

Cultural Studies Association 2003 Conference Proposal for  
Panels on Disability Studies

CHANGING THE INTERPRETATION OF DISABILITY BY THE MAINSTREAM AMERICAN CULTURE

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We are a coalition of scholars, administrators, activists, and artists who are involved with disability scholarship and the disability community. Our offering to this conference is to introduce the new field of Disability Studies, which is aimed at re-visioning cultural constructions of the disabled body and the lived life with disability. To this end, we are submitting three panel proposals: Disability and Agency, Disability and the Academy, and Disability as Performance. This triadic approach will allow us to focus on three core areas of disability as they relate to Cultural Studies: disability and cultural constructions of agency, cultural constructions of disability within academia with regard to the development of Disability Studies, and disablement as the performance of the aesthetic gesture.

1) Panel on Disability and Agency

"Living in Two Cultures: Reflections From Both Sides of the Mirror"  
Al Condeluci and Lucy Spruill

This paper is a dialogue in two voices, one without and one with disability, both of which have assumed the liminalized role of "gatekeeper," negotiating between the abled and disabled worlds. Americans with disabilities live in what may be regarded as mainstream American culture, but as a marginalized people. Like other minority individuals, they are often in a position of perceived "invisibility," a disempowering cultural construction that nonetheless casts the disabled as the empowered owner of the unobserved gaze. Claiming active and visible membership in both cultures often is accompanied by role strain on the disabled individual. However, this position places the disabled person in a unique position to interpret the complex nature of the relationship between disabled and non-disabled, allowing the disabled individual to act as a "gatekeeper" to what can be referred to as disability culture, potentially reducing oppression. With the emergence of a sophisticated and complex disability culture and sociopolitical movement, people without disabilities who have worked and/or socialized among people with disabilities find that they now experience similar contradictions, role strains, oppression from both groups, and opportunities. As people with disabilities assert their rights to choice, control, and self-expression, people without disabilities are forced to relinquish status and power previously conferred upon them by social roles that were not egalitarian.

"Emergences: Disability Culture and the American Scene"  
Carol Marfisi

This paper will discuss the various benefits, as well as dangers, of merging or infusing disability culture with mainstream American culture. The discussion will be probative in nature and will address the following questions: What are the political, social, and ethical implications of a sub-culture retrofitting its identity to accommodate norms and values of a dominant culture? What would be gained and what would be lost? What would be the incentive of the dominant culture to align itself or pursue a relationship with the disability culture? How would negotiation take place between the two cultures in deciding the configuration of identity of the disability culture? This paper will conclude by paralleling this same phenomenon with other socially marginalized groups and the possible lessons to be utilized.

"At the Interstices of Classification: Cultural Modeling of Disability"  
Patrick Devlieger

In this paper, three arguments will be given to support the development of a cultural modeling of disability. First, a critique of the social model of disability reveals that not much thought has been put toward the processes of giving and taking through which the lived meanings of disability can be negotiated. In particular, the impact of information and media has grown in importance, and specifically the control over language and image that are utilized in the representation of individuals with disabilities. Second, the discussion of disability culture has developed into one in which the conditions under which disability cultures emerge and sustain themselves now can be scrutinized. For example, the ethnographic work of this author among violently-disabled African Americans supports the emergence and sustenance of a disability culture under certain circumstances. Third, this paper considers the extent to which disability cannot be captured in existing cultural categories, i.e. its interstitial nature, and the implications for the possibility of disabled people to play very specific roles in cultures, such as the potential to critique the limitations of existing categories or to provide links between differently classified cultural arenas.

"The Experience of People with Violently-Acquired Disabilities with Mainstream Cultural Integration"  
Miriam Hertz, Willa Martin, and a representative from the Community Empowerment Association.

This paper will discuss research (survey and interview protocols) on Pittsburgh residents who have disabilities as a result of intentional street violence. The majority of these individuals are low-income African American men who were, and are sometimes still, involved with street gangs. Generally, before they acquired disabilities, these individuals did not adhere to employment roles that are valued by dominant mainstream American culture. Now, following disablement, they are facing the triple stigmatization/discrimination of being poor, African American, and disabled. This paper will deliver preliminary findings on the degree to which these individuals are able to interface with mainstream American culture as they seek and utilize social programs and health services and as they desire

and/or undertake to participate in the community, including finding wage-earning employment. The paper will conclude with recommendations on how societal institutions can be improved upon to encourage better cultural integration for these individuals.

## 2) Panel on Disability and the Academy

"Changing the Interpretation of Disability: Special Educators with Disabilities"

Beverly Barkon

Cultural constructions of the disabled student have evolved in the aftermath of the Brown vs. Board of Education of Topeka "separate is not equal" ruling, which began the process of integrating marginalized student populations into the mainstream classroom. In essence, disability has come to be viewed as another category of classroom diversity. One group, educators with disabilities, is at once part of the community of special educators but also separate and disenfranchised from that community. They are not welcomed as colleagues by the profession that is charged with the education of children who learn in non-traditional ways. This paper will challenge prejudices within the academic institution that are based on cultural constructions rarely articulated and typically not experienced at a conscious level by those who tacitly have them.

"Disability Studies Across the Curriculum: Selected Initiatives and Challenges"

Ellen R. Cohn

In recent years there has been substantial growth nationwide in Disability Studies academic programs that support multiple instructional initiatives through the presence of programmatic and intellectual synergies. However, wider challenges persist: the need to infuse culture-altering content into various curricula already severely challenged by insufficient time to impart expanding technical knowledge and also meet standardized requirements for professional certification; the need to enlarge the perceived locus of responsibility to all sectors of the University community; insufficient time and programming for research-based faculty to acquire and implement new curricular approaches; and, the need to orient financial resources to incorporate wider participation by consumers and community groups in academic planning and delivery. At the heart of these challenges is the re-imagining of Disability Studies within the academy.

"Roundtable on Disability Studies and the Academy"

Beverly Barkon, Ellen R. Cohn, and Miriam Hertz

This roundtable discussion invites the audience to talk about the role of Disability Studies in academia, including intersections and creative alliances with Cultural Studies.

### 3) Panel on Disability as Performance

This panel will be scheduled at the Oakland, Pittsburgh site of a disability art show, which is being organized to be held in conjunction with this conference, or in a conference room as is most convenient.

"Under our Skins: Living Disability"

Lin Wei-Lee

A grant given by the Cultural Studies Association will help underwrite "Under our Skins: Living Disability," a multi-media art show curated by Lin Wei-Lee that subversively reclaims the disabled body as artistic object. In this reversal, it is the disabled, the artistic subjects, who lay claim to the right of self-representation. It is a resistance then of the externalized cultural enfiguration of the disabled as other, freakish, monstrous, teratistic, aberrant in a revisioning of disability as experiential. This presentation will provide an overview of the art show.

Media needs: VCR, if no on-site slide projector.

"Crooked, Crooked Lives"

Ramona Ragano

This is a paper in the form of spoken word poems: art that challenges corporeal theories that have cast the disabled body as literally and culturally "crooked." These poems portray a narrative and commentary on disablement as loss and instigator of the grieving process, a delving into the cycle of disability, tensions between the externalized dichotomy of disabled/non-disabled existence and the disabled experience, and, finally, mediation towards a revised cultural construction that mirrors the coexistence of these worlds in nature.

## BIOGRAPHICAL PROFILES

Beverly Barkon, Ph.D. is an Associate Professor of Special Education in the Division of Teacher Education at Carlow College in Pittsburgh, PA. She is the Human Rights Liaison with the Educators with Disabilities Caucus of the Council for Exceptional Children. She is the Editor of The Learning Consultant Journal, a publication of the Association of Learning Consultants, a professional organization in the State of New Jersey.

Ellen R. Cohn, Ph.D. is Assistant Dean for Instruction at the University of Pittsburgh School of Health and Rehabilitation Sciences and Associate Professor in the Department of Communication Science and Disorders. She holds a secondary appointment in the University of Pittsburgh School of Pharmacy. She teaches classes in rhetoric and communication, telecommunications, orthodontics, and cleft palate. Recently, she spearheaded the curricular design of a new Concentration in Disability Law in the University of Pittsburgh School of Law's Masters of Studies in Law (MSL) degree program.

Community Empowerment Association (CEA) is a Pittsburgh community-based non-profit organization that works with families to build, foster, and empower the African-American community through jobs, economic development, housing, and family support systems. It delivers programs and advocacy in education and employment, violence prevention, and health and human services to hard-to-reach at-risk children, youth, and families. CEA is collaborating with Hertz in research on Pittsburgh residents who have violently-acquired disabilities.

Al Condeluci, Ph.D. is the CEO of United Cerebral Palsy of Pittsburgh, a member of a family of corporations dedicated toward "working towards a community where each belongs." He is associated with the University of Pittsburgh's School of Social Work and School of Health and Rehabilitation Sciences, as well as Duquesne University's School of Education. He speaks regularly to national and international audiences reaching some 10,000 people each year. His award winning books include Interdependence (1991,1995), Beyond Difference (1996), The Essence of Interdependence (1999), and Cultural Shifting (2002).

Patrick Devlieger, Ph.D. is a cultural anthropologist and a Professor at the University of Leuven, Belgium where he directs the Culture and Disability Research Program. He has published on the culture and disability interface in Africa and in the United States. Currently, his interests have turned to accessibility of historic European cities by people with visual impairments.

Miriam Hertz, Ph.D. is an Assistant Professor at the School of Health and Rehabilitation Sciences at the University of Pittsburgh. She is the director of the school's graduate-level Disability Studies Certificate Program and teaches courses in Disability Studies. She also is currently undertaking grant-funded research on the needs assessment and utilization of social services by Pittsburgh residents who have disabilities as a result of intentional street violence. She identifies as a person with a disability.

Carol Marfisi, MA is an instructor at the Institute on Disability at Temple University in Philadelphia.

Willa Martin, BA is a graduate of the University of Pittsburgh and is currently pursuing her masters degree in Literature in English at Georgia State University. She is a research associate on Hertz and CEA's study of Pittsburgh residents with violently-acquired disabilities.

Ramona Ragano, BA is a graduate student in Rehabilitation Counseling at the University of Pittsburgh, School of Health and Rehabilitation Sciences. Her poems have been published in the newspaper, Pittsburgh Post-Gazette and in local chapbooks. She has performed at venues throughout western Pennsylvania.

Lucy Spruill, M.S.W. is a part-time Instructor in the School of Health and Rehabilitation Sciences and Adjunct Instructor in the School of Social Work at the University of Pittsburgh, as well as Attendant Care Program Director for Community Living and Support Services (CLASS) at United Cerebral Palsy of Pittsburgh. Ms. Spruill has received national recognition for advocacy, consultation, and training in the field of inclusion and community participation for people with disabilities. Ms. Spruill has a lifelong mobility impairment and is a user of wheeled mobility devices.

Lin Wei-Lee is a Ph.D. student in the cultural theories of rerogenetics and aesthetic genomics in the English Department and Cultural Studies and Women's Studies programs at the University of Pittsburgh. She is a recipient of the academic Zonta fellowship, awarded to one Pittsburgh-area female doctoral student each year. Last fall she received a Pennsylvania Council for the Arts grant for her work as a visual artist, poet, and art curator.