York: Harper & Row, 1980), with an emphasis on the economics of disability.

Brown, Christy, My Left

Foot (Martin, Secker & Warburg, Ltd., 1954). An Irish autobiography which is effective and moving in describing growing up with a non-verbal disability and the connections, and lack thereof, made in Brown's life.

Brown, Steven E., Independent Living: Theory and Practice (Las Cruces, NM: Institute on Disability Culture, 2260 Sunrise Point Rd., 1994). An exploration of the theoretical constructs and daily work of independent living programs. See also, Investigating a Culture of Disability: Final Report (Las Cruces, NM: Institute on Disability Culture, 1994), containing a brief description of Americans' perceptions about disability and the first in-depth exploration of a cross-disability culture of disability.

Brown, Susan T., ed., An Independent Living Approach to Disability Policy Studies (Oakland, CA: World Institute on Disability, 1993). A compilation of essays looking at the new field of disability policy studies many first delivered at the Society for Disability Studies annual conference in 1993 with an introduction by Irving Kenneth Zola and a bibliography by David Pfeiffer.

Browne, Susan E., Debra Connors, Nanci Stern, eds., With the Power of Each Breath (Pittsburgh and San Francisco: Cleis Press, 1985). A powerful anthology depicting women's views about life, disability, anger, activism, belonging, and many other topics.

Bullard, David G. and Susan E. Knight, eds., Sexuality and Physical Disability: Personal Perspectives (St. Louis, C.V. Mosby, 1981). Personal stories about sexuality and disability; a topic still rarely addressed in depth fifteen years later.

Callahan, John, Don't Worry, He Won't Get Far on Foot: The Autobiography of a Dangerous Man (New York: Vintage, 1989). A life story about the dissatisfactions and satisfactions of life before and after alcoholism and disability which comes across to many as strikingly realistic and naturally includes many wonderful cartoons. Also available in chronological order and all published by the New York firm of William Morrow are the following compilations of Callahan's cutting-edge cartoons: Do Not Disturb Any Further (1990), Digesting the Child Within (1991), Do What He Says! He's Crazy (1992), The Night They Say, Was Made for Love plus My Sexual Scrapbook (1993), What Kind of God Would Allow a Thing Like This to Happen?!! (1994), and, most recently, a fairy tale, The King of Things and the Cranberry Clown (1994), which is not about disability--or is it?

During, Simon, ed., The Cultural Studies Reader (London: Routledge, 1993). Although disability almost never appears in this anthology of twenty-nine articles about cultural studies, the discussion of culture and cultural studies in the "Introduction" and the content of many of the articles offers a good grounding in why many individuals and groups so easily identify with a culture of disability as well as why others might not.

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Finger, Anne, Past Due: A Story of Disability, Pregnancy, and Birth (Seattle: Seal, 1990). A compelling writer recounting her discovery of her pregnancy, how it impacted her perception of herself as a woman with a disability, and then discovering anew life as the mother of a child with a disability.

Gallagher, Hugh Gregory, By Trust Betrayed: Patients, Physicians and the License to Kill in the Third Reich (New York: Henry Holt, 1990). The story of the Holocaust commencing with the genocide of people with disabilities is terrifying enough, but what sticks with me is the post-Nazi era (that is, *now*) of former Nazi physicians, among others, continuing to promote the theoretical foundations that led to that genocide and the pervasive, ongoing practice of "mercy-killing" of people with disabilities around the world. See also, FDR's Splendid Deception (New York: Dodd, Mead, 1985), the first work to examine seriously FDR's disability and the impact it had on his life. Historians and other scholars who acknowledge Gallagher's contribution to understanding FDR still tend to skip over the effect of his disability, seeing it as a hurdle he overcame or a path to identification with the "common American," despite a multitude of evidence that his post-polio disabilities were far more complex and significant.

Hevey, David, The Creatures Time Forgot: Photography and Disability Imagery (London: Routledge, 1992). An outstanding achievement and the best work describing the telethon mentality and its deleterious effects on disabled people. Expensive, because of the photographs, but well worth it.

Ingstad, Benedicte and Susan Reynolds Whyte, eds., Disability and Culture (Berkeley: University of Berkeley, 1995). Fourteen essays by twelve authors, all anthropologists, including five essays by the editors, discuss perceptions about disability in primarily non-Western cultures. This is one of the best books around depicting disability with an international perspective, but it also is problematical because of its lack of inclusion of many authors with disabilities or from the cultures discussed. A more in-depth critique of the work is forthcoming in Disability and Rehabilitation.

Kingsley, Jason and Mitchell Levitz, Count Us In: Growing Up with Down Syndrome (San Diego: Harvest, 1994). The disability rights movement has been criticized at times for being too focused on people with physical impairments. But at the very least, it has enabled others to enjoy the fruits of its labors. Two young adults with Down Syndrome have published a wonderful, honest,

and funny book based on several years of conversations, primarily with their parents.

Milam, Lorenzo Wilson, Crip Zen: A Manual for Survival (San Diego, CA: Mho & Mho Works, 1993). Milam's inimitable style is brought to play discussing and rendering advice about wide range of topics concerning living with a disability from travel to drugs to literature to sex. See also, The Cripple Liberation Front Marching Band Blues (San Diego, CA: Mho & Mho Works, 1984), an autobiographical exploration of being at Warm Springs Rehabilitation Center post-FDR and learning about life, love, disability, sexuality, and passion. A hard read for many - Milam does not mince words - but worth the effort.

Miller, Vassar, ed., Despite This Flesh: The Disabled in Stories and Poems (Austin: University of Texas Press, 1985). An uneven, but interesting, compilation of short stories, poetry, and essays.

Moore, Frank, Art of a Shaman (Available from inter-relations: PO Box 11445, Berkeley, CA 94712, 1991). Frank Moore is a Berkeley performance artist who is a mostly unsung treasure of the disability arts and culture movement. Although his proclivity for nudity in performances and videos will repel some, his compilation of a fairly recent lecture, the Art of a Shaman is the only American work I know of that approaches Hevey's sophistication of exploration of complex issues.

Murphy, Robert, The Body Silent (New York: Henry Holt, 1987). Murphy's status as a respected anthropologist and a person living with, and then dying from, an acquired disability combined to make him an authority about disabling conditions. Unfortunately, he sometimes tends to be presented as *the* authority. Most disturbing is the assumption that what Murphy had to say in the late 1980s would stand unchanged in the mid-1990s. Murphy's own description of the liminal status of disability might just as aptly apply to his own work - standing at the crossroads between perceptions of disability as a negative condition making it difficult to function in society and today's refined idea of disability as a natural process of life which is not only *not* completely negative, but has characteristics non-disabled society could benefit from emulating.

Nagler, Mark, ed., Perspectives on Disability, 2nd ed. Palo Alto, CA: Health Markets Research, 1993). This second edition of Perspectives on Disability is an excellent compilation of fifty-three articles many reprinted from other sources, discussing identity, society, family, sexuality, medicine, education, and legal issues among others.

Panzarino, Connie, The Me in the Mirror (Seattle: Seal, 1994). Very interesting autobiography about growing up with a disability prior to the advent of the disability rights movement, being a part of that movement's beginnings, and how it transformed the author's life.

Scotch, Richard K., From Good Will to Civil Rights: Transforming Federal Disability Policy (Philadelphia: Temple,

1984). A detailed examination of the protests and demonstrations leading to the promulgation of 504 regulations.

Shapiro, Joseph P., No Pity: People with Disabilities Forging a New Civil Rights Movement (New York: Times Books, 1993). A journalist's account of the development of the disability rights movement: the personal stories are the strongest aspects of the work, the analysis of how disability rights fits into and compares with the patterns of other movements are the weakest portions.

Shaw, Barrett, ed. The Ragged Edge: The Disability Experience from the Pages of the First Fifteen Years of the Disability Rag (Louisville: Advocado, 1994). Much of the discussion about disability culture in the 1980s occurred in the pages of the Rag. This is a compilation of forty-seven articles and poems some of which specifically address a culture of disability; many others describe the culture itself in discussions including sexuality, suicide, and community.

Shilts, Randy, And the Band Played On: Politics, People, and the AIDS Epidemic (New York: St. Martin's Press, 1987). The late author's book reads like a detective novel integrating the search for what caused the AIDS virus, how it spread, and how it might be cured, with the machinations of public policy and professional rivalries across the world. But the focus remains on those impacted by AIDS and their place in a brand-new world, one in which HIV becomes first deadly, then disabling.

Snow, Judith A., What's Really Worth Doing and How to Do It: A Book for People Who Love Someone Labeled Disabled (Toronto: Inclusion, 1994). As a young child, Snow dreamed of being a truck-driver, an unrealistic goal considering her disability. But the fantasy, it turns out, was not so much about driving a truck as being mobile and, as she discusses how she has traveled all over the world, she offers tips for others to be able to follow their dreams.

Wade, Cheryl Marie, ed., Range of Motion: An Anthology of Disability Poetry, Prose and Art (Albany, CA: Minuteman, a KIDS Project/Squeaky Wheels Press, Box 448, Berkeley, CA 94701-0448, 1993). Wade is a performance artist who has become one of the most well-known of the recent crop of disability culture advocates. She has edited several anthologies. The most recent is chock full of poignant writing. It introduced me to Frank Moore and many other artists.

Zola, Irving Kenneth, Missing Pieces: A Chronicle of Living with a Disability (Philadelphia: Temple, 1982). This spellbinding account of time spent in Het Dorp, a housing cooperative in the Netherlands, is Zola's coming out as an activist with a disability and a member of the community of people with disabilities. See also, ed., Ordinary Lives: Voices of Disability and Disease (Cambridge: Apple-wood, 1982), an early compilation of fact and fiction.

Books: Fiction

Dunn, Katherine, Geek Love (New York: Warner, 1989). The

life of a circus family, whose mother has ingested all kinds of drugs and done whatever she could to give birth to "freaks" who will keep people coming to the bigtop. Very graphic and at times difficult to read, but realistic in looking at how what we would today call people with disabilities could find community in this setting.

Finger, Anne, Bone Truth (Minneapolis: Coffee House Press, 1994). The main character is an artist with a disability who is becoming reconciled to her past, a radical family with an abusive father, and her present as a woman with a younger lover who has just discovered her pregnancy.

Gilman, Charlotte Perkins, The Yellow Wallpaper (New York: Feminist Press at City University of New York, 1973). A nineteenth century short story that brings the reader into a world of mental unbalance and oppression of women.

Groom, Winston, Forrest Gump (New York: Pocketbooks, 1994, 1st published 1986). Quite different than the Oscar-winning movie, the novel is rougher, Forrest is not as smart, as smooth, as naive, or quite as lucky in love.

Heinlein, Robert, Waldo & Magic, Inc. (New York: Del Rey, 1986, 1st copyrighted, 1940, 1942, 1950). This science fiction writer, who had a disability, wrote Waldo, a novella, about a character with Myasthenia Gravis who lives in space to become nondisabled when freed from gravity.

Shelley, Mary, Franken-stein, or the Modern Prometheus (First published 1818). The "monster" battles isolation, searches for companionship and community. Is he a person with a disability?

Stewart, Jean, The Body's Memory (New York: St. Martin's Press, 1989). The first novel that captures the spirit and reality of the disability rights movement as a young woman comes to terms with cancer and its aftermath.

Trumbo, Dalton, Johnny Got His Gun (New York: Bantam, 1967). An anti-war novel about a man who, after his wounds in battle, can move only his eyes.

Books: Photography

Gans, Lydia, To Live with Grace and Dignity (Horsham, PA: LRP Publications, 1994). A look at people who use personal assistance services in the Berkeley area. Photographs are accompanied by essays about both the person with the disability and their assistants.

Hekking, Angelina M. A., Seeds of Light: Images of Healing, Self-Portraits (San Francisco, Angel, 1990). A woman with Multiple Sclerosis takes us on a journey exploring her disability through photography and diary entries.

Books: Poetry

Brown, Steven E. Pain, Plain - and Fancy Rappings: Poetry from the Disability Culture (Las Cruces, NM: Institute on Disability Culture, 1995). Autobiographical and imaginative poems looking at living with pain, participating in disability rights activism, and celebrating the culture of disability.

Dykes, Disability, & Stuff,

"The Poetry Special," (Boston: Women's Educational Fund, 1994). Dykes, Disability, & Stuff is a little-known newsletter specifically geared to lesbians with disabilities. This is an audiotape compilation of some poems previously printed in the newsletter.

Hershey, Laura, Dreams of a Different Woman: New Poems by Laura Hershey (Denver: Dragonfly, PO Box 9004, 1994). Poems about being a woman, being disabled, and life. See also, On the Lawn: Nairobi Women's Conference Poems (Denver: Dragonfly, 1994) and In the Way, ADAPT Poems (Denver: Dragonfly, nd). Also available on tape.

Williams, Robert, In a Struggling Voice: The Selected Poems of Robert Williams (Washington, D.C.: United Cerebral Palsy Associations, Inc., 1522 K St., Suite 1112, Washington, D.C. 20005, 1989). Currently Commissioner of the Administration on Developmental Disabilities of the U.S. Department of Health and Human Services, Bob has compiled a book of his poetry about life and disability.

Articles: Journals and Magazines

Backman, Eric, "Amazing Grace," Mainstream: Magazine of the Able-Disabled, 18, (10), (Aug. 1994), 40-43. Story about Grace Lin, artist, dancer, and current coordinator of the World Institute on Disability's quarterly art shows.

Bennets, Leslie, "Letter from Las Vegas," Vanity Fair, (Sept. 1993), 82, 84, 86, 90, 92, 94, 96, 98. Discussion of the Muscular Dystrophy telethon. See narrative for more detail.

Brown, Steven E., "Creating a Disability Mythology," International Journal of Rehabilitation Research, 15, (Winter 1992), 227-33. A look at creating a positive mythology about disability which begins with an exploration of people with disabilities as heroes. See also, "I Was Born (in a Hospital Bed) - When I Was Thirty-One Years Old," Disability and Society, 10, (1), (1995), 103-110, an awakening to a positive life as a person with a disability, "The Walkout," Disability Rag, 6, (9), (September 1985) 39-40, a description of putting our jobs on the line over the issue of people with disabilities running our own organizations, and "The Chart: Disability Rights/Culture/Pride Paradigm," (Las Cruces, NM: Institute on Disability Culture, 1995).

Epstein, Susie, "Am I Crip Enough Yet?" Mainstream: Magazine of the Able-Disabled, 19 (8) (May 1995), 15-19. An excellent article discussing what makes someone disabled, both in their own perceptions and from those of outsiders.

Gill, Carol J., "Continuum Retort - Part II," Disability Rag & ReSource, 15, (2), (March/April 1994), 3-7. The most consistent voice promoting the concept of a culture of disability from the mid-1980s onward, Gill discusses the need to recognize a separate disability identity. See also, "Disability and the Family," Mainstream: Magazine of the Able-Disabled, 18, (5), (Feb. 1994), 30-35, "Dual Citizenship & Conditional Acceptance," Disability Rag, 13, (3), (May/June 1992), 12-13, "What the Doctors Didn't Want to

Know," Disability Rag, 13, (3), (May/June 1992), 11-13, and "When is a Woman Not a Woman?" Disability Rag, 13, (3), (May/June 1992), 26-27, all of which explore the themes of people with disabilities interacting in a society geared to non-disabled people.

Golfus, Billy, "The Do-Gooder," Disability Rag, 11, (4), (July/Aug 1990), 14-18, 19. Before the video "When Billy Broke His Head..." were articles including this indictment of the helping professional and the helping professions. See also, "The Trouble with Do-Gooders," Mouth, V, (3), (Sept/Oct 1994), 6-10.

Groch, Sharon A., "Oppositional Consciousness: Its Manifestation and Development, The Case of People with Disabilities," Sociological Inquiry, 64, (4), (November 1994), 369-95. A discussion of the development of disability consciousness from the viewpoint of opposing typical societal institutions.

Gwin, Lucy, "The Myth of Rescue," Mouth, V, (3), (Sept/Oct 1994), 4-5. The Mouth editor wondering why people with disabilities are waiting for others to make our lives better when that is not the historical pattern we have encountered. See also, "Facing the Dragon," Mouth, V, (5) (Jan-Feb 1995), 10-11, and "Who we are not," New Mobility: Disability Lifestyle, Culture & Resources, 5, (18), (Nov-Dec 1994), 32-34.

Hahn, Harlan, "The Los Angeles Uprisings of 1992: A Disability Perspective," Disability Studies Quarterly, 13, (1), (Winter 1993), 80-84. A fascinating approach to combining a disability perspective with a glimpse at urban revolts in general and this one in particular.

Hershey, Laura, "Pride," Disability Rag, 12, (4), (July/Aug 1991), 1, 4-5. A look at why there is a need to develop and maintain a disability pride and how difficult it can be at times.

Hirsch, Karen, "Studying Culture," Disability Rag, 8, (3), (May/June 1987), 38-39. An early editorial discussing the need for recognizing and studying a culture of disability.

Hooper, Ed, "A Question of Cure," Disability Rag, 9, (1), (Jan/Feb 1989), 18-21. If a cure were offered, would a person with a disability take it? This question, often perceived as the cornerstone of one's pride, was posed by one of the first writers to discuss community. See also, "Seeking the Disabled Community," Disability Rag, 6, (8), (Aug 1985), 1, 4-6, 8.

Johnson, Mary, "Emotion and Pride," Disability Rag, 8, (1), (Jan/Feb 1987), 1, 4-10. This *is* the big one for many! A plea to recognize and develop pride in a community of people with disabilities. Carol Gill is quoted liberally throughout about how we must reconcile ourselves emotionally to disability and celebrate ourselves as people with disabilities.

Kaltenheuser, Skip, "Hugh Gallagher: ADA's Hidden Architect," New Mobility: Disability Lifestyle, Culture & Resources, 6,(23) July-Aug. 1995, 40-43. A look at Gallagher's role as writer, historian, and policy maker who paved the way for the Architec-

tural Barriers Act of 1968.

Lathrop, Douglas, "Johnny's Song," Mainstream: Magazine of the Able-Disabled, 17, (8), (May 1993), 12-18. A discussion of the disability pride songs of Johnny Crescendo and the meaning of a culture of disability.

Linton, Simi, "Teaching Disability Studies," Disability Studies Quarterly, 14, (2), (Spring 1994), 44-46. At the Society for Disability Studies annual conference in 1993 Linton and others discussed the need for a definition of disability studies for the 1990s. This article includes the definition that resulted from that discussion.

Longmore, Paul, "The Life of Randolph Bourne and the Need for a History of Disabled People: Review of Bruce Clayton's Forgotten Prophet: The Life of Randolph Bourne," in Reviews in American History, (Dec. 1985), 581-87. Longmore used the opportunity of this review to decry the writing about individuals with disabilities without understanding disability as a social and cultural condition as well as a medical one and advocated for the historical study of disability from a disability perspective.

Peters, Anne, "Developing a Language: Naming is Power," Disability Rag, 7, (4), (April 1986), 25. In the midst of the ongoing debate over the words "handicap" and "disabled" Peters wrote this article discussing the importance of the dialogue. See also, "Developing a Language: What about 'gimp'" Disability Rag, 7, (5), (May/June 1986), 20.

Peters, D.J., "Human Experience in Disablement: The Imperative of the ICIDH," Disability and Rehabilitation, 17 (3/4), (1995), 135-44. An admirable attempt to integrate a medical, academic, and disability perspective into new paradigms.

Pfeiffer, David "Is There a Culture of Disability?" 1984 and Beyond, Proceedings of 1984 AHSSPPE Conference, 1984. An argument that there is a learned culture of disability. See also, "Hip Crip 101," Mainstream: Magazine of the Able-Disabled, 19, (4), (Dec-Jan 1994-95), 32-37, a discussion of books about disability, including several top ten reading lists.

Piastro, Dianne B., "Telethons...Where Do We Go from Here?" Disability Rag & ReSource, 16, (4), (July-Aug. 1995), 24-26. A columnist who has railed against telethons argues it may be time for a different approach.

Schein, Andrea, "Is There A Culture of Disability?" 1984 and Beyond, Proceedings of 1984 AHSSPPE Conference, 1984. Schein describes an evolution from medical failures to civil rights advocacy in concluding there are disability sub-cultures.

Smith, Michael and Beth Haller, "Media and Disability Policy: An Annotated Bibliography," Disability Studies Quarterly, 15, (2), (Spring 1995), 22-26.

Stothers, William G., "It's Time to Wake Up to Our History and Power," Mainstream: Magazine of the Able-Disabled, 17, (3), (Nov. 1992), 50. Many people find Stothers' editorials one of the highlights of each issue. This one reminds us that disabled people have a history

and that we need to recognize and promote it.

Wade, Cheryl Marie, "Crazy, etc." Disability Rag & ReSource, 16, (2), (March/April 1995), 33-36. Performance artist Wade now writes an ongoing column for the Rag depicting various aspects of the culture of disability. This one is about artists with mental health disabilities. See also, "Creating a Disability Aesthetic in the Arts," Disability Rag & ReSource, 15, (6), (Nov-Dec 1994), 29-31, "Documentaries, Crip Style," Disability Rag & ReSource, 16 (1), (Jan-Feb 1995), 30-33, "Identity," Disability Rag & ReSource, 16, (5), (Sept/Oct 1994), 32-36, "Look, Ma, It's a Poem," Disability Rag & ReSource, 16, (3), (May/June 1995), 33-36, and, "Other Voices: Creating Crip Text," Disability Rag & ReSource, 16, (4), (July-Aug 1995), 34-37.

Waxman, Barbara Faye, "Hate," Disability Rag, 13, (3), (May/June 1992), 1, 4-7. A look at hate crimes against people because they have disabilities. See also, "It's Time to Politicize Our Sexual Oppression," Disability Rag, 12, (2), (March/April 1991), 23-26, and, "The Year of the Disabled Woman, or Girls, It's Time to Flaunt Your Sexuality," Disability Rag, 14, (3), (May/June 1993), 28-29.

Wolfe, Kathi, "Backlash!" Mainstream: Magazine of the Able-Disabled, 19, (8), (May 1995), 31-34, 35-36. A discussion of current anger expressed verbally and physically against individuals with disabilities and in the context of the development of a culture of disability. See also, "I Do Want to Talk About It, Disability Rag & ReSource, 16, (1), (Jan-Feb 1995), 34-35, "Springtime for Hitler: A Journal," Disability Rag, 14, (6), (Nov/Dec 1993), 11-13, and "Stonewalled? A Journal," Disability Rag & ReSource, 15, (6), (Sept/Oct 1994), 21-22, 27-28.

Zola, Irving Kenneth, "In the Active Voice: A Reflective Essay on Three Books," Policy Studies Journal, 21, (4), Winter 1993, 802-805. When Zola passed away in December 1994, we lost one of our most prolific, creative, and enthusiastic explorers about disability and its role. This essay clearly identifies dichotomies between being perceived with and without a disability from within and without. See also, "Shaping an Interdisciplinary Field of Disability Studies: The Perspective of Sociology," in Brown, ed., An Independent Living Approach, 5-9, describing, among other things, the development of the Disability Studies Quarterly, and "Disability Statistics, What We Count and What It Tells Us: A Personal and Political Analysis," Journal of Disability Policy Studies, 4, (2), 1993, 9-39.

Newspapers, Newsletters

Ann-Lewis, Victoria "The Secret Community: Disability and the American Theater," Impact, II, (1), (Fall/Winter 1994-1995), 2-3. In the World Institute on Disability newsletter, Ann-Lewis describes disability in the world of theater, particularly at her own Mark Taper Forum in Los Angeles.

Auberger, Mike, "Address by Mike Auberger, D.C. - May 9, 1993," Incitement, 9, (4),

(June/July 1993), 6, 12. Contains the powerful statement, "Martin Luther King had a dream. We have a destiny, not a dream, a destiny, to realize. We shall have the right to choose how we live, and where we live."

Bechdol, Barb, "Welcome Mercedes," Dykes, Disability & Stuff, 5 (1), 6-7. Mercedes is a newly-acquired wheelchair.

Brown, Steven E., "American Apartheid," Advocate (Progressive Independence, Norman, OK), (January 1988), 1. An early discussion of the treatment of people with disabilities paralleling the South African oppression of blacks. See also, "Declaration of Principles," Cleveland County Independent Living Advocate (August 1983), 1, an endeavor to describe what we will and will not accept from society, "The Disability Identity," OCCD (Oklahoma Coalition of Citizens with Disabilities) Newsletter, VII, (Winter 1986) 9-10, a positive glimpse of living with a disability, and, "The Truth About Telethons," OCCD Newsletter, VII, (Summer/Fall 1985) 4-5, a discussion of why separate is still never equal, including when disabilities are singled out at specific times of the year.

Marcus, Neil, ed., "A Limited Edition Collection of Special Effects Newsletter," (Santa Barbara, CA: Access Theatre, 1988). Neil, actor-author-playwright, has been putting many of his thoughts into this newsletter for years and distributing it randomly. This is a collection of what he considers his best efforts.

Piastro, Dianne B., "Creating a Group Identity, Culture," in "Living with a Disability" column distributed by Newspaper Enterprises Association, May 4, 1992. Discussion of the development of the University of Minnesota's Disabled Student Cultural Center. See also, "Disability Culture," in "Living with a Disability" column distributed by Newspaper Enterprises Association, July 18, 1993, discussed in narrative.

Zinman, Sally, "The Legacy of Howie the Harp Lives on," National Empowerment Center Newsletter, (Spring/Summer 1995), 1, 9. One of the leaders of the mental health disability rights movement is remembered in this touching and evocative article.

Monographs

Leon, Joan, ed., Just Like Everyone Else (Oakland: World Institute on Disability, 510 16th St., Suite 100, Oakland, CA 94612, 1992). Culture, political advances, and independent living are interspersed with photographs, directories, and quotations.

Lenihan, John, Performance: Disabled Americans: A History (Washington, D.C.: President's Committee on Employment of the Handicapped, 1976-77). Dated, but still contains information about the history of disability found nowhere else.

Levy, Chava Willig, A People's History of the Independent Living Movement (Lawrence, KS: University of Kansas Research and Training Center on Independent Living, 4001 Dole Building, Lawrence, KS, 66045, 1988). A brief look at the development of the independent living movement though the lives of some of its

key players.

Kailes, June Isaacson, Language is More Than a Trivial Concern (Available from author, 6201 Ocean Front Walk, Playa del Rey, CA 90293, 1992, revised from original 1984 version.) The best analysis of why language is so important, what to use, what not to, and why.

Videos (most recent prices included, where known)

Able to Laugh (1993) [Video--27 minutes] Produced by Michael J. Dougan. (Available from Fanlight Productions, 47 Halifax St., Boston, MA 02130). $195. Six professional comics who have disabilities.

Black Diamond [Video--9 1/2 minutes] (Available from Melanie Media, 2951 Derby St. #101, Berkeley, CA 9470)] $25.00. Afi-Tiombe Kambon performs story of fate of a child born with a disability to a woman in slavery.

Exploding Myths: Exploring the Emerging Culture of Disability. (1993). [Video]. (Available from Corporation on Disability and Telecommunications of Northern California, PO Box 1107, Berkeley, CA 94704). A look at Bay Area artists, including Cheryl Marie Wade, Neil Marcus, and Bruce Curtis.

Fairy Tales Can Come True. (1981). [Video--35 minutes]. (Available inter-relations, PO Box 11445, Berkeley, CA 94712) $30.00. Explores fantasies about a young man with a disability becoming sexual and having a relationship. Includes nudity.

Gospel according to Berkeley. (1992). [Video]. (Available from World Institute on Disability, 510 16th St., Oakland, CA 94612). A look, via the British Broadcasting Company, at the development of the independent living movement, focusing primarily on Berkeley.

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

No Apologies. (1995). [Video--28 minutes]. (Available from Wry Crips, PO Box 21474, Oakland, CA 94620). Institutions: $55.00; Individuals--Sliding Scale: $25.00-35.00. Add $4.00 S & H charges. Disabled Women's Theater in an early performance.

Out of Isolation. (1989). [Video--105 minutes]. Produced by Frank Moore. (Available from inter-relations, PO Box 11445, Berkeley, CA 94712) $30.00. Surreal look at life in an institution. Includes nudity.

Mr. Roberts. (circa 1988). Sixty Minutes. [Video--approximately 15 minutes]. (Available from World Institute on Disability, 510 16th St., Oakland, CA 94612). $20.00. Harry Reasoner interviewing Ed Roberts and his mother, Zona, discussing Ed's early years, his experience with polio and his decision to live, and the founding of the Physically Disabled Student Program, Center for Independent Living, and the World Institute on Disability.

Redefining Ourselves. [Video package--83 minutes]. (Available from Corporation on Disabilities and Telecommuni-

cations/Northern California, PO Box 1107, Berkeley, CA 94704). Two week rental prices: Non-profit organizations and schools: $90.00; Governmental agencies and businesses: $100.00. Includes Here: The Moving Body, featuring Bruce Curtis in experimental movement and dance; The Commercial, a comical look at how to avoid someone with a disability performed by Wry Crips Disabled Women's Theater; Black Diamond, Afi-Tiombe Kambon performs story of fate of a child born with a disability to a woman in slavery; Migraine 2000, featuring art work of Peni Hall; Melvin's Brat, a satirical look at TV tele-a-thons for kids with disabilities featuring Pamela Walker; and Into the Echo Chamber/Dream Weave, featuring six disabled artists collaborating on exploring the creative process and combining their music, dance, and poetry.

Tell Them I'm a Mermaid. (1982) [Video-23 minutes] (Available from Films Incorporated Video, 5547 N. Ravenswood Ave., Chicago, IL 60640-1199) $99.00. Victoria Ann-Lewis and six other women describe life as women with disabilities.

We Won't Go Away... (1981) [Video]. (Available from World Institute on Disability, 510 16th St., Oakland, CA 94612). $20.00. A look at the 504 demonstrations in San Francisco and the early independent living movement.

When Billy Broke His Head...and Other Tales of Wonder. (1995) Produced by Billy Golfus and David E. Simpson. [Video-Open captioning available -57 minutes] (Available from Fanlight Productions, 47 Halifax St., Boston, MA 02130). $245.00. WOW!!! Dare I say it? This *is* inspirational: includes activism, art, bureaucracy, family, friends, and a look at everyday life - all in a very funny hour.

Films

"Above Suspicion" (1995). Once again recent movies are providing many of the most outrageous cliches about disability and using a wheelchair. This one includes lines like "he's just not a wheelchair kind of guy" and "I don't want to live as half-a-man." There are twists with this one though, both in the movie and real life: first, in the movie, Christopher Reeve, best known for roles as Superman, becomes injured while on the job as an extremely efficient policeman, partly through the incompetence of his brother. Reeve discovers his brother and his wife have been having an affair, but rather than confronting them, asks that they kill him. It is a set-up; Reeve arranges everything, including unloaded guns. He then kills them and it turns out he has recovered, at least partially from paralysis, and can walk with a cane. He has used the wheelchair as a mask to convince everyone that he is now helpless. The real-life irony is that not long after the release of this movie Reeve was thrown from a horse and has apparently become a high-level quad. Stay tuned.

"Benny and Joon" (1993). Poignant film about a brother and sister who is mentally ill and unusual man who comes into their life. Not quite retarded, not quite typical, a Buster

Keaton clone with sweet personality who is misunderstood by most. He and the sister fall in love. Mental illness is dealt with realistically and empathetically, as are family relationships.

"Best Years of Our Lives," (1946). The story of three veterans returning from World War II and their chaotic attempts to fit into the world they left. Harold Russell, who lost both hands in the war, plays someone who is trying to fit in despite his disability. He is finally redeemed by his pre-War girlfriend who still loves him. A classic because of the perception of the many varieties of difficulties of post-war life and the realistic treatment of disability.

"Bob Roberts" (1992). Political satire that finds the protagonist, Bob Roberts, faking an assassination attempt and paralysis in his successful quest for a Pennsylvania Senate seat.

"Born on the Fourth of July" (1989). Ron Kovic, Vietnam Vet who is paralyzed and becomes an anti-war protester is portrayed. There is little about what it is like to have a disability beyond its hopelessness and permanency.

"Butterflies are Free" (1972). Story of a blind man and a flighty woman, both trying to make it on their own, who move in next door to one another in a San Francisco apartment.

"Children of a Lesser God" (1986). Based on Mark Medoff's play, which is reputed to deal with issues of deafness in a more sophisticated way, this becomes a love story between a nondisabled teacher of the deaf and a beautiful, but isolated, deaf woman. The woman is played by Marlee Maitlin, a deaf actress who won an Oscar for her role in the film.

"Coming Home" (1978). Emotionally wrenching story of the Vietnam War's effect on people in the U.S. - both those who stayed and those who return. Jane Fonda falls in love with paraplegic Jon Voight while husband Bruce Dern is at the front. Some of the best scenes occur in the VA Hospital with soldiers angry and wondering what this war is about.

"Forrest Gump" (1994). Tom Hanks is Forrest Gump whose 75 IQ does not stop him from becoming a star athlete, military hero, successful businessman, and husband and father. Most of his worldly success comes from accidents of fate which is appropriate since he is also constantly intersecting with history, e.g., Elvis, Bear Bryant, Kennedy, Vietnam, slogans, etc., but his personal interactions and successes come because he respects people for who they are unless they are hurting someone else. As interesting as is the film is the reaction to it which has ranged from an allegory for our times to an insipid tale.

"Freaks" (1932). About circus freaks, using the real thing for many of the characters, presented as a horror story full of grotesque anomalies of nature. It is early independent living with a community/culture, love, hate, jealousy, and families shown in the backdrop of one of the freaks - "a dwarf" who falls for a "big woman" who is only toying with him. The freaks band together.

"Homer and Eddie" (1989).

James Belushi stars as a man who is "slow" from being hit by a baseball as a kid and Whoopi Goldberg as an escaped mental patient with controllable fears and violent streaks. They are on a picaresque journey to see Homer's parents who had no time or need for him. When they get there the father has died. The two have become friends, but Goldberg is shot - ironically, in one of her few non-robbery attempts. Lots of other people with disabilities show up along the way - stutterer, man who thinks he is Jesus, and others.

"I Don't Want to Talk About It" (1994). Spanish. Story of a mother who refuses to let her daughter be different or to recognize her short stature and of an older man who falls in love with the adolescent dwarf, woos her, and then loses her when a circus of dwarves comes to town.

"Johnny Belinda" (1948). Classic, sensitive, story of "deaf-mute" young girl who is befriended by doctor who knows some sign language and is only person who really communicates with her. Of course, they fall in love.

"Lorenzo's Oil" (1992). based on a true story of two parents who would not accept doctors' diagnoses that son with ALD, a rare, terminal disease, would die within a short time. Fighting doctors, the ALD Foundation, and pharmacies, the pair discover an oil that neutralizes ALD and is now being used all over the world. Excellent acting and portrayal of parents.

"Lunatics: A Love Story" (1992). Sweet love story about delusional paranoid man and woman who believes she kills by her presence.

"Mac and Me" (1988). Notable only for featuring a wheelchair using kid as a wheelchair user.

"Magnificent Obsession" (1935 and 1954). Story of selfish playboy whose carelessness causes woman to lose vision and his dedication to going to medical school and healing her. Of course, they fall in love.

"Man of a Thousand Faces" (1957). Stars James Cagney as Lon Chaney, growing up bitter with deaf parents, marrying a disturbed woman, and playing series of characters who are crippled physically, most notably in "Phantom of the Opera."

"Man Without a Face" (1993). Mel Gibson stars as 60s teacher who has been disfigured in car accident which also killed a student. He has been convicted of child molestation and secluded himself since. A troubled boy comes to him for tutoring and film follows their friendship, but Gibson is again accused of molestation, primarily because people cannot see beyond his face. Moving drama, realistic reactions to disfigurement.

"Mask" (1985). Based on the true story of Rocky Dennis, whose face is disfigured by a rare disease and the consequences it brings.

"Monkey Shines" (1988). Based on a book about a monkey who assists a quadriplegic, it becomes a horror story as the monkey begins to read the mind of the quad, who is bitter and brilliant, and begins acting out the quad's homicidal fantasies.

"Now, Voyager" (1942). Bette Davis excels as woman with

a psychiatric disability who finally adapts with the help of compassionate doctor, but is ever aware of her fragile mental health.

"Nuts" (1987). Good portrayal of someone who is labeled "mentally ill" and may or may not be.

"Philadelphia" (1994). A lawyer with AIDS who sues his firm for firing him - suit is based on 504, odd given the late date of the film that ADA is unmentioned - Tom Hanks won Best Actor Oscar in 1994 for his portrayal of the lawyer.

"The Piano" (1993). Story of a woman who chose to be mute at the age of 6, abuses she faces, and how she speaks and falls in love by playing the piano - critics call it "lyrical," I thought it slow, more focused on abuse than muteness, and equating silence with death. Holly Hunter won 1994 Best Actress for her portrayal of the woman, Anna Paquin Best Supporting Actress for playing pre-teen daughter, and Jane Campion for script writing.

"The Point" (1971). Singer-songwriter Harry Nillson's classic animated tale about a boy born with a rounded head in a land where everyone and everything has a point. The boy is outcast, but learns that it is what's inside that counts, not what is on the outside. A classic parable for disability.

"Regarding Henry" (1991). Story of lawyer who has brain injury from bullet wound. Provokes diverse reactions from sappy to nice as a story of man adapting to a disability. Injury serves to redeem Henry from former savage lifestyle to becoming a nice man.

"Tim" (1979). Sweet story of young mildly retarded man, his family, and older non-disabled woman who falls in love with him. Tim is integrated in most ways with exception of schooling since he could not learn, he was withdrawn at 15 - but in movie he begins to learn to read.

"The Waterdance" (1992). Fact-based story of scriptwriter who becomes a paraplegic and his life in a rehabilitation center.

"What's Eating Gilbert Grape?" (1994). A slice-of-life family tale. The family includes an eighteen year old with mental retardation and an obese mother. The juxtaposition of child and mother is interesting; mother is far more handicapped, almost never leaving her house, and ashamed of her appearance; son is outgoing and mostly happy.

Radio

"On a Roll!" America's only live weekly radio talk show on disability. Gregory A. Smith, Sr., Host/Producer, KFNN Radio 4800 N. Central, Phoenix, AZ 85012 (602) 759-8916, (602) 241-1540 (FAX).

Music - Tapes

Coleman, Diane, "Free Our People" (Available from The Schoolhouse, Inc., 1478 Slayton Rd., Cumberland Furnace, TN 37501, 1994) $6.50. An ADAPT activist sings both the current and past ADAPT theme songs and other songs of disability pride and protest.

Creschendo, Johnny, "Easy Money" (Available from Mouth, 61 Brigton St., Rochester, NY 14607, 1990). Johnny's first

tape of rock'n'roll disability pride songs from England. See also, Crescendo, Johnny and the P.O.P. (Piss on Pity) Squad, "Pride" (Available from Mouth, 61 Brighton St., Rochester, NY 14607, 1993).

Higgins, Mike, "Thank You for Your Application" (Available from Mouth, 61 Brighton St., Rochester, NY 14607, no date). An English activist in the folkwriter-singer tradition.

Moyer, Jeff, "Do You See Me as an Equal?" (Available from Jeff Moyer, Music from the Heart, 445 Richmond Park West #630-B, Richmond Heights, OH 44143, no date). Described as the resident musician of the 504 sit-in at the Federal Building in San Francisco, Moyer's folk songs are filled with disability lore.

Stanton, Ian, "Free-wheelin'" (Available from Mouth, 61 Brighton St., Rochester, NY 14607, 1992). Another English activist in the folkwriter-singer tradition. See also, "The Incredible Shrinking Man" (Available from Mouth, 61 Brigton St., Rochester, NY 14607, 1989).

Comics

Griffith, Bill, Zippy Stories (San Francisco: Last Gasp, 1986). A compilation of pinhead comics with an introduction explaining how Zippy's creator came up with the idea and a look at the model for the cartoon character.

"Superman: Lost Love," D.C. Comics, New York, NY: Dec. 1987. The superhero falls in love with a woman who uses a wheelchair.

Tales from the Cripped, Volume One...Wheelchair-Bound to Boil You Alive (Rochester, NY: Free Hand Press, Available from Mouth, 61 Brigton St., Rochester, NY 14607, 1994). Some of the best comics from the Mouth.

Cultural Artifacts: Calendars

Dunning, Tajuana, Kym King, and Laura Smith, "1995 Disability Media Calendar" (Houston: Independent Living Research Utilization, 2323 S. Shepherd, Suite 1000, Houston, TX 70719). One of a series of ILRU calendars including photos and a wealth of information about disability events and activities.

"Entering the 1990's...A New Generation" (Berkeley: Center for Independent Living, 1991). A look at young leaders in the Berkeley area.

"Who Says We Don't Have Leaders? People with Disabilities Moving Ahead in 1994" (Louisville: Advocado Press, 1993). A look at national leaders.

Women's Press, Everywoman's Almanac, 1995 (517 College St., Suite 233, Toronto, Ontario, Canada, M6G 4A2, 1995). Women with disabilities fill every month with twelve fascinating personal stories.

Cultural Artifacts: Catalogs

"The Big Mouth Catalog of Publications" (Available from Mouth, 61 Brigton St., Rochester, NY 14607). Each issue Mouth sells T-shirts, music, books, posters, pendants, and other cultural artifacts.

Cultural Artifacts: Posters

"Disabled Women: Hidden

from History" developed by Anne Finger. Limited edition; portraits and biographies of Helen Keller, Frida Kahlo, Harriett Tubman, Carrie Buck, and Dorothea Lange.

"Paths to Equality" West Virginia Developmental Disabilities Planning Council with poem by Shirley Klein, "To Reverend Martin Luther King." Poster includes both art and the above poem which discusses disability in the context of civil rights and Martin Luther King, Jr.

Poetry

Martyrs

Steven E. Brown

I.

The following have drawn their last breath,
They've been courted by death
Many gave their lives to the cause
Their passing should give us pause
Many gave all their hearts had to give
So the rest of us might live

II.

Sandra Beasley...

Wade Blank...

Sheldon Berrol...

Roger Chambers...

John Clogston...

Tim Cook...

Gerald Davis...

Dave De Weerd...

Phil Draper...

Cheryl Elliott...

III.

The list is not complete
There will never be such a feat;
The deeds are not done
Many more tales have yet to be sung:

My list, my friends, my foes, the lines grow longer every day,
Leaving me breathless, with much too little to say,
Tribute to those whose voices we no longer hear,
Tribute to those whose vision we still are privileged to see,
Tribute to those whose dreams are yet to be;
Death be not too loud,
Life's accomplishments demand be proud:

IV.

Pat Fallin...

Lockhart Follin-Mace...

Gerald Garner...

Lynn Hart...

John Hessler...

Cristina Hopkins...

Gini Laurie...

Durward McDaniel...

Kirk MacGugan...

Sharon Nelson...

V.

Remember, we remember, tears and
laughter,
Friends and foes
Hugs in victory, surrender from
those we oppose,
Remember, we remember, laughter
and tears,
Cries and fears;
Remember, we remember, heroes
and martyrs,
Deals and barters,
Remember, we remember, those who
have gone before,
Remember, we remember, those who
paved the way,
Remember, we remember, for those
of us who stay,
Remember, we remember, for all
our descendants who will be
here one day.

Remember, we remember...
Remember, we remember...
We remember...we remember...
Remember...we remember...
Memories will stay,
It's up to all of us,
To make sure and say,
Memories will remain to energize
each day,
Memories will keep the wolves at
bay,
Memories will sustain our way.

No list will ever be complete
There will never be such a feat;
The deeds are not done
Many more tales have yet to be
sung:

VI.

Lonnie Nungesser...

Randy Shilts...

John Simpson...

Benjamin Stuart...

Ed Roberts...

Bill Tainter...

Diana Viets...

Ray Zanella...

Irving Kenneth Zola...

VII.

These tales we tell have begun,
Songs and poems and stories in
all their glories
These tales we tell have begun,
I don't believe an ending will
ever come.

Book Reviews

Lonsdale, Susan. (1990). Women and Disability: The Experience of Physical Disability among Women. London, England: MacMillan Education Ltd., 186 pp., including bibliography.

Although the book primarily describes social conditions as they exist in England, the experiences of the women with disabilities interviewed closely parallel those of women in the United States. Women in both cultures struggle to overcome barriers to education, employment, and housing. The author refers to legislation in both the United States and England which has been enacted to expand the rights and opportunities for all people with disabilities.

The author acknowledges that women with disabilities are

not a homogeneous group. They range across different ages, educational backgrounds, and socioeconomic classes. They have a variety of personal circumstances and may experience a mild, severe, congenital, or acquired disability. The two things they do have in common are their gender and the fact of their physical disabilities. Different physical impairments have differing disabling effects, but most people with disabilities are "handicapped" primarily in the range of choices available to them.

Independence is not only a function of individual abilities, but the interaction between those abilities and the environment - physical and social. Dependency is most commonly reported as: being overprotected; having one's privacy invaded at home, particularly by health care professionals; and not being allowed to make decisions. Through her interviews with women with disabilities, Lonsdale describes incidents of women receiving inappropriate medical treatment and being placed in situations where their independence has been discouraged or hindered. A couple of women interviewed said that importance was placed on them being "good" patients, being passive and obedient. Being independent, motivated, and active was seen as "bad." A common complaint was the intrusiveness of caregivers who did not feel the need to request permission before touching or manipulating the bodies of women who have disabilities. This was a further indication that their humanity and sexuality were being denied.

One woman mentioned that what offended her sense of dignity the most was not being able to keep the details of her bank account private because she was unable to get into her wheelchair inaccessible bank. Others expressed a wish to have more asked of them. They noticed that people rarely asked them for favors; to them, this was further evidence that people viewed them as inferior and dependent.

Women who had attended special schools reported that more emphasis had been placed on their medical care than on academics. Even when they were provided with training in basic living skills, these often did not include skills which would lead to independence. The training was geared to coping with disability rather than with learning to be independent. Some of the interviewees reported that it was not unusual for a woman with a disability to be labelled "unrealistic" when she attempted to live indepen-dently especially if her plans did not conform to the expected female role.

The prevalence of disability in any society depends on the way it is defined and measured. Lonsdale provides an historical overview of the way disability has been characterized over the years. There has been a move away from defining disability purely on the basis of medical or physiological criteria to a classification system which takes into consideration the interaction between environmental and social processes on disability. The traditional medical approach often did not accurately measure the extent to which an individual could or could not

perform functional activities and was generally more oriented towards physical rather than mental processes. More credence is now given to the social context in which tasks must be performed. The importance of the disability also extends to the perceptions that people have about how certain groups should look or behave. Norms of femininity or masculinity are also likely to influence whether, and the extent to which, individuals are stigmatized because of their disabilities.

In the media men with disabilities are often portrayed as villains or monsters. By contrast, women with disabilities, if depicted at all, are often seen as victims. Men with disabilities are portrayed as doing evil while women are portrayed as having evil done to them. Although less prevalent today there is still evidence of stereotypes which associate sin with disabi-lity. One woman born with quadrilateral limb deficiencies reported having an exorcism performed on her. Religious teachings may still offer legitimacy to the belief that disability indicates possession by the devil.

A woman with a disability may be untroubled in a user-friendly environment one day, but be severely handicapped by a hostile one the next. Requiring assistance and support should not automatically imply that a woman is incapable or that she needs to be cared for; on the contrary, it may provide a means of facilitating greater independence and control over her own life. The book concludes by considering ways in which women with disabilities can achieve greater independence and self-determination.

The book's title may be somewhat limiting in that its content is actually broader than it would suggest. Many of the experiences described by the women are characteristic of the type of discrimination and limitations which all people with disabilities have been subjected to and continue to be subjected to (including males, and both women and men with mental, sensory, and hidden disabilities). The book may be of most interest to readers who have not had much exposure to women's issues in general. People who have been insensitive to or ignorant of discrimination directed toward women will find this book most enlightening. Likewise, women with disabilities who have tended to identify more with other people with disabilities than with women in general may find some comfort in knowing that many of the disadvantages they have faced are perhaps as much a consequence of their gender as their disability. The book is somewhat dated, and, therefore, it does not reflect the most recent changes in legislation related to accessibility. It does, however, provide a valuable context for understanding the origins of some stereotypes and the impact that the social climate has on the way all people are regarded in our society. The author raises the chicken and the egg question: Do changes in social policy drive legislation or does legislation change public opinions and attitudes?

(Reviewed by Yvette Hachtel, Occupational Therapy Program,

Lewiston-Auburn College of the University of Southern Maine)

Falk, Pasi. (1994) The Consuming Body. London: Sage Publications, 238 pages.

The Consuming Body examines historical relationships between body, self, and culture including the changing nature of corporeality. Falk's focus is on orality, the social meanings of food and eating rituals. His final chapter on pornography and the way it represents "presence" (i.e., the sense of being on the scene) seems a bit like an afterthought.

The body, according to Falk, is the model for the constitution of the self which in post modern cultures takes place through consumption. Orality is the central "organ" of consumption both in terms of eating and of speaking. In contrast to the relatively more open pre-modern body, the modern body is more closed and thus the mouth becomes a central arbiter in the control of boundaries between "self' and the "external" world, between body and the world and what flows back and forth over these boundaries.

In "modern" orality the meal is marginalized and accompanied at the same time with the rise of various forms of non-ritual eating (e.g., snacks). Eating becomes more privatized. The modern communal meal, unlike the pre-modern form, bonds its participants not on the basis of shared incorporated food, but on symbolic exchanges - a shift from "food to words." Falk argues that a shift has occurred from an interest in expressions of corporeality to increased interest in inner experience. The "modern hedonist" thus enjoys "auto affective pleasure realized in the imagination." The contact senses (e.g., smelling) recedes in importance with an emphasis on the distant senses (e.g., seeing). Falk repeatedly emphasizes the fact that this tendency does not mean a decline in sensuality since the "hungry eye" experiences its own mode of pleasure and sensuality.

The chapter on food taboo systems is a sophisticated review of classification systems of what is edible, for instance, or not. Taboos are not static, it is important to remember, and here Falk appealingly answers the question of how "forbidden fruit" becomes "sweet" (desired). Transgressions (i.e., breaching sociocultural boundaries) can be pleasurable. In "modern" society he argues the more multidimensional and articulated restrictions become, the more diverse and sophisticated are the "transgressions." As the body is shielded ("closed") and made into a tool for social performance ("instrumentalized") the field of subjective experience widens, becomes more diverse and sensitive.

In advertising (especially food) there is a shift from an emphasis on claims of product efficacy to making the product a representation of the good life emphasizing consumption as an experience. Representation and its product "referent" become increasingly independent from each other. Falk uses an as example the transformation of patent medicine from products that make claims into products that function as icons of the good life (for instance, Coca

Cola underwent a metamorphosis from headache tonic to "Coke is it").

In a number of places Falk strongly dissociates himself from theories of consumption based on "need satisfaction" or on the view that consumption is structured by political economy. Instead he is interested in consumption in the post modern world as a means of self building - completing self and separating self from others. Completion involves sensory interjection, eating with the mouth and eye, while maintaining boundaries involves differentiating the self from others (social distinctions in taste).

Missing in Falk's work are social structural dimensions - class, gender, etc. - as well as a clear sense as to how consumption articulates with contemporary capitalism. The exclusive focus is on culture and symbolic representation. There is not enough emphasis on the political, economic, and social structural integument which structures not on representation of the body and a sense of bodily boundaries, but also structures the body itself as well as "the self as project" and consumption.

While there is little here of direct relevance to disability studies, there is, however, a wealth of analysis not the least of which is socio-psycho history of sensuality, orality, consumption, self, and body. This book constitutes an important contribution to the sociology of body and an excellent resource for those interested in this area.

(Reviewed by Peter Freund, New York, NY)

Thornburgh, Ginny (editor). (1994) Loving Justice: The ADA and the Religious Community. Washington, D.C.: National Organization on Disability, 36 pages, $10.00 softback.

The much-anticipated companion volume to That All May Worship is now available. This important reference edition builds upon the foundation of its predecessor with particular emphasis on the ADA and other relevant disability laws as they relate to the religious community.

This interfaith work is the collaborative product of disability leaders and lawyers from Christian and Jewish traditions. These representative groups are concerned with increasing the religious participation of persons with disabilities. In addition, the core information will be published under the same name, Loving Justice, through denominational offices of the Roman Catholic, United Methodist, Evangelical Lutheran and Episcopal faiths. Highly readable in content and presentation, the guide benefits from informed, but down-to-earth input from noted authorities in the fields of religion, disability, and the law.

The obvious question is raised on the inside cover. Quoting Jim Brady (former White House Press Secretary and NOD Vice Chairman), "Are religious organizations subject to the ADA?" Contrary to popular belief, the answer is a surprising "Yes! And to a higher authority as well."

In 36 concise pages, Loving Justice informs the reader of portions of the ADA which do indeed apply to religious

institutions. Chapter one offers an easily digested summary of the act's key provisions along with frequently asked questions. The second chapter describes the relationship between the ADA and other significant legislation. In narrative question and answer format, chapter three addresses specific requirements of the law as they pertain to the religious community. A comprehensive list of resources and glossary of key terms are included at the end of the guide.

The message of this guidebook is clear: justice and love will triumph only when segregating walls are knocked down and when the barriers of architecture, communication, and attitudes are removed. Only then will people with disabilities become full participants in the celebrations and obligations of their faith.

(Excerpted from a review by Robert C. Anderson, Lakeshore Rehabilitation Hospital, ReLife Rehabilitation System, Birmingham, AL, with permission from the copyright holder, The Haworth Press.)

Benton, Janice LaLonde (editor). (1994) A Loving Justice: The Moral and Legal Responsibilities of the U.S. Catholic Church under the Americans with Disabilities Act. Washington, D.C.: National Catholic Office for Persons with Disabilities, 58 pages, $7.50, available in alternate format.

In 1990 the National Conference of Catholic Bishops reaffirmed their support of the ADA and said that it "reminds all of us of our continuing obligation to work for the full participation of people with disabilities in our faith community and the broader society." They went on to say that the ADA was good for all society and that the church and the nation will benefit from it.

This publication is intended to take the "mystery" out of the federal regulations on the ADA. It is for church leaders, school administrators, hospital and social agency personnel. Written in a user friendly way it is a resource for every Catholic office and agency.

(Excerpted from material provided by the National Catholic Office for Persons with Disabilities.)

Film Clips

Cohen, Susan Hadary, & Whiteford, William A. (Producers). (1995). Bong and Donnell. Color, VHS 1/2", 52 minutes, 1995. Baltimore, MD: Video Press (100 Penn Street, Suite 133, Baltimore, MD 21201-1082; ph: 1-800-328-7450).

Bong Delrosario and Donnell Green are teenagers. They are endearing, irreverent, irresponsible, charming, obnoxious, cocky, loving, creative, sexual, sexist, lazy, hardworking, and ambitious. In short, they are average American teens, embodying all the angst, exuberance, and conflict of the teenage years. They have been close friends for years, attending inner city schools in Baltimore. Bong is Asian American and Donnell is African American. Bong also has a significant physical disability, which stems from arthogryposis. He uses a

wheelchair and writes with a pencil between his teeth.

Bong's disability is incidental in this video. It is ironic to note, however, that the video would probably never have been made had he not had a disability because Video Press is a division of the University of Maryland at Baltimore School of Medicine. The producers have followed the exploits of other kids with disabilities for a variety of other videos, including one about Bong called "Beginning with Bong." But do not let the association with a medical school frighten you away from this video or others by the Video Press. The film makers successfully stay away from "medicalizing" disability or people with disabilities. They stay away as well from presenting Bong as a "supercrip." All in all, the whole approach is refreshing.

The video does its job so successfully that the viewer forgets about Bong's disability. A number of times Bong is acting the "smart mouth" or talking back to his mother and you want to send him to his room until he can learn to behave. And when Bong reveals his sexual encounters you want to sit him down and have a long talk with him about sexually-transmitted diseases.

But, mostly, the video delights because it allows the personalities of Bong and Donnell to shine. Their insights, descriptions, and feelings rule. Viewers may come away amazed that they were actually watching a video and not personally interacting with the two young men.

The video sets the stage for the "slice of life" approach from the beginning with Bong and Donnell getting ready for their senior prom. It then recounts earlier footage of Bong and Donnell by showing the two in their elementary school classroom about ten years before. These earlier images allow viewers to observe Bong's accommodations in an inclusive classroom as well as introducing two cute, innocent boys who will later be filmed as streetwise teens. And the earlier footage introduces Bong's mother who is a single mother and has immigrated from the Philippines and Bong's worship of her at that time which serves as a contrast to the family discord during Bong's teenage years.

Next, the video fast forwards four years and the boys, now in their early teens, discuss what is going on in their lives - bad grades, their obsession with girls, and drugs in their school. The film follows Bong and Donnell into school where their friends comment on Bong as a friend. This segment seems a bit forced. The video is at its best when it lets the teens speak for themselves or when it unobtrusively follows them through the day.

At this stage the video begins to explore the family problems that arise from Bong's misbehavior at school. At one point, after being suspended from school, he explains why it took the school two days to catch him: "We made up such good lies, they didn't know if we did hook or not" (i.e., skip school). Bong continues: "I lie like a dog. That's why my mother doesn't believe me anymore." His mother's facial expression is etched with disappointment throughout this

scene. The video captures intense (and sometimes upsetting) family conflict. The family enters counseling. Bong later reveals how much it has rejuvenated the once good relationship between his mother and him.

One particularly endearing scene is one in which Bong gives a presentation about disabilities to children who appear to be kindergarten age. Their honest questions and his honest answers are a delight. The children admire Bong for his ability to write with his teeth, and they look at him as "totally cool" when he gives them each an autograph.

At age 15 Bong and Donnell reveal the stressors of inner city high school life - drugs, dropping out, physical violence, sex. Donnell explains that he has been expelled once. Bong reveals he has become sexually active and that he has run away from home three times. But their carefree days are shown as well - playing video games, hanging out at the mall, and performing rap music at an open mike in Baltimore's Inner Harbor.

The video culminates with a major event in the teens' lives at age 17. They write, produce, and direct their own video starring themselves. In teenage boy fashion, the plot centers on a competition between the two over who can get the most dates in one day. The video wins a national award bringing the teens to the attention of the media. Interestingly, one journalist who interviews the teens sees the story only in terms of Bong's disability. He asks Bong how he "overcame" such a serious "handicap." This segment brings the viewer back to reality about the customary media representations of people with disabilities. The typical media images rarely reach the high caliber of "Bong and Donnell." But the journalist who interviews Bong does seem to change his impression of people with disabilities. He is amazed by Bong's constant pursuit of girls and you can see that the journalist begins to see the normalcy of the disability experience.

The video ends with the teens traveling to their senior prom complete with stretch limo. There is an upbeat feeling because the viewer sees that Bong and Donnell have weathered the teenage storms. Donnell has a good and enjoyable job working at a day care center and Bong proudly describes the paycheck he brings home from his job at the Social Security Administration.

This video could only be improved by some tighter editing. It seems a bit long, although it is only 52 minutes. A quicker pace to the video, accomplished through editing, could help. Other than that, it is a video that should be in every school library and should be shown to middle school and high school students nationwide. It could be used to facilitate discussion on a variety of subjects, not just disability.

Unfortunately, Video Press has not been seeing much interest from schools in its videos on youth. Susan Hadary Cohen, the co-producer of "Bong and Donnell" and other Video Press films, said recently that they sell or rent numerous videos that feature older persons with disabilities, but

they have received little response to their videos about younger people. This is a sad commentary on educational interest in disability issues, especially considering that their first video on Bong, "Beginning with Bong," won an Emmy award.

Bong and Donnell's video, "The Mall," is also available for purchase from Video Press.

(Reviewed by Beth Haller, Penn State, Harrisburg)

Hogan, P.J. (Director). (1995). Muriel's Wedding. Color, 105 minutes. New York, NY: Miramax Films (375 Greenwich Street, New York, NY 10013).

This Australian black comedy has an overriding theme that explores the superficiality of appearance and a subtheme that includes the acquisition of a disability. Muriel (Toni Collette) is overweight, seemingly unattractive, and living a slug-like existence with her dysfunctional family in Porpoise Spit. Her superficial, appearance-obsessed "friends" constantly belittle her and finally drop her from their clique. Her "friends" claim she is not even marriage material. Depressed, 22-year-old Muriel steals money from her bully, con-man father (Bill Hunter) and goes for a holiday. There, she runs into an old high school acquaintance, Rhonda (Rachel Griffiths), who has moved to the big city, Sydney, to make an independent life for herself.

Muriel decides to make the break and lies and steals her way to Sydney running away from her equally slothful family. (Her family's behavior provides the real dark side to the movie. In fact, it is the disturbing and depressing aspect to the film.) In Sydney, Muriel gets a job at a video store, but continues her ritual of playing ABBA music ad nauseam and watching a videotape of the Princess Di-Prince Charles nuptials. She is obsessed with weddings, hence the name of the movie.

More interesting from a disability standpoint is the character, Rhonda. Rhonda has a zest for life that even infects the couch potato, Muriel. They club hop, pick up men, and have a grand old time as carefree young singles. However, late in the movie, Rhonda acquires a disability from a tumor and becomes a wheelchair user. Some reviewers criticized this turn in the plot as a device to unnecessarily invoke pathos. But it was handled in such a way that I think it normalizes the disability experience rather than stigmatizing it.

Yes, Rhonda is upset with acquiring a disability. But she learns to live with it and accepts the fact that she will never walk. Muriel does not seem to care whether her friend can walk or not. She still sees her as the same Rhonda. She initially provides personal assistance services for Rhonda as she continues to be her roommate. Rhonda happily maintains an independent lifestyle as a person with a disability - for a while, that is - until Muriel's obsession with weddings and her own insecurities about her appearance send her down the road of superficiality.

Muriel's high-profile "green card" wedding means Rhonda is left without the minor

assistance she needs to maintain an independent lifestyle. She must move back to Porpoise Spit to live with her mother. Muriel has broken her promise to Rhonda. At this point the film makes a subtle point about personal assistance services and accessible lifestyles. Without access to them, Rhonda is made dependent and child-like - in the care of her mother once again.

Muriel continues her superficial binge getting a makeover, reconnecting with her superficial friends, marrying for the wrong reasons, and on and on. But in the end, it is the superficial friends' treatment of Rhonda that makes her see the light. Muriel sees that Rhonda has been her true friend. Yes, there is a mushy moral to the story, but the film avoids many of the stereotyping roles that disabilities usually play.

Rhonda continues to desire her independent, fun-loving life, but it is lack of appropriate assistance that hampers her, not her disability. Also, Muriel learns that she has enough worth as a person to deserve an independent life. And Rhonda is the friend with whom she wants to share her independence. To Muriel, Rhonda's disability seems to have little relevance in that mix. The content of Rhonda's character is a much more significant factor.

"Muriel's Wedding" is not a movie about disability. It is a movie about independence. Some may disagree, but I think Rhonda's disability is handled in an incidental way, which is as it should be. Her disability is just part of the human experience and it just happened to occur to Rhonda's character in this movie. Too many films tend to focus on disability in terms of either "the cure" or "the tragedy." "Muriel's Wedding" instead focuses on the supports needed to maintain independence as a person with a disability. A much better theme indeed.

(Reviewed by Beth Haller, Penn State, Harrisburg)

Solicitations

Zola Emerging Scholar Award

Society for Disability Studies (SDS) is pleased to announce its Irving Kenneth Zola Emerging Scholar Award competition. Papers may be submitted by graduate students and new faculty or researchers in the area of disability studies. The award includes: certificate of recognition, cash award of $200, place on the program to present the award-winning paper at the 1996 SDS conference, and SDS conference registration fee waiver. Papers will be judged on: (a) significance of the topic, (b) advancement of knowledge, (c) quality of research design, (d) analysis of findings and their implications, (e) organization, and (f) clarity of writing. The submission deadline is: January 8, 1996. Send three (3) copies of your paper to: Gary Kiger, Department of Sociology, Social Work, and Anthropology, Utah State University, Logan UT 84322-0730. Phone: (801) 797-1235 (V/TTY). E-mail: gkiger@wpo.hass.usu.edu (questions only). Please send papers only, no theses or dissertations.

The John Clogston Endowment Fund for Students

In February 1995, John Clogston, a ground-breaking scholar in the area of mass media and disability issues, died at the age of 41. The Media & Disability Interest Group of the Association for Education in Journalism and Mass Communication decided to honor John's memory by setting up an endowment fund that would assist students who do research in the area of mass media and disability issues. The fund will finance a student to present research on that topic at the AEJMC annual meeting.

Please make your donations to: John Clogston Endowment Fund, AEJMC, 1621 College St., University of South Carolina, Columbia, SC 29208-0251. All types of monetary donations are welcome - individual, group, corporate, etc.

Coming (and Past) Events

On September 28, 1995, Community Works in Boston held its annual awards presentation. The following awards were given: the Artists for Social Change Award to Barry Crimmins; the Social Action Award to Michael Liu, The Network for Battered Lesbians, and James Murray; the Irv Zola Award to Clemintina and Joseph Chery, parents of Louis D. Brown (see Resources below).

On October 14, 1995, the Boston Society for Gerontologic Psychiatry, Inc., presented a conference "Even Unto Old Age: The Long-Term Effects of Traumatic Experience" in Cambridge, MA. A second conference, "Current Trauma in the Lives of Older Adults: Surviving and Healing the Wounds," is planned for March 30, 1996. Other conferences include "Ethical Dilemmas" on December 1, 1995; "Managed Care: Who Survives" on January 20, 1996; and Influence of Regulations on Mental Health Treatment" on March 9, 1996. More information can be obtained from the Society at 83 Horace Road, Belmont, MA 02178.

On October 14-17, 1995, the Society for Medical Decision Making and the George Washington University Medical Center sponsored the Annual Meeting of the Society for Medical Decision Making in Tempe, AZ. More information can be obtained from the Society at The George Washington University, Office of CME, 2300 K Street, NW, Washington, D.C. 20037.

On November 2-3, 1995, the New Hampshire Rehabilitation Association held its Fall conference and annual meeting on the theme "Future Shock: Embracing Change." More information can be obtained by calling 603-434-9937.

On November 3-4, 1995, the Braintree Hospital Rehabilitation Network presented "Stroke Survivors: Recovery & Rehabilitation Conference" in Boston. On November 5-7, 1995, the Network presented the 16th annual "Traumatic Brain Injury Conference" in Boston. More information can be obtain from the Network at 250 Pound Street, Braintree, MA 02185.

On November 9-10, 1995, Public Responsibility in Medicine and Research presented a conference on "Clinical AIDS Research: The Present Status and Future Outlook." More information can be obtained from

them at 132 Boylston Street, Boston, MA 02116.

On March 19-23, 1996, the Center on Disabilities at California State University, Northridge, will sponsor "Technology and Persons with Disabilities" in Los Angeles. More information can be obtained from the Center at 18111 Nordhoff Street, Northridge, CA 91330-8340.

On March 27-31, 1996, the Society for Applied Anthropology will hold its annual meeting in Baltimore, MD. More information can be obtained from the Society at P.O. Box 24083, Oklahoma City, OK 73124.

On March 29 to April 1, 1996, the International Parent-to-Parent Conference "Keep Alive the Dream" will held in Albuquerque, NM. More information can be obtained from Parents Reaching Out to Help, Inc., P.O. Box 2640, Los Lunas, NM 87031.

On April 25-28, 1996, the National Council on the Aging, Inc., will have its annual conference in Washington, D.C. More information can be obtained from the Council at 409 Third Street, SW, Washington, D.C. 20024.

On August 10-13, 1996, the Association for Education in Journalism and Mass Communication will have its annual meeting in Anaheim, CA. More information can be obtained from Jeffery John at 513-873-2145 or Beth Haller at 717-948-6203. Haller's email address is bah17@psuvm.psu.edu and she will answer questions.

On September 27-29, 1996, the Third International Conference of Health Behavioral Science will be held at Sophia University, Tokyo. More information can be obtained from Professor Tsunetsugu Munakata, Institute of Health and Sports Sciences, University of Tsukuba, 1-1-1 Tennoudai, Tsukuba, Japan 305.

Retrospect

An informal conference on autism was held in Dallas, TX, in late January 1995. Participants included clinicians and researchers from major medical centers. Several speakers reported the favorable response of many children with autism to a treatment program which featured dietary changes, nutritional supplements (especially vitamin B6 and magnesium), and antifungal medications. William Shaw, Children's Mercy Hospital and the University of Missouri, presented clinical and laboratory studies which showed autism may be yeast related. He said that fungal metabolites were found in the urine of all eighteen children with autism who were studied. Over 75% of them had a history of frequent infections which had been treated with antibiotics. Following treatment with oral antifungal medications (nystatin, Nizoral, or Diflucan) for seven days, laboratory findings returned to normal and the children showed significant improvement.

Current Research

Diane Robin Wright (Sonoma State University), "Physical Disability: The Long Term Effects of Child Sexual Abuse."

The purpose of the study was to determine if there is a

relationship between a physical disability and accessing memories of childhood sexual abuse. Interviews were held with professionals in the field of disability and child sexual abuse along with a sample of adult women with acquired physical disabilities. The findings were that there are a variety of issues, responses, and states of readiness to deal with a history of child abuse that occur when confronting a new physical disability. The shock of becoming physically disabled can trigger memories of trauma. More information can be obtained from Ms. Wright at 1429 Morning Glory Drive, Petaluma, CA 94954-6818.

Call for Manuscripts

The Media & Disability Interest Group of the Association for Education in Journalism and Mass Communication announces its call for papers for the August 10-13, 1996, annual meeting in Anaheim, CA. The research on which the papers are based should look at disability and its relation to mass media such as media images of disability, photography, disability culture in the media, access to media jobs, the disability press, language, advertising, technology, and attitudes. The deadline is April 1, 1996. Send six copies of the paper, one abstract, and one computer disk to Jeffrey Alan John, Communications Department, Wright State University, Dayton, OH 45435. More information can be obtained from Jeffery John at 513-873-2145; or Beth Haller at 717-948-6203, bah17@psuvm.psu.edu on The Internet.

The Journal of Disability Policy Studies announces its call for papers on the topic of policy issues for women with disabilities for a special issue to be published in 1997. Barbara Altman and Sharon Barnartt, Guest Editors, and Kay Schriner, General Editor, will edit the issue. Appropriate papers will focus on the impact of current disability policy on women with disabilities, the history of disability policy as it has been applied to women over the years, examining policy differences as they apply to men and women with disabilities or women with and without disabilities, the relevance of pending policy changes in financing programs to women with disabilities, the participation of women with disabilities in the creation of policy, or other topics that incorporate social policy and relevance to women with disabilities. Research on the topics from the fields of sociology, psychology, law, economics, political science, and other related disciplines is solicited. Deadline for submission is August 16, 1996. Submissions should be sent to Kay Schriner, Editor, Journal of Disability Policy Studies, Department of Rehabilitation, 346 N. West Avenue, University of Arkansas, Fayetteville, AR 72701.

Resources

The Louis D. Brown Peace Curriculum is a values program that develops students' character as well as enhances reading and writing capabilities. The program seeks to cultivate peace among young

people and adults in all the neighborhoods of Boston. The Peace Curriculum targets high school tenth graders. It teaches the value of peace through the life story of Louis Brown.

Brown, a tenth grader and an honor student at West Roxbury High School, dreamed of becoming the first black president of the United States. He did not want to lead a troubled society so he joined the Teens Against Gang Violence (TAGV) program. On December 20, 1993, while on the way to a TAGV meeting a stray bullet from warring rival gang members, killed Louis Brown.

More information can be obtained from the Louis D. Brown Social Development Corporation, 5 Dahlgren Street, Dorchester, MA 02124-1011.

Telability Media has published America's Telability Media, a directory of mass media for persons with disabilities with more than 500 entries including over 70 magazines, nearly 40 newspapers, dial-in newspapers, 15 newspaper columnists, almost 330 newsletters, professional organizations, and over 40 radio and TV programs. It costs $25 and is available in alternative format. More information can be obtained from Telability Media, P.O. Box 1488, Columbia, MO 65205-1488.

Strategies for Teaching Universal Design is available from Adaptive Environments, 374 Congress Street, Suite 301, Boston, MA 02210. It discusses the first year of a project of Adaptive Environments which supported faculty initiatives at twenty two universities teaching universal design. The book highlights the history of related curriculum efforts and includes case studies and resources for faculty interested in developing their own courses.

Announcements

The Disability Law Center in Boston is soliciting feedback from the disability community on its proposed 1996 priorities which are discrimination, community services, benefits, self determination and personal liberty, and assistive technology. You can write them at 11 Beacon Street, Suite 925, Boston, MA 02108; call them at 617-723-8455 (voice and TTY); or attend one of their public meetings: Wednesday, November 8, 1995, 3:00 to 5:00 pm, at their western Massachusetts office at 22 Green Street, Northampton; Wednesday, November 15, 1995, 11:00 am to 1:00 pm, at their southeastern Massachusetts office at 21 South Sixth Street, New Bedford; or Wednesday, November 29, 1995, 11:00 am to 1:00 pm at their Boston office at 11 Beacon Street, Suite 925, Boston, MA 02108.

The World Institute on Disability, Oakland, CA, announces that Sue Suter, long time disability advocate and public policy analyst, was appointed Interim President. Suter joined WID's board of directors in 1993. She is the director of the Springfield, IL, office of the Rehabilitation Institute of Chicago and is president of Suter and Company which provides consultation and technical assistance on the ADA

and disability issues. From 1984-88 she served as director of the Illinois Department of Rehabilitative Services. She later served as Commissioner of the Rehabilitative Services Administration in the U.S. Department of Education.

Elaine Ostroff, executive director of Boston's Adaptive Environments, received the 1995 Achievement Award from the Environmental Design Research Association. She was honored for her work in "making architectural access a civil right."

The National Organization on Disability announced that Michael R. Deland was elected chairman of its Board of Directors. Deland, a wheelchair user, is vice chairman of American Flywheel Systems, Inc.

Comment

The Evolution of a Definition

Mary Jane Owen, M.S.W.
National Catholic Office for Persons with Disabilities

A major theme in my essay, "Viewing Christian Theology Through Evolving Disability Lenses," which appeared in the Summer 1995 issue of Disability Studies Quarterly, was distorted when the word "moral" was substituted for "normal" in definition of disability I was proposing. It should have read: "Disabilities are the expected, normal and anticipated result of the risks, stresses and strains of the living process itself."

The substitution aroused questions of whether those involved with the overlap between religion and disability noticed the error. There are many professionals working in the area of spiritual development who strive for relevance in a rapidly shifting environment, where self-perceptions and legal status of those of us with disabilities have changed drastically over the past two decades. However, a mission to serve the less fortunate continues to be a strong motivation for many.

For it was mere decades ago when alms tossed to the blind, dumb, imbecilic or lame beggars on the streets seemed appropriate. And the height of benevolence for the religiously inclined involved shelters of one sort or another where these "in-valids" could live out their relatively short lives with a modicum of inconvenience to the community at large.

The first time I became aware "we," as a group, established some initial steps in defining ourselves outside the medical model which had developed to rescue us from our previous sorry state, was at the same Rehabilitation International Convention in Winnipeg, Canada, where Disabled People International was established. A series of resolutions clearly stated that those in a stabilized condition were not patients and that the problems such individuals face are not medical, but can best be defined as social, environmental, political and economic. "Disabled" was defined as what we are; "impairments" as the medical conditions and "handicapping conditions" were those exterior factors which blocked our full participation

in the life of our communities.

In that short essay in DSQ I attempted to capture in a very brief reference to the definition I had coined a decade earlier, what may have been a rather far-ranging leap of faith for those not comfortable with those shifting paradigms.

I first proposed that definition 10 years ago when I was asked to coordinate a panel of Washington disability advocates for a presentation at the Biannual Convention of the Gray Panthers. Naomi Harward, who served on their national board and chaired their Task Force on Disability, requested a few resolutions with the charge, "If we want something to come out of this session, we'd better have something already drafted."

The first of the two resolutions was easy. It involved the statement that each day we become a day older and therefore growing older is a normal part of living. Therefore, that fact should play a part in all social planning and community services.

It was not difficult to move from that first "obvious" recognition to a similar orientation toward disabilities: "Disabilities are the normal, anticipated outcome of the risks, stresses and strains of the living process. They can occur before, during or after birth, in childhood or as one grows older. For they are a natural consequence of the fragility of the human body. Thus, they are not merely individual tragedies but are expected events in every community. Therefore, all social and environmental planning must seek to develop ways to accommodate this expected diversity of function."

This base, upon which a resolution was built and passed, was initially read by colleagues who joined me on that panel. Both Justin Dart and Evan Kemp, Jr. studied the statement for some time. Then Justin said, "Mary Jane, that's profound, very profound. But I'm not sure you'll be able to 'sell' the idea."

However, the simple truth of such a view is difficult to shake off once one has truly heard it. And this idea, that disabilities are normal, has pervaded the thinking of most of those disability leaders with whom I come in contact. It is a new idea to many who see their role as "servicing" those whom they may consider less fortunate than themselves. After all, good people still use the phrase, "There, but for the grace of God go I," making a negative judgement of the spiritual status of the individual they would appear to pity.

Given the fragile vessels into which God places the gift of life, we might question if He was out of His mind. I think not for it is through our sense of fragility that we are moved to realize the need for the civilizing impact of community. The intertwining threads of mutual need can surely weave the strongest social fabric. Isn't that the social medicine we need today?

The Psychopathology of Publishing

Chris Borthwick
Brunswick, Victoria
Australia

In developing areas such as the study of intellectual disability, academics who repackage twenty five year old texts and reissue them essentially unaltered are perpetrating a dangerous fraud on the public. The Psychopathology of Language and Cognition (New York: Plenum Press, 1994) by Robert Rieber and Harold Vetter is such a work. The chapters appear to have been only marginally revised since appearing in Vetter's 1969 Language Behaviour and Psychopathology. Of the seventy references in the chapter on mental retardation, twenty two date from the 1970s and three from the 1980s. However, they have simply been patched on to previous references and have not been allowed to influence judgements in the text.

The book contains statements such as: "Early infantile autism has until recently been diagnosed as a form of childhood schizophrenia." The term "recently" can not conceivably refer to any date after 1965. And it has the following statement: "The profoundly retarded are considered 'incapable of profiting from any type of training or education,' and most 'require life-long residential care' (Stevens, 1964, p. 4)." No writer in the field today would describe any person, whatever their level of retardation, as untrainable. It is virtually criminal for Rieber and Vetter to recycle this exploded prejudice in 1994 in a book which the casual reader might take to be representing a contemporary consensus.

Parents, teachers, and librarians would be well advised to treat this work as unreliable. Protests should be made to Plenum Press for issuing it.

The Society for Disability Studies

The Society for Disability Studies is a nonprofit scientific and educational organization. It is a multidisciplinary and international organization composed of social scientists, scholars in the humanities, and disability rights advocates concerned with the problems of disabled people in society. The purpose of the Society is to bring together people from diverse backgrounds to share ideas and to engage in dialogues that cut across disciplinary backgrounds and substantive concerns. The Society is committed to developing theoretical and practical knowledge about disability and to promoting the full and equal participation of persons with disabilities in society.

The Society's annual meeting is usually held in June of each year. Likely themes for disability studies papers or panels are topics such as policy, history, sexuality, law, culture, methods, politics, media, literature, pedagogy, gender, self image, cross cultural studies, family, advocacy, activism, and related topics.

Further information on membership and the 1996 annual meeting can be obtained by TDD at 617-523-3682 or by voice at 617-523-3429. The mailing address is: Society for Disability Studies, c/o Department of Public Management, Suffolk University, Eight Ashburton Place, Boston, MA 02108-2770 USA.

Dues for membership in the Society are based on income and are as follows:

Less than $15,000	$15.00
$15,000 - $30,000	$25.00
$30,001 - $45,000	$35.00
Over $45,000	$45.00

Subscription Information

Disability Studies Quarterly comes out four times a year. Each volume is the same as a calendar year. Although the Quarterly is associated with the Society for Disability Studies, the subscription price for the Quarterly is <u>not</u> included in the dues for the Society. However, members of the Society are entitled to a reduced rate. The prices for a one year subscription are as follows.

Individual	$35.00
Institution	$45.00
SDS member	$30.00
Student	$20.00
Low Income	what you can afford

<u>Additional postage</u>:

Canadian subscribers by air	$12.00
Other international (not air)	$ 6.00
Other international by air	$16.00

International subscriptions can be obtained by the exchange of newsletters and/or publications relating to disability.

Please specify if you wish to receive the Quarterly on audio tape cassette, by email, or on diskette (IBM compatible WP5.1 and ASCII, 5 1/4" or 3 1/2", high density). There is no additional cost for an alternative format.

The Samuel Gridley Howe Library in Waltham, Massachusetts, is the repository for past issues of Disability Studies Quarterly. Irv's papers and books as well as the books, papers, and manuscripts of Rosemary and Gunnar Dybwad are also deposited there. Bonnie Stecher is the librarian at the Howe Library. The Library is available for research into all aspects of disability.

Past issues of Disability Studies Quarterly are available for $7.00. Make out the check to Disability Studies Quarterly and send to David Pfeiffer, Department of Public Management, Suffolk University, Eight Ashburton Place, Boston, MA 02108-2770, USA. Please specify the theme of the issue and the volume and issue number. Your request will be forwarded to the Howe Library.

SPECIAL NOTICE

Since Irv Zola died many persons wondered about the future of the Quarterly. Disability Studies Quarterly will continue. For the calendar year 1996 (and longer if necessary) I will be the editor of the Quarterly. The Steering Committee feels confident that subscription and other income will provide sufficient funds to pay for its publication. We are receiving some support from Suffolk University, but we need much more.

Please consider making a donation to ensure that the Quarterly will continue during this transition time. For persons (or organizations) who can afford large contributions, please make one now. All donations are welcome, however. Make the check payable to Disability Studies Quarterly and MARK ON IT DONATION. Send it to David Pfeiffer, Department of Public Management, Suffolk University, Eight Ashburton Place, Boston, MA 02108-2770, USA. Thank you.

David Pfeiffer, Editor

Table of Contents