INFORMATION PACKAGE ON DISABILITY STUDIES

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This information package includes a reprint that we are unable to produce here on our web site. We have indicated contact information for this resource, or you can obtain a complete copy of this information package by contacting <u>Center on Human Policy</u>.

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INTRODUCTION

Over the past several decades, what we now refer to as "disability studies" has been a powerful influence on policy and practice in regards to people with disabilities. Disability studies has evolved as a means of addressing how people with disabilities have been treated historically and how they continue to be treated. Once seen through a medical model as people who are sick and

in need of a cure, through a sociological model where people with disabilities are labelled and stigmatized by others, or through a psychological model where their experiences have been individualized and pathologized, people with disabilities are now being seen through different perspectives. Although medical and psychological models are still present, they are being resisted by a relatively new field called disability studies, its philosophy being that disability is a social construction. While disability studies does not deny that there are differences, either physical or mental, between people, they argue that "the nature and significance of these differences depend on how we view and interpret them" (Bogdan and Taylor, 1994). Therefore, rather than seeking to "fix" a person or to separate him or her from the rest of society, a disability studies perspective would seek to problemitize society rather than the individual. The solution therefore lies not in the person, but rather in breaking down the barriers that limit people with disabilities from full participation in their communities and in society in general.

Disability studies seek to examine the social, economic, and political forces that for years have served to marginalize and oppress people with disabilities. The field has emerged over the last several years, drawing on theories and perspectives from sociology, social science, women's studies, cultural studies, and education. It often focuses on the idea that people with disabilities are a minority group who has been discriminated against. In this sense, the study of disability is similar to the study of race, class, and gender inequalities. In addition, disability studies provide the intellectual and methodological tools needed to create disability research and policy. The theories and philosophies of disability studies can then be applied to real issues in the law, in community inclusion, and in public policy.

The field of disability studies continues to grow and change. Recent additions to the field such as feminist disability studies and cultural studies have challenged "traditional" disability studies, and have forced the field to be more inclusive of different perspectives and positions in society. Moreover, disability studies most often focuses on issues around people with physical, rather than cognitive disabilities. One major challenge for the future of disability studies is the inclusion of the experiences of people with cognitive disabilities and how they shape this emerging field.

This package provides current information about the field of disability studies. In order to address this next challenge to disability studies, we have annotated very recent books (and just a few journal articles) about disability studies. They are divided into the following sections: disability studies texts, feminist disability studies, personal narratives/autobiographies, and movies and documentaries. Next, we have included a number of academic programs around the country which offer coursework and degrees in disability studies, as well as a list of journals and magazines and membership societies all pertaining to disability studies. Following this is a small section on Internet resources on disability studies. At the end, we have included an article by Steve Taylor from Disability Studies Quarterly regarding the construct of mental retardation and disability studies. Also included in this reprint is a selected annotated bibliography that includes information on a number of books that address the same issue. The last section is a reprint of several articles from Radical Teacher, which recently devoted a large section of its publication to the field of disability studies.

Reference

Bogdan, R., & Taylor, S. J. (1994). *The social meaning of mental retardation: Two life stories*. New York: Teachers College

Disability Studies Texts

The following section is comprised of books that could be used as "text books" for a disability studies course. Most of them are edited books that cover a variety of topics such as disability rights, identity politics, cultural studies and disability, social perspectives on disability, and perspectives of people with disabilities. Also included are a number of fictional pieces and poetry. It is worthy of note that the majority of this material is written from the perspective of or includes the perspective of only those with physical disabilities. Unfortunately, over the past several years, "texts" such as these which include developmental disability and disability studies have not been published. For a disability studies perspective (from less recent texts) which incorporates developmental disabilities, see the annotations by Steve Taylor and Perri Harris which are located at the end of this information packet.

TITLE: Nothing about us without us: Disability oppression and empowerment

AUTHOR: Charlton, J. I.

PUBLICATION INFORMATION: 1998

University of California Press 2120 Berkeley Way Berkeley, CA 94720 FAX 510-643-7127 http://www-ucpress.berkeley.edu/

The author uses a disability rights standpoint to discuss the international oppression of people with disabilities. He provides a theoretical framework for understanding disability oppression not as something that has come from the attitudes of people without disabilities, but because of systems and structures of oppression from which these attitudes stem. He uses interviews with disability rights activists from around the world to back his argument.

TITLE: Speechless: Facilitating communication for people without voices

AUTHOR: Crossley, R.

PUBLICATION INFORMATION: 1997

Dutton
Penguin USA
375 Hudson Street
New York, NY 10014
http://www.penguin.com/

Rosemary Crossley has been a pioneer of and outspoken advocate for facilitated communication since the 1970s. Her latest book, *Speechless: Facilitating communication for people without voices*, is an in-depth look at the experiences of 18 individuals who use facilitated communication. She describes the frustrations and complexities they face in their attempt to make themselves understood by others in their environment. She also explains the process of using facilitated communication, answering many of the questions raised about FC and demystifying many of the aspects of it that have troubled others.

TITLE: The disability studies reader

AUTHOR: Davis, L. J. (Ed.).

PUBLICATION INFORMATION: 1997

Routledge 29 West 35th Street New York, NY 10001 212-216-7800 FAX 212-564-7854

http://www.thomson.com/routledge

This edited reader is a collection of classic and new essays, as well as fiction and poetry, in the field of disability studies. This perspective places disability in a political, social, and cultural context that theorizes the construction of disability in this society. The authors address such areas as feminist theories of disability, the construction of deafness, and disability as metaphor. The book is divided into seven sections, including historical perspectives, politics of disability, stigma and illness, gender and disability, disability and education, disability and culture, and fiction and poetry. This is progressive reading, but it should be of note that it is traditional in the sense that disability studies translates to "physical disability studies" and there is little mention of developmental disability.

TITLE: Staring back: The disability experience from the inside out

AUTHOR: Fries, K. (Ed.).

PUBLICATION INFORMATION: 1997

Plume
Penguin Putnam Inc.
375 Hudson Street
New York, NY 10014
http://www.penguin.com/

This book, edited by Kenny Fries, explores the experience of disability through writings by contributors who have disabilities. The collection includes nonfiction, poetry, fiction, and drama by such authors as Nancy Mairs, John Hockenberry, Anne Finger, Adrienne Rich, Mark O'Brien, and Marilyn Hacker. Each chapter explores disability not as something that limits one's life, but as an experience all its own. Fries considers the theme of this edited book as one of human

connection, "connection with the past, connection with one another, connection with our bodies, connection with ourselves."

TITLE: The disabled God: Toward a liberation theology of disability

AUTHOR: Eiesland, N.

PUBLICATION INFORMATION: 1997

Abingdon Press 201 Eighth Ave. South P. O. Box 801 Nashville, TN 37202-0801 1-800-251-3320

Through this book, Eiesland, who became disabled as a child when she had polio, helps the reader to see how the "hidden history" of conventional bodies living ordinary lives with grace and dignity, disgust and illusion, can make for both a theological and pastoral contribution. Arguing for a liberation theology, she calls on us to move away from our defining of people with disabilities as people who need to adjust to a minority group that is subject to social stigmatization. While her examples tend to be based on the experiences of people with physical disabilities, what she has to say also is insightful for those working to include people with developmental disabilities in faith communities.

TITLE: Disability and culture

AUTHORS: Ingstad, B., & Whyte, S. R. (Eds.).

PUBLICATION INFORMATION: 1995

University of California Press 2120 Berkeley Way Berkeley, CA 94720 FAX 510-643-7127

http://www-ucpress.berkeley.edu/

This edited book takes a global look at disability. Each chapter reflects understandings of disability from different cultures. Its anthropological focus examines the relationship between disability and culture, explaining disability in terms of social processes from a multicultural perspective. Contributing authors, who have done research in places such as Borneo, Kenya, Uganda, Nicaragua, as well as Europe and North America, explore the meanings of different types of disabilities to different cultures, and seek to understand the assumptions about humanity and personhood derived from their understandings of disability.

TITLE: Claiming disability: Knowledge and identity

AUTHOR: Linton, S.

PUBLICATION INFORMATION: 1998

New York University Press 70 Washington Square South New York, NY 10012-1091 1-800-996-6987 FAX 212-995-3833

mailto:orders@nyupress.nyu.edu/ http://www.nyupress.nyu.edu/

In this new book, Simi Linton studies disability in relation to identity. She argues that disability studies must understand the meanings people make of variations in human behavior, appearance, and functioning, not simply acknowledge that these variations "exist." Linton explores the divisions society constructs between those labeled disabled and those who are not. She avoids a medicalized discussion of disability and promotes the notion that people with disabilities need to claim their identities as disabled and as contributing members to the understanding of disability as a socio-political experience.

TITLE: Disability studies/Not disability studies

AUTHOR: Linton, S.

PUBLICATION INFORMATION: 1998

Disability & Society, 13(4), 525-540.

In this article, Simi Linton seeks to define the boundaries between what should be considered disability studies and what should not. For reasons that she outlines, she proposes that curriculum and research that emphasize intervention should be viewed as separate from disabilities studies, which is a socio-political-cultural examination of disability. Linton advocates a liberal arts-based model similar to that which frames women's studies and African-American studies.

TITLE: End results and starting points: Expanding the field of disability studies

AUTHORS: Makas, E., & Schlesinger, L. (Eds).

PUBLICATION INFORMATION: 1996

Society for Disability Studies c/o Robert Scotch School of Social Science University of Texas Box 830688, Mail Station GR3.1 Richardson, TX 75083-0688 http://www.wipd.com/sds/ This edited book is comprised of chapters from extended abstracts of some of the presentations given at the Society for Disability Studies in Rockville Maryland in 1994. The authors discuss numerous topics relating to disability studies, although the focus is almost exclusively physical disabilities. The book is divided into sections, including: Disabiling and Nondisabling Images of Disability, Family Reactions to Disability, Cultural Differences in Response to Disability, Acknowledging Challenges to Self Determination, A Progress Report on the ADA, Increasing Access to Services, Designing Relevant Research, Expanding Approaches to Disability, Contact and Communication as Vehicles for Change, Self Definition and Self Support, and The Power of Community as an Agent of Social Change.

TITLE: The body and physical difference: Discourses on disability

AUTHORS: Mitchell, D. T., & Snyder, S. L. (Eds.)

PUBLICATION INFORMATION: 1997

The University of Michigan Press 839 Greene Street, P.O. Box 1104 Ann Arbor, Michigan 48106-1104 mailto:umpress-www@umich.edu http://www.press.umich.edu/

This edited book by Mitchell and Snyder seeks to introduce disability studies to the humanities by exploring how writers have used physical and cognitive disabilities in literature. The chapters explore how disability is seen in our culture in relation to "aberrance" and "normalcy," and explores the meanings of health, the construction of the body, citizenship, and morality in relation to disability. The authors present a variety of literary perspectives in two parts. Part I is "Representations in History," and chapters include such topics as "Constructions of Physical Disability in the Ancient Greek World: The Community Concept" by Martha Edwards; "Defining the Defective: Eugenics, Aesthetics, and Mass Culture in Early Twentieth-Century America" by Martin S. Pernick; and "Conspicuous Contribution and American Cultural Dilemmas: Telethon Rituals of Cleansing and Renewal" by Paul K. Longmore. Part II is "A History of Representations," and includes chapters such as "Feminotopias: The Pleasures of 'Deformity' in Mid-Eighteenth-Century England" by Felicity A. Nussbaum; "The "Talking Cure' (Again): Gossip and the Paralyzed Patriarchy" by Jan Gordon; and Disabled Women as Powerful Women in Petry, Morrison, and Lorde: Revising Black Female Subjectivity" by Rosemarie Garland Thomson.

TITLE: Perspectives on disability (Second Edition)

AUTHOR: Nagler, M. (Ed.).

PUBLICATION INFORMATION: 1993

Health Markets Research 851 Moana Court Palo Alto, CA 94306 In this second edition edited by Mark Nagler, he once again explores the meaning of disability in our society. Using an interdisciplinary perspective, he offers articles by sociologists, psychologists, therapists, and others to explore the ways in which disability is constructed and understood. The book includes a foreword by Evan Kemp Jr. and an introduction by Nagler. He divides the book into the following sections: "What it means to be disabled," "Society and disability," "The family and disability," "Sexuality and disability," "Medical and psychological issues and disability," "Education, employment, social planning and disability," and "Legal and ethical issues and disability." The selections for this second edition are good, but there are not many articles relating to people with developmental disabilities. This is the one main weakness of this text.

TITLE: The ABC-CLIO companion to the disability rights movement

AUTHOR: Pelka, F.

PUBLICATION INFORMATION: 1997

ABC-CLIO, INC 130 Cremona Drive, P.O. Box 1911 Santa Barbara, CA 93116-1911 http://www.abc-clio.com/

This text is a general introduction to the disability rights movement and the people and court cases that support or challenge it. It includes entries on such people as Ed Roberts and Judy Heumann. The book is organized as a dictionary, and has references from every aspect of the disability rights movement, from court cases to famous people, to historical events and disability culture. It also includes a chronology, beginning with the founding of the American School for the Deaf in 1817 and concluding in 1996.

TITLE: Teaching sociology of disabilities

AUTHORS: Schlesinger, L., & Taub, D. (Eds.).

PUBLICATION INFORMATION: 1998

American Sociological Association (ASA) Teaching Resources 1722 N Street, N.W. Washington, DC 20036 http://www.asanet.org/

Teaching sociology of disabilities is a collection of syllabi and instructional materials on disability issues. It can be purchased by ASA members for \$17.00 and by non-ASA members for \$21.00. A copy can be downloaded from the ASA web site at no charge.

Amazon.com

This is a list of books we found on the web site Amazon.com, which is probably the most well known on-line bookstore. Their address is http://www.amazon.com/. We found these books either under the heading "Disability Studies" or "Sociology of Disability," and have listed books that have recently been published or are to be published within the next year. We have not read these books, and therefore cannot attest to the content. We are basing this list only on titles.

Disability Studies: A Reader
Stuart Carruthers, Jim Sandu/Paperback/To be published in 1999

The Disability Reader: Social Science Perspective
Tom Shakespeare (Editor)/Hardcover and Softcover/To be published in June 1998

Sexuality and People with Intellectual Disability Lydia Fegan, et al/Hardcover/Published 1997

Gender and Disability: Women's Experiences in the Middle East Lina Abu-Habib/Paperback/Published 1997

Struggles for Inclusive Education: An Ethnographic Study (Disability, Human Rights and Society)

Anastasia D. Vlachou/Paperback/Published 1997

Disability and Society: Emerging Issues and Insights (Longman Sociology Series)
Len Barton (Editor)/Paperback/Published 1996.

Beyond Disability: Towards an Enabling Society (Open University Set Book) Gerald Hales (Editor)/Hardcover/Published 1996

The Sexual Politics of Disability: Untold Desires
Tom Shakespeare, et al/Hardcover/Published 1996

In Search of Freedom: How Persons with Disabilities Have Been Disenfranchised from the Mainstream of American Society

Willie V. Bryan/Paperback/Published 1996

Understanding Disability: From Theory to Practice
Michael Oliver/Paperback/Published 1996

Bad-Mouth ing: The Language of Special Needs
Jenny Corbett/Hardcover/Paperback/Published 1995

Disabling Laws, Enabling Acts: Disability Rights in Britain and America (Law and Social Theory)

Caroline Gooding/Hardcover/Published 1995

Enforcing Normalcy: Disability, Deafness, and the Body Lennard J. Davis/Paperback/Published 1995

The Eye of the Beholder: Deformity and Disability in the Graeco-Roman World Robert Garland/Hardcover/Published 1995

Feminist Disability Studies

The books and articles selected for this section represent a recently recognized branch of disability studies: feminist disability studies. This field may have begun with British women such as Jenny Corbett and Jenny Morris, who take a feminist stance that the personal is political, and explore their lives as women with disabilities through this political lens. More recently, feminist scholarship in the United States has begun to explore disability studies within feminism. Scholars such as Rosemarie Garland Thomson call for feminist to recognize disability as a category of otherness, such as race, class, gender, and sexual orientation, and to locate feminist disability studies in the broader area of identity politics.

The selections here represent just some of the voices and perspectives in this relatively new and rapidly growing field. Many of these are also included in the information package, <u>Women with Disabilities: Issues, Resources, Connections, Revised.</u>

TITLE: Redrawing the boundaries of feminist disability studies

AUTHOR: Garland Thomson, R.

PUBLICATION INFORMATION: 1994

Feminist Disability Studies, 20(3), 583-597.

In this review essay, Rosemarie Garland Thomson argues for the recognition of feminist disability studies within feminism. She states that feminist critical analysis does not usually recognize disability as a category of otherness (as it does with race, class, and gender) unless the study specifically states this focus. Although helpful, she would like to see a shift away from women's autobiographical accounts of their own experiences with disability, which often promote the "disaster/terror/pity scenario of disability", to an articulation of feminist disability studies as a "major critical subgenre within feminism." She asserts that feminist disability studies can be located in the broader area of identity politics if discourses of the body marked as deviant are included. To illustrate her argument, Thomson draws on four feminist works. The first three, Invalid women: Figuring feminine illness In American fiction and culture, 1840-1940 by Diane Price Herndl, Monstrous imagination by Marie-Helene Huet, and Tattoo, torture, mutilation, and adornment: The denaturalization of the body in cultural text edited by Frances E. Mascia-Lees and Patricia Sharpe, do not deal with "disability" specifically, instead, Thomson interprets these works in a feminist disability studies perspective. She uses the fourth book, Barbara Hillyer's Feminism and disability because it specifically addresses the issue of disability and feminism, and because it embodies the feminist principle that the personal is political. Thomson hopes that these four books introduce perspective into the emerging field of feminist disability studies.

TITLE: Feminism and disability

AUTHOR: Hillyer, B.

PUBLICATION INFORMATION: 1993

University of Oklahoma Press 1005 Asp Avenue Norman, OK 73019-0445 http://www.ou.edu/oupress/

Written out of a need in the feminist movement to include women with disabilities and a need in the disability rights movement to address the unique experiences of women, *Feminism and disability* combines the personal, political, and intellectual aspects of feminist theory and disability theory. Hillyer discusses such issues as body awareness, community, nature and technology, and the ways in which cultural standards of language, independence, and even mother-blaming are constructed. She also challenges political movements which stress productivity and normalization in order to include more types of people and more aspects of the human condition.

TITLE: What happened to you? Writings by disabled women

AUTHOR: Keith, L. (Ed.).

PUBLICATION INFORMATION: 1996

The New Press 450 West 41 Street New York, NY 10036

http://www.wwnorton.com/newpress/welcome.htm

Lois Keith compiled collections of fiction, essays, and poetry by disabled women in her new book, *What happened to you?* Her goal is to give women with disabilities a space to express their views on such topics as abuse, equality, sexuality, prejudice, and legislation dealing with disability issues. These narratives construct disability as a cultural and political issue, not only as a personal one.

TITLE: Mustn't grumble: Writings by disabled women

AUTHOR: Keith, L. (Ed.).

PUBLICATION INFORMATION: 1994

The Women's Press 34 Great Sutton Street London EC1 V0DX ENGLAND

<u>mailto:jas@interbooks.com</u> <u>http://www.the-womens-press.com/</u>

This edited book, compiled by a woman with a disability, presents writings by other women who have a range of physical disabilities. The short stories and poems included in this book range in

topic from issues of accessibility to abuse to equality. Disability is framed by these narratives as a social, cultural, and political issue, not only as a personal one. This is an excellent account of disability issues from a woman's perspective. It is powerful, moving, and educating for all readers.

TITLE: Does she boil eggs? Towards a feminist model of disability

AUTHOR: Lloyd, M.

PUBLICATION INFORMATION: 1992

Disability, Handicap & Society, 7(3), 207-221.

The author examines disability from the perspective of women with disabilities. She focuses on the social model of disability rather than a medical model and asserts that disability is another form of oppression experienced by women. She argues that disabled women have been excluded from both the women's movement, which is oriented toward non-disabled women, and from the disability rights movement, which is oriented toward disabled men. Using the history of black feminism, the author argues for a reframing of the analysis in which to explore the simultaneous experiences of gender and disability.

TITLE: Women and disability

AUTHOR: Lonsdale, S.

PUBLICATION INFORMATION: 1990

St. Martin's Press 175 Fifth Avenue New York, NY 10010 http://www.stmartins.com/

Lonsdale explores how women with physical disabilities experience the double discrimination of being both a woman and a person with a disability in society. Placing physical disability in a social and political context rather than an individual one, she uncovers how women with disabilities have been rendered invisible, how they see their self image and body image, how physical disability often leads to dependence, and how women experience a loss of civil liberties and how they face discrimination. Lonsdale also considers the ways in which these situations can change for women, specifically, how policy practices can change so women can achieve greater independence. Chapters include subjects such as the social context of disability, invisible women, self-image and sexuality, employment, financial consequences of disability, discrimination, and independence.

TITLE: Feminism and disability

AUTHOR: Morris, J.

PUBLICATION INFORMATION: 1993

Feminist Review, 43, 57-70.

The author discusses the absence of women with disabilities from feminist scholarship and feminist theory. Morris claims that a significant failure of feminism is that it fails to incorporate disabled women into its politics, theory, research, and methodology. She argues that feminist theory would benefit from the inclusion of the concerns and experiences of disabled women, and that feminist theory and feminist methodology have major contributions to make to the disability research. The author discusses her anger and frustration with feminism in two ways: first, that disability is generally invisible from feminism's mainstream agenda, and second, that when disability is a subject of research by feminists, the researchers objectify disabled people so that the research is alienated from their experiences rather than attempting to understand the experiences of disabled women.

TITLE: Personal and political: A feminist perspective on researching physical disability

AUTHOR: Morris, J.

PUBLICATION INFORMATION: 1992

Disability, Handicap & Society, 7(2), 157-166.

Morris asserts that feminist theory and methodology have largely ignored and alienated women with disabilities and the research conducted by disabled people. She argues the feminist theory needs to take up the challenge of applying their principles to the study of disability and to examine the lives of disabled women. In turn, Morris feels that disabled women and disability research in general has much to learn from feminist methodology; mainly the principle of making the personal political. In addition, Morris outlines the role she sees for nondisabled researchers interested in researching disability-related issues. She views the role of the non disabled researcher as an ally, and calls on non disabled as well as disabled researchers to continue to study the ways in which the non disabled society oppresses its members with disabilities. Lastly, she argues that disability research is of great importance in the general understanding of the perpetuation of inequalities in society.

TITLE: Pride against prejudice

AUTHOR: Morris, J.

PUBLICATION INFORMATION: 1991

New Society Publishers
P.O. Box 189
1680 Peterson Rd
. Gabriola Island, BC V0R 1X0
CANADA
mailto:nsp@island.net

http://www.newsociety.com/

Morris, a disabled feminist and activist, provides a feminist analysis to the study of the experiences of women with disabilities. Basing her arguments on the feminist principle that the personal is political, Morris eloquently challenges such issues as prejudice, abortion, and the notion that people with disabilities lead lives that are not worth living. She further discusses the history of people with disabilities in institutions and under the Nazi regime. Morris also examines the meaning of disability in Western culture and the meanings of history of segregation, dependence, and an emerging independence of people with disabilities. Pride against prejudice is a commentary on political activism and rights, and stresses the need to fight back against the prejudice, stereotypes, and oppression of an abelist culture.

TITLE: The lives of women with mental retardation: A multiple minority perspective

AUTHOR: Olson, D. L.

PUBLICATION INFORMATION: 1991

Unpublished doctoral dissertation Syracuse University Syracuse, NY 13244

This dissertation by Deborah Olson explores the lives of women labeled mentally retarded. She argues that this label, along with their gender, has placed these women in the disadvantageous position of being in a multiple minority group. Through in-depth interviews with five women labeled mentally retarded, Olson seeks to understand how they see themselves as women with mental retardation and how they interact with people who have impact on their lives. The major finding from this work is that women with a label of mental retardation are more prepared to handle disability discrimination than gender discrimination, and that the women's movement has not provided them with the awareness of choices it has provided for other women who do not have cognitive disabilities.

TITLE: Toward a feminist theory of disability

AUTHOR: Wendell, S.

PUBLICATION INFORMATION: 1997

In L. J. Davis (Ed.)., *The disability studies reader* (pp. 260-278). New York: Routledge.

Routledge 29 West 35th Street New York, NY 10001 212-216-7800 FAX 212-564-7854

http://www.thomson.com/routledge

The author argues that disability is not a "biological given," rather it is a social construction of biological reality (like gender) and because of this, the fact that 16% of women have disabilities,

and that feminist thinkers have raised the most radical issues concerning cultural attitudes to the body, a feminist theory of disability is needed. Wendell argues that those with disabilities are constructed as "the other" and because of this are seen as failing to control their bodies (control of our bodies is demanded by society) and as symbolizing the threat of pain, limitation, dependency, and death. She calls for people with disabilities and their knowledge and experience with their bodies to be fully integrated into society, and concludes that in this way bodies would be liberated.

TITLE: The rejected body: Feminist philosophical reflections on disability

AUTHOR: Wendell, S.

PUBLICATION INFORMATION: 1996

Routledge 29 West 35th Street New York, NY 10001 212-216-7800 FAX 212-564-7854

http://www.thomson.com/routledge

In *The rejected body*, Susan Wendell, a woman with Chronic Fatigue Syndrome, draws parallels between her own experiences with illness to feminist theory and disability studies. She argues (as many others have), that feminist theory has neglected to incorporate the perspectives and experiences of women with disabilities, and that these perspectives must be included in future discussions of feminist ethics, the body, and the social critique of the medical model. Wendell also examines how cultural attitudes about the body contribute to disability oppression and society's unwillingness to accept different types of bodies.

Autobiographies/Personal Narratives

This section highlights some of the current autobiographies and personal narratives of people with disabilities. This is just a sampling, since the previous annotated bibliographies in this packet have presented a much more detailed list.

TITLE: Life as we know it: A father, family, and an exceptional child

AUTHOR: Bérubé, M.

PUBLICATION INFORMATION: 1996

Vintage Books
Random House, Inc.
Customer Service, Dept. #05001
Random House Distribution Center
400 Hahn Road
Westminster, MD 21157

<u>mailto:customerservice@randomhouse.com</u> http://www.randomhouse.com/

This remarkable book is a father's story of the life of his 4-year-old son James, who has Down syndrome. It is far more than just a personal memoir of his son's birth and young life. In following the developmental stages, social experiences, and involvement with social services that James passes through, Bérubé explores their social implications, including such topics as IQ testing, the politics of education, disability law, social services, health care, and entitlements. Implicit in these discussions are not just his own family's experiences in these realms, but also concepts such as social justice, what it means to be human, and what kind of society is valued and by what means we determine this value.

TITLE: Body, remember

AUTHOR: Fries, K.

PUBLICATION INFORMATION: 1997

Plume
Penguin Putnam Inc.
375 Hudson Street
New York, NY 10014
http://www.penguin.com/

In this memoir, Kenny Fries explores his life and experiences with his disability. Having been born with congenital deformities that affected the lower part of his body, Fries searches medical records, talks with family and friends, and examines past relationships in order to better understand his disability. In addition to an understanding of his physical body, Fires also explores his sexuality and personal relationships. This is a memoir about disability, but it is also about the discovery and understanding of his identity.

TITLE: Thinking in pictures: And other reports from my life

AUTHOR: Grandin, T.

PUBLICATION INFORMATION: 1995

Bantam Doubleday Dell Publishers Groups, Inc.
1540 Broadway
New York, NY 10036
mailto:webmaster@bdd.com
http://www.bdd.com/

Thinking in pictures is about the childhood and development of Temple Grandin, a woman with autism. She likens herself to the robotic character, Data, on the science fiction television program, **Star Trek: The Next Generation**. She says words are like a second language to her, noting that she thinks primarily in images. Grandin, who holds a Ph.D. in animal science and has

designed equipment that revolutionized the livestock industry, proposes that genius and autism may sometimes be closely related.

TITLE: Moving violations: War zones, wheelchairs, and declarations of independence

AUTHOR: Hockenberry, J.

PUBLICATION INFORMATION: 1995

Hyperion 114 Fifth Avenue New York, NY 10011

Moving violations is an honest and often humorous account of Hockenberry's life as a man with a disability. He takes the reader on a journey in which he reflects upon the events in his life, from the accident that, at age 19, caused a spinal cord injury to his work as a nationally renown broadcast journalist. He does not flinch at talking about the personal aspects of disability. And he shares the adventures of his career, such as riding a mule up a mountainside with Kurdish refugees who were being driven from their land by the Iraqis after Desert Storm. Hockenberry also explains how his disability, rather than limiting him, is a window through which he frames his view of the world---how it expands his gaze and gives him insight that defines who he is and what he does.

TITLE: Bus girl: Poems by Gretchen Josephson

AUTHORS: Lubchenco, L. O., & Crocker, A. C.

PUBLICATION INFORMATION: 1997

Brookline Books
P.O. Box 1047
Cambridge, MA 02238
mailto:BROOKLINEBKS@delphi.com
http://people.delphi.com/brooklinebks/index.html

This book consists of 25 poems written by Gretchen Josephson, a woman with Down syndrome. She started writing poetry while still in her teens, when she began a job as a bus girl at a restaurant. Her poetry chronicles her life experiences with family, friends, love, and other areas of life. The editors have divided her poetry into sections, which include Bus Girl, Love for Always, Vacations and Travel, Family, Death and Greed, Faith, and Other Poems. Unlike other artistic works such as *Musn't grumble* edited by Lois Keith, Josephson does not write about disability. Instead, she simply creates poetry about her life.

TITLE: Waist-high in the world: A life among the disabled

AUTHOR: Mairs, N.

PUBLICATION INFORMATION: 1997

Beacon Press 25 Beacon Street Boston, MA 02108 617-742-2100

mailto:lpemstein@beacon.org http://www.uaa.org/Beacon/

Nancy Mairs, a brilliant essayist and poet who has authored six previous books, reflects upon her experiences as a woman with multiple sclerosis in *Waist-high in the world*. She discusses such topics as adjusting to change, reconciling body image, experiencing sexuality and pleasure, and seeking equality and justice. She also probes other disability issues, such as assisted suicide and selective abortion, and she revisits an article she once wrote for Glamour magazine that focused on young people with disabilities.

TITLE: The me in the mirror

AUTHOR: Panzarino, C

PUBLICATION INFORMATION: 1994

Seal Press
3131 Western Ave., Suite 410
Seattle, WA 98121-1041
mailto:sealprss@scn.org
http://www.sealpress.com/

Written by writer, disability activist, and artist Connie Panzarino, *The me in the mirror* is an autobiography of the life of this amazing woman. Born with Spinal Muscular Atrophy Type III, a rare disease, Panzarino describes her life as one of struggles and triumphs, and tells the stories of her relationships with her family, friends, lovers, her turn to lesbianism, and of her years of pioneering work in the disability rights movement. This book is a must read for anyone interested in understanding the experiences of women with physical disabilities.

TITLE: Nobody, nowhere: The extraordinary autobiography of an autistic

AUTHOR: Williams, D.

PUBLICATION INFORMATION: 1992

Avon Books
1350 Avenue of the Americas
New York, NY 10019
http://www.avonbooks.com/avon/about.html

Donna Williams, who was diagnosed with autism when in her mid 20s, wrote *Nobody, nowhere* in an attempt to understand herself and to explore how she fit into the world around her. She candidly describes the teasing and mistreatment she experienced at the hands of her family and her ability to use role-playing to interact with others. Williams said of her book, "This is a story

of two battles, a battle to keep out 'the world' and a battle to join it. I have, throughout my private war, been a she, a you, a Donna, and finally, an I."

TITLE: Somebody somewhere: Breaking free from the world of autism

AUTHOR: Williams, D.

PUBLICATION INFORMATION: 1994

Times Books
Random House Trade Group
New York, NY
http://www.randomhouse.com/trade/

This autobiography by Donna Williams poignantly and defiantly illustrates her life and struggle with autism. She powerfully articulates her "awakening to the world" and how she fought for others to do the same. She presents her perspective of autism and reminds the readers that it is crucial that they seek to understand her perspective and the perspectives of others with autism rather that imposing their own notions onto someone else. She asserts that she has taken control of her autism, that it does not control her.

TITLE: Like colors to the blind

AUTHOR: Williams, D.

PUBLICATION INFORMATION: 1996

Times Books
Random House Trade Group
New York, NY
http://www.randomhouse.com/trade/

Like colors to the blind is Donna Williams' third book about her life as a person with autism. When she was diagnosed with autism at the age of 25, she wrote Nobody, nowhere as an attempt to explore her experiences as a person with autistic symptoms. In her sequel, Somebody, somewhere, she continued to analyze how role playing and ritualistic behavior helped her to cope with her environment, and how she was able to begin to replace these mechanisms with genuine interactions. This, her latest work, builds upon the last, addressing relationships and emotions. Williams describes her relationship with Ian, who became her best friend and eventually her husband.

TITLE: Women with disabilities: Found voices

AUTHORS: Willmuth, M., & Holcomb, L.

PUBLICATION INFORMATION: 1994

The Haworth Press. Inc. 10 Alice Street Binghamton, NY 13904-1580 mailto:getinfo@haworthpressinc.com

http://www.haworthpressinc.com/

Written almost entirely by woman with disabilities, Women with disabilities: Found voices is a deeply personal and compelling discourse of the body, violence, sexuality, and disability. The authors offer a multicultural perspective which speaks frankly about their experiences. They discuss the abuses they have endured and explain how they have struggled with the issue of being a woman with a body that does not conform to the image that society values.

Movies and Documentaries

This section offers just a few of the many movies and documentaries which are related to the field of disability studies. We have highlighted a select few that reflect a variety of perspectives, and have listed many more (the more mainstream films). For descriptions of these films, we recommend the web site of the Office of Special Education at the University of Virginia, Individuals with Special Needs in Films. Their web address is:

http://curry.edschool.virginia.edu/go/cise/ose/information/film

Another web site to refer to is "Films Involving Disabilities." The web address is:

http://www.disabilityfilms.co.uk/

You may also want to check under a more general directory. For that, we recommend the Internet Movie Database. Its address is:

http://us.imdb.com/

While we certainly would recommend many of these titles, we are not certain of the availability of all of them.

TITLE: **Breathing lessons**

DIRECTOR: Jessica Yu

PRODUCER: Inscrutable Films

DATE: 1996

35 minutes

The award-winning documentary, **Breathing lessons**, addresses what life as a person with a disability is like from the perspective of Mark O'Brien. O'Brien, who is a poet and journalist, is paralyzed and uses an iron lung. Through his poetry and his insightful commentary, he reflects on such issues as the meaning of life, death, sex, relationships, creativity, and religion.

TITLE: Brother's keeper

DIRECTORS: Joe Berlinger and Bruce Sinofski

PRODUCER: American Playhouse Theatrical Films

DATE: 1992

120 minutes

The lives of the Ward brothers, farmers in a rural community in upstate New York, are disrupted when the oldest brother, Bill, dies and his brother, Delbert, is accused of his murder. Brother's keeper focuses on the outpouring of support Delbert received from the community. To the townspeople, the Ward boys, as they were affectionately called--Bill, Delbert, Lyman, and Roscoe--were quiet men who lived in a run-down shack and farmed the land on which they grew up. The film chronicles the events surrounding Bill's death and Delbert's trial, including the townspeople's efforts to raise funds for Delbert's defense, their support of his innocence, and their refusal to see the Ward brothers through the lens of mental retardation.

TITLE: Self Advocates Becoming Empowered

PRODUCER: Act Video Products

DATE: 1997

20 minutes

Self Advocates Becoming Empowered is about people with cognitive disabilities forming a national organization to work on issues they deem important, such as closing institutions, exercising their rights as citizens, supporting people to live in communities, and opposing injustice in the criminal justice system. Likening their movement to the civil rights movement of the 60s, many of the advocates speak out about the importance of their mission to people with disabilities.

TITLE: Selling murder: The killing films of the Third Reich

DIRECTOR: Joanna Mack

WRITER AND RESEARCHER: Michael Burleigh

PRODUCER: Domino Films

DATE: 1991

This is a chilling Nazi propaganda film about the genocide of people with disabilities during the Second World War. Under what the Third Reich termed the "hereditary health law," they convinced doctors that killing people with mental or physical disabilities was for their own good, and the good of the Aryan nation at large. The original film makers used shadows and poor lighting to make people seem grotesque, and played on the medical model of disability in terms of what is "abnormal" and "normal," and even "human" and "not human." This is a powerful film that should generate interesting discussions if used in a disability studies class.

Please note: This film was aired on the Discovery Channel a few years ago, and we are not sure of its availability, but it is definitely worth a good search.

TITLE: Titicut follies

DIRECTOR: Frederick Wiseman

PRODUCER: Zipporah Films

DATE: 1967

83 minutes

Although more than 30 years old, *Titicut follies* remains a classic, depicting institutional life in a mental health facility. The 1967 Wiseman film is named for and centers around a talent show, the Titticut Follies, held for the inmates of the Bridgewater State Mental Hospital, in Massachusetts. While scenes from the talent show are disbursed throughout the film, the stark reality of daily life in the institution is revealed. There is little regard for the inmates' human dignity; not only is what they have to say dismissed, but they are subjected to strip searches, lack of privacy, ridicule, and isolation. *Titicut follies* is a grim film that reflects the barren existence of life in a mental hospital.

TITLE: Vital signs: Crip culture talks back

DIRECTORS: David Mitchell and Sharon Snyder

PRODUCER: Studio Pulse Communication, Green Bay, WI

DATE: 1997

48 minutes

In the documentary *Vital signs: Crip culture talks back*, participants in a national Disability and the Arts conference explore the politics of disability through their performances, which include such texts as art, fiction, poetry, stand-up comedy, drama, and personal stories. It features such disability rights activists as Cheryl Marie Wade, Mary Duffy, and Harlan Hahn, and also includes group debates and behind-the-scenes conversations. The film also addresses the culture

of disability and the shared struggle people with disability have in gaining access to influential cultural institutions.

TITLE: When Billy broke his head... and other tales of wonder

DIRECTOR AND PRODUCER: Billy Golfus and David E. Simpson

WRITER AND NARRATOR: Billy Golfus

DATE: 1995

First premiering on PBS in 1995, this film by Billy Golfus explores the concept of disability rights and takes a close look at the disability rights movement and those involved. Golfus, who has a traumatic brain injury, intertwines his story with the experiences of others who are struggling for their rights. This is a must see.

TITLE: No apologies

PRODUCERS: Disabled Women's Theatre

DATE: 1994

This 28-minute video is by Wry Crips Disabled Women's Theatre, which is a comedy troupe of women who are at the forefront of the disability culture movement in the San Francisco Bay area. It is comprised of disabled and able-bodied women of diverse racial, social, and class background. Wry Crips uses humor as a form of resistance. Their performances, comprised of poetry, readings, signing, performing skits, and reading narratives, all resist medical paradigms, social stereotypes, economic oppression, or individualist assumptions regarding disability issues. The women of Wry Crips embrace disability, seeing beauty and acceptance where able-bodied people only see difference and abnormality.

LIST OF MORE MAINSTREAM FILMS

Awakenings
Benny and Joon
The Big Parade
Born on the Fourth of July
Charly
Children of a Lesser God
Coming Home
Dominick and Eugene
The Elephant Man
Forrest Gump
Freaks
Gattaca
Mask

The Miracle Worker
My Left Foot
One Flew Over the Cuckoos Nest
Orphans of the Storm
Passion Fish
Rain Man
Skallagrig
Sling Blade
The Waterdance
What's Eating Gilbert Grape
Whose Life is it, Anyway?

Academic Programs

The following section offers a description of colleges and universities that offer classes, programs, or concentrations in Disability Studies. They range from academic institutions that offer classes representative of the Disability Studies perspective to institutions that offer advanced degrees in this field or related fields. For an overview of Disability Studies in general, please see "Disability Studies 101: From Werewolves to Hephaetus" by Joshua Harris Prager in *The Wall Street Journal*, August 31, 1998, and "Pioneering Field of Disability Studies Challenges Established Approaches and Attitudes," by Peter Monaghan, in *The Chronicle of Higher Education*, January 23, 1998.

Academic Institution:

Syracuse University

Program Name:

Disability Studies Concentration

Address:

Cultural Foundations of Education School of Education 805 South Crouse Avenue Syracuse, NY 13244-2280

Contact:

Steven J. Taylor, Ph.D. Coordinator, Disability Studies Concentration

Phone:

(315) 443-3851

E-Mail:

staylo01@mailbox.syr.edu

www:

http://soeweb.syr.edu/thechp/disstud.htm

Location on Campus:

Cultural Foundations of Education, School of Education

Program Description:

The Disability Studies concentration applies social, cultural, historical, and philosophical perspectives to the study of disability in society. Building on the tradition of Syracuse University's School of Education in the area of disability, the concentration is designed to help students understand and work to overcome the barriers to full participation of people with disabilities in community and society.

Consistent with the Syracuse tradition, this concentration stands at the forefront of change and new ways of thinking about and accommodating people with disabilities. While it adopts a cross-disability perspective, it devotes special attention to people who have been labeled as developmentally disabled or mentally retarded.

Program Emphasis:

As a graduate student pursuing this concentration, you will have a program of study that matches your own interests with the current activities of faculty and associates. Through course work, independent studies, thesis or dissertation research, or internships at the School of Education's disability centers and institutes, you will examine a range of issues confronting people with disabilities, including deinstitutionalization and community integration, current trends and controversies, advocacy and self- advocacy, the sociology of deviance and acceptance, community and family support services, media images of disability, gender and disability, and disability policy. In addition, you will be exposed to strategies for policy analysis, program evaluation, and community education. Depending on your interests and program of study, you will be encouraged to take courses both in the School of Education and other schools at Syracuse University, including the Maxwell School of Citizenship and Public Affairs, the Law School, and the School of Social Work.

Program Requirements:

Master of Science (M.S.)

- A minimum of 24 credits beyond the bachelor's degree and a thesis (3 or 6 credits) or a minimum of 30 credits beyond the bachelor's degree and a comprehensive examination.
- An internship (3 or 6 credits) at one of the School of Education's disability centers or institutes or another organization approved by the student's advisor.
- A minimum of 3 credits of qualitative or quantitative research methodology.

Doctor of Philosophy (Ph.D.)

- A minimum of 90 credits beyond the bachelor's degree; one-half of the credits, excluding dissertation hours, may be transferred from another university with the advisor's approval.
- A minimum of 12 credits of research methodology.
- A research apprenticeship (journal quality scholarly article) completed under the supervision of a faculty member.
- Qualifying examinations.
- An internship (6 to 12 credits) at one of the School of Education's disability centers or institutes or another organization approved by the student's advisor.
- Dissertation (typically, doctoral students register for 12-24 dissertation credits during the course of their studies).

Academic Institution:

Suffolk University

Program Name:

Master's of Public Administration/Disability Studies

Address:

Eight Ashburton Place Boston, MA 02108-2770

Contact:

Professor Richard Beinecke

Phone:

(617) 573-8062

E-Mail:

ssominfo@acad.suffolk.edu

Location on Campus:

Department of Public Management of the Frank Sawyer School of Management

Program Description:

Students take three semester credit courses, and also have independent studies, an internship, and a comparative policy course in Dublin and/or Puerto Rico.

Program Emphasis:

Policy Analysis and Public Management

Program Requirements:

Nine required MPA courses plus five additional courses required by the disability studies concentration. Three additional classes are also required.

Courses offered:

Disability Rights, Disability Issues, Disability and Public Policy, The U.S. Health System, Changes in Disability Policy

Academic Institution:

University of Illinois at Chicago

Program Name:

Department of Disability and Human Development

Address:

Institute on Disability and Human Development 1640 West Roosevelt Road Chicago, IL 60516

Contact:

William J. Schiller, Clinical Assistant Professor of Human Development

Phone:

(312) 413-1536

E-mail:

wjschill@uic.edu

www:

http://www.uic.edu/depts/idhd/idhdfull.html

Location on Campus:

College of Associated Health Professionals

Degree Programs:

Masters in Disability and Human Development

Masters in Rehabilitation Technology

Ph.D. program in Disability Studies jointly developed with the Department of Occupational Therapy and the Department of Physical Therapy.

Post-doctoral research fellowships in the following areas: aging and disability, assistive technology, dual diagnosis, and policy analysis.

Program Description:

This interdisciplinary program provides students with experience and education in the College of

Associated Health Professions, the School of Public Health, and the Colleges of Education, Engineering, Social Work, and the Department of Psychology. The program provides field experience through clinical programs in assistive technology, diagnostics, and mental health for people with mental retardation. Field-based internships are also available.

Program Emphasis:

Master's Program - emphasis in the newly proposed Department of Disability and Human Development, with specializations in Disability Studies, Rehabilitation Technology, and Disability Policy and Organization.

PhD Program: The program has an interdisciplinary approach to the study of disability, examining the social, political, biological, and cultural determinants of disability. The focus of student learning may include one of the following: a socio/cultural approach to disability, policy and practice, political and economic issues, vocational issues, family issues, and many more.

The DHD web site has extensive information, including program requirements and class listings for both the Master and Ph.D. programs. Please see the URL listed above for more information.

Academic Institution:

University of Maine, Orono

Program Name:

Interdisciplinary Disability Studies

Address:

115 Corbett Hall Orono, ME 04469

Contact:

Elizabeth DePoy

Phone:

(207) 581-1469

E-Mail:

liz depoy@voyager.umeres.maine.edu

www:

http://cardinal.umeais.maine.edu/~cci/ccihi.html

Location on Campus:

Center for Community Inclusion

Program Description:

This program prepares both undergraduate and graduate students to be leaders in the field of developmental and related disabilities. It is a University-Affiliated Program (UAP) which provides an interdisciplinary education in the field of disability. The program offers practica, coursework, assistantships, and internships in university and community settings throughout the state, and is affiliated with other universities in Maine.

The College of Education, in collaboration with the Center for Community Inclusion, offers a program that prepares students to aid people with disabilities in school-to-work transition. Many of these courses are interactive television courses, which allows people from all over Maine to enroll.

Program Emphasis:

Developmental Disabilities

Program Requirements:

Students can choose elective courses from departments such as Education, Communication Disorders, Human Development, Nursing, Psychology, Sociology, Public Administration, and Social Work.

Practica also are available and are developed individually to meet the needs of students.

Degree Program:

Personnel Preparation Program for Transition Specialists

Courses Offered:

Developmental Disabilities Across the Lifespan Interdisciplinary Seminar in Developmental Disabilities (Intro and Advanced) Positive Approaches for Challenging Behavior

Academic Institution:

Medaille College

Program Name:

Disability Studies Certificate

Address:

18 Agassiz Circle Buffalo, NY 14214

Phone:

(716) 884-3281

Fax:

(716) 292-1582

www:

http://www.medaille.edu/ds.html

Program Description:

Students may receive certificates in disability studies, approved by the State Education Department. A total of 33 credit hours are required.

Program Requirements:

Students must complete each course listed below and maintain a cumulative grade point average of at least 2.00. The last 12 credit hours must be completed at Medaille College and an application for the certificate must be filed in the Office of the Registar prior to registering for the last course.

Courses Offered:

HSV 100 - Introduction to Human Services Across the Life Span or

CYS 100 - Introduction to Child and Youth Services

CYS 280 - Understanding Multicultural and Diverse Populations

HSV 120 - The Dynamics of Interviewing

HSV 210 - Introduction to Disabilities

HSV 211 - Introduction to Disability Law

HSV 285 - Workshop in Major Disabilities

HSV 301 - Program Planning and Administration

HSV 377 - Field Experience II

CYS 377 - Field Experience I (6 credits)

SSC 200 - Human Relations

WRT 175 - College Writing II

Academic Institution:

Hunter College of the City University of New York

Address:

695 Park Avenue New York, NY 10021

Phone:

(212) 772-5745

Contact:

Phyllis Rubenfeld or Simi Linton

E-Mail:

phyllis.rubenfeld@hunter.cuny.edu

Location on Campus:

Disabilities Studies Project

Program Description:

An undergraduate program in disability studies has been proposed for the 1998-1999 academic year. No further information is available.

Academic Institution:

The University of Leeds

Program Name:

MA/Diploma in Disability Studies and MA/Diploma in Disability Studies by Distance Learning

Address:

Leeds, LS2 9JT UNITED KINGDOM

Phone:

0113 233 4408

Fax:

0113 233 4415

www:

http://www.leeds.ac.uk/sociology/pgbroch.disabil.htm

Contact:

Colin Barnes, Director and Debbie Westmoreland, Postgraduate Secretary

Location on Campus:

Department of Sociology and Social Policy

Program Description:

This advanced scheme of study is designed for people working or planning a career in the field of disability, and is especially suitable for service providers, practitioners and policy makers including: educational psychologists, educationalists in further and higher education, physiotherapists, occupational therapists, social workers, community nurses, doctors, architects, town planners etc. These courses can easily be fitted in with a busy working life. Students are required to attend the University only one afternoon or one evening a week over one or two years, depending on the option chosen.

This unique and popular program of study provides students with an in-depth perspective on a wide range of disability related issues. It is offered on a modular basis, and each module is designed to give fresh insights into the concepts associated with disablement in modern society and will provide a basic grounding in the principles and theories upon which practice is based.

Program Emphasis:

Disability as an equal opportunities issue will be explored through the study of contemporary organizations and institutionalized practices. The course is designed to enable students to bridge the gap between theory and practice.

For the Diploma in Disability Studies students are required to study four modules as follows:

Module 1: Theories and definitions of disability

Module 2: Social policy, politics and disabled people

Module 3: Culture, researching disability and changing practice

Module 4: Disability project

For the MA in Disability Studies students are required to study modules 1, 2, and 3 as for the Diploma in Disability Studies and two further modules described in more detail at the WWW site at the address listed above. Information on the MA/Diploma in Disability Studies by Distance Learning can be viewed at http://www.leeds.ac.uk/sociology/pgbroch.disabdl.htm

Academic Institution:

University of Hawai'i at Manoa

Program Name:

Pacific Partnerships in Disability and Diversity Studies

Address:

Center on Disability Studies University of Hawai`i at Manoa 1776 University Ave UA 4-6 Honolulu, HI 96815

Contact Person:

David Pfeiffer, Ph.D.

Phone:

(808) 956-9202

Fax:

(808) 956-3162

E-Mail:

pfeiffer@hawaii.edu

Program Description:

Beginning September 1998, the primary disability studies program at the University is the Pacific Partnerships in Disability and Diversity Studies, which prepares students to be leaders and researchers in areas pertaining to children and youth with disabilities. The program has a dual focus designed to increase leadership personnel to implement program improvement, and to infuse cultural competence in services for children and youth with disabilities.

The program is an interdisciplinary approach, includes core seminars, research, and internship experiences.

Key components of leadership development in disability studies and cultural diversity is faculty and student mentorship. Peer mentorship also will be fostered by linking "partner" doctoral students, based on professional and personal interests in Pacific cultures.

Other programs include Maternal and Child Health Leadership Education in Neurodevelopmental and Related Disability Programs, as well as more than 20 others relating to community outreach in the Pacific Rim, Hawaiian children with mental health problems, assistive technology, and other areas.

Journals and Magazines

TITLE:

Disability & Society

ADDRESSES:

Subscriptions: 875-81 Massachusetts Avenue Cambridge, MA 02139

Submissions:

Professor Len Barton Disability & Society Division of Education University of Sheffield 388 Glossop Road Sheffield S10 2JA UNITED KINGDOM

PHONE:

1-800-354-1420

www:

http://www.carfax.co.uk/dso-ad.htm

SUBSCRIPTION RATES (annually):

Institutional: \$416 Individual: \$118

FREQUENCY:

Published 5 times a year (February, April, June, September, and November)

AVAILABILITY:

Journal and on-line (with paid subscription)

Disability & Society is an international journal providing a focus for debate about such issues as human rights, discrimination, definitions, policy and practices. It appears against a background of change in the ways in which disability is viewed and managed.

Definitions of disability are more readily acknowledged to be relative; custodial approaches are seen as inadequate and unacceptable--placing greater emphasis on community care and integration. However, policy intentions may not have the desired effects on the realities of everyday practice and policy changes themselves may be merely cosmetic, or appropriate but unfunded.

While publishing articles that represent all the professional perspectives, the journal also provides an opportunity for the consumers of the services to speak for themselves.

TITLE:

Disability Studies Quarterly

ADDRESSES:

Subscriptions:
David Pfeiffer
Center on Disability Studies
University of Hawai'i at Manoa
1776 University Avenue, UA-4-6
Honolulu, HI 96822

Submissions:

Every article published in the *Quarterly* is invited and reviewed by the editor or special editor. A call for manuscripts on specific topics is usually announced in each issue. Contributions or suggestions can be sent to David Pfeiffer at the address above.

SUBSCRIPTION RATES (annually):

Institutional \$45 Individual \$35 SDS member \$30 Student \$20 Low-income Whatever is affordable

(FYI: Subscription is not included in membership)

FREQUENCY:

Published 4 times a year by the Society for Disability Studies.

AVAILABILITY:

Journal, diskette, or via e-mail.

The *Disability Studies Quarterly* is a multidisciplinary and international journal of interest to social scientists, scholars in the humanities, disability rights advocates, and others concerned with the problems of people with disabilities. The purpose of the Quarterly is to provide a place where people from diverse backgrounds can share ideas and to engage in dialogues that cut across disciplinary backgrounds and substantive concerns. The *Quarterly* is committed to developing theoretical and practical knowledge about disability and to promoting the full and equal participation of persons with disabilities in society.

TITLE:

Journal The Association Of Persons With Severe Handicaps (JASH)

ADDRESSES:

Subscriptions: 29 W. Susquehanna Avenue Suite 210 Baltimore, MD 21204 (410) 828-8274 FAX (410) 828-6706

Submissions:

Lori Goetz, Editor JASH Editorial Offices

Department of Special Education & Communicative Disorders

San Francisco University

1600 Holloway Avenue

San Francisco, CA 94132

(415) 338-1306

SUBSCRIPTION RATES (annually):

Agency or library \$190

General \$85

Student or parent \$45

(FYI - Membership in TASH includes the journal; see membership information under "ORGANIZATIONS")

FREQUENCY:

Published quarterly

The *Journal of The Association for Persons with Severe Handicaps (JASH)* is a quarterly journal published by TASH (formerly The Association for Persons with Severe Handicaps), that emphasizes articles that report original research, authoritative and comprehensive reviews, conceptual and practical positions papers that offer new directions, and effective assessment and intervention methodologies and service delivery model program descriptions.

TITLE:

Journal of Disability Policy Studies

ADDRESSES:

Subscriptions:

Department of Rehabilitation, Education, and Research University of Arkansas 346 N. West Avenue Fayette, AR 72701

Submissions:

Kay Fletcher Schriner, Ph.D., Editor Department of Rehabilitation, Education, and Research University of Arkansas 346 N. West Avenue Fayette, AR 72701

PHONE:

(501) 575-3656

FAX:

(501) 575-3253

SUBSCRIPTION RATES (annually):

Individual and institutional \$24 Additional \$5.00 charge for international subscriptions

FREQUENCY:

Published quarterly

AVAILABILITY:

Journal, tape, or diskette

The *Journal of Disability Policy Studies* addresses a broad range of topics on disability policy from the perspectives of a variety of academic disciplines and publishes articles pertaining to both macro-policy issues (such as the social constructions which direct and constrain policymakers) and micro-policy issues (such as legislative remedies and regulatory matters).

TITLE:

Mental Retardation

ADDRESSES:

Subscriptions: AAMR 444 North Capitol Street, NW Suite 846 Washington, DC 20001-1512 (202) 387-1968 or 1-800-424-3688 FAX (202) 387-2193

Submissions:

Steven J. Taylor, Ph.D., Editor Center on Human Policy School of Education, Syracuse University 805 S. Crouse Avenue Syracuse, NY 13244-2280 (315) 443-3851 FAX (315) 443-4338

TTY: (315) 443-4355

SUBSCRIPTION RATES:

1 year \$ 95 2 years \$170 3 years \$255 Single issue \$ 30 Additions: For Canada \$ 6 Overseas \$ 15

FREQUENCY:

Bi-monthly

Mental Retardation (MR) is a journal of policy, practices, and perspectives in the field of mental retardation. As a journal with an applied focus, MR publishes essays, qualitative and quantitative research articles, conceptual papers, comprehensive reviews, case studies, policy analyses, and innovative practice descriptions and evaluations. The style, methodology, or focus of an article is less important than its quality and contribution to our knowledge.

TITLE:

Mouth

Address:

P.O. Box 558 Topeka, KS 66601-0558

FAX:

(785) 233-1238

SUBSCRIPTION RATES (annually):

Organization/school/hospital: \$48

Personal subscription + 1 "hardship" subscription: \$32

Person with a disability or family member: \$16

"Hardship" subscription \$ 2

"Recovering Professional" (personal plus 2 hardship subscriptions) \$48

Outside US add \$7.00 USD

FREQUENCY:

Published 6 times a year

AVAILABILITY:

Magazine, large print, round-trip audiocassette.

This thought-provoking magazine features investigative journalism, news, and interviews with disability rights activists, reserving some of its harshest criticism for the "helping professions." *Mouth* also publishes poetry and essays written by people with disabilities, and does not include commercial advertisements.

TITLE:

The Ragged Edge (formerly The Disability Rag)

Address:

The Advocado Press P.O. Box 145 Louisville, KY 40201

SUBSCRIPTION RATES (Annually):

Organization \$35.00 Individual \$17.50 International \$42.00

FREQUENCY:

Published 6 times a year

AVAILABILITY:

Magazine, on-line at: http://www.ragged-edge-mag.com/index.shtml#edge

Ragged Edge is successor to the award-winning periodical, **The Disability Rag**. In **Ragged Edge**, and on their web site, you'll find the best in today's writing about society's "ragged edge" issues: medical rationing, genetic discrimination, assisted suicide, long-term care, attendant services. They cover the disability experience in America--what it means to be a crip living at the end of the 20th century.

ORGANIZATIONS

Association on Higher Education and Disability (AHEAD)

P.O. Box 21192 Columbus, OH 43221-0192 mailto:ahead@postbox.acs.ohio-state.edu http://www.ahead.org/index.htm

AHEAD is an international organization of professionals committed to the full participation of individuals with disabilities in higher education. The Association provides programs, workshops, publications, and conferences that promote "excellence through education, communication and training."

MEMBERSHIP FEES:

Institutional \$250 Active professional \$100 Additional professional \$65 (addendum to institutional membership with voting rights) Paraprofessional (Student) \$50

Center for Disability Studies

Hawai'i University Affiliated Program University of Hawai'i at Manoa 1776 University Avenue, UA-4-6 Honolulu, HI 96822 (808) 956-4454 http://www2.hawaii.edu/~huap/

The Hawaii University Affiliated Program (UAP) was established in 1988 as part of a network of more than 60 UAPs in the United States. UAPs were first developed in the 1960s in response to the Developmental Disabilities Act to provide training, research, and services for improved

quality of life for persons with disabilities. The Center for Disabilities Studies activities extend throughout the state and region with more than 25 funded projects in five initiative areas: Mental Health, Special Health Needs, Pacific Outreach, Transition/Supported Employment, and School and Community Inclusion. The Center also serves as the editorial office of the *Disability Studies Quarterly*.

Center for Health Policy Research

The Center the Study and Advancement of Disability Policy George Washington University 2175 K Street, N.W., Suite 700 Washington, DC 20037 (202) 496-8452 V/TTY FAX: (202) 467-2251

mailto:ihorxs@gwumc.edu http://www.gwumc.edu/chpr/

The Center for Health Policy Research conducts research and analysis of public policy issues that affect persons with disabilities and their families. It also provides public education, leadership development and training, technical assistance and information dissemination to disability groups and others interested in learning about issues pertaining to people with disabilities. The focus of the Center is on projects that foster the inclusion, integration, and empowerment of individuals with disabilities and their families.

Disability Research Unit

Department of Sociology and Social Policy
The University of Leeds
Leeds, LS2 9JT
UNITED KINGDOM
+44 113.233.4414
Fax +44 113.233.4415
mailto:disability-research-request@mailbase.ac.uk
http://www.leeds.ac.uk/sociology/dru/dru.htm

The approach of the DRU to research is grounded in social model approaches which recognizes that disability is above all a form of institutional discrimination and social exclusion, rather than a product of physical difference between individuals. The DRU has been at the forefront of promoting this approach amongst the international research community.

The DRU seeks to adopt "committed" and "emancipatory" methods in all research projects. This is achieved wherever possible by devolving control over the production and dissemination of research--to individual research participants and to democratic organizations controlled by people with disabilities.

National Council on Disability

1331 F Street, N.W., Suite 1050 Washington, DC 20004 (202) 272-2004

TTY: (202) 272-2074 FAX: (202) 272-2022 mailto:mquigley@ncd.gov http://www.ncd.gov/

The National Council on Disability (NDC) is an independent federal agency that "promotes policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities, regardless of the nature of severity of the disability; and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society."

Center on Human Policy

Syracuse University 805 South Crouse Avenue Syracuse, New York 13244-2280 (315) 443-3851

TTY: (315) 443-4355 FAX: (315) 443-4338 Toll free: 1-800-894-0822 mailto:thechp@sued.syr.edu http://soeweb.syr.edu/thechp/

The Center on Human Policy produces a range of informational materials on community integration. The Center continues to identify and document innovative approaches to help people with developmental disabilities participate in the community, and is especially interested in home ownership approaches, self-directed personal assistance, inclusive social-recreational programs, individualized funding streams, and strategies to meet the needs of culturally diverse groups.

Society for Disability Studies

c/o Robert Scotch School of Social Science University of Texas Box 830688, Mail Station GR3.1 Richardson, TX 75083-0688 (972) 883-4122 FAX: (972) 883-2735 http://www.wipd.com/sds/

The Society for Disability Studies is a not-for-profit scientific and educational organization composed of social scientists, scholars in the humanities, disability rights advocates, and providers of services for persons with disabilities. Its stated purpose is "to bring together people from diverse backgrounds to share ideas and to engage in dialogues that cut across disciplinary backgrounds and substantive concerns. SDS is committed to developing theoretical and practical knowledge about disability and to promoting the full and equal participation of persons with disabilities in society."

MEMBERSHIP FEES (based on income):

Less than \$15,000 \$15 \$15,000 - \$30,000 \$25 \$30,000 - \$45,000 \$35 Over \$45,000 \$45

TASH (formerly The Association for Persons with Severe Handicaps)

Suite 210 Baltimore, MD 21204 410-828-8274 FAX: 410-828-6706

mailto:info@tash.org
http://www.tash.org/

TASH is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life.

Membership in TASH includes the *Journal of The Association for Persons with Severe Handicaps*, the TASH Newsletter, and reduced rates for the annual conference.

MEMBERSHIP FEES:

Contributing member \$200 Agency, business or educational institution \$190 Individual \$85 Parent (non-professional), student, or paraprofessional \$45 Family (group rate) \$90

World Institute on Disability

510-16th Street, Suite 100 Oakland, CA 94612-1500 (510) 763-4100 TTY: (510) 208-9496 FAX: (510) 763-4109 mailto:webmail@wid.org http://www.igc.org/wid

The World Institute on Disability is a non-profit public policy center dedicated to the promotion of independence and full inclusion in society of people with disabilities. Founded in 1983 by leaders of the Independent Living/Civil Rights Movement for people with disabilities, WID is committed to bringing policy into action.

Over the past 13 years, WID has earned an excellent reputation for high quality research and public education on a wide range of issues that impact people with disabilities. WID's board and staff includes experts in the fields of public policy, research, law, non-profit management, education, training, development, and business. More than half of the board and staff are people with disabilities. This enables WID to bring a cross-disability perspective to the policy arena. WID's innovative personnel policies are national models of affordable reasonable accommodation for people with disabilities, including personal assistance, adaptive technology, flexible work scheduling and telecommuting options.

INTERNET RESOURCES

TITLE:

Disability Studies Forum

SPONSORED BY:

Centre for Psychotherapeutic Studies, University of Sheffield, United Kingdom

PURPOSE:

This forum addresses the social construction of disability and examines both the limitations and abilities of persons with disabilities. The group discusses therapeutic work, self-help and social forms of empowerment and other ways of circumventing societal barriers encountered by persons with disabilities.

ACCESS INFORMATION:

Send e-mail message to: listserv@maelstrom.stjohns.edu In body of message, type "sub DISABLED."

TITLE:

Disability Studies Web Ring

SPONSORED BY:

Canadian Centre on Disability Studies

PURPOSE:

This Web Ring was created to bring together web sites that are related to the field of Disability Studies, which examines the history, perspectives, culture, literature, sociology and experience of people with disabilities.

ACCESS INFORMATION: http://www.escape.ca/~ccds/webring.html

TITLE:

Disability Social History Project

PURPOSE:

This site looks at the role people with disabilities have played in history, how they have been treated throughout time, and significant events in the history of disability civil rights. An electronic mailing list is also available.

ACCESS INFORMATION:

http://www.disabilityhistory.org/dshp.html

E-Mail: mailto:sdias@disabilityhistory.orgor pchad@disabilityhistory.org

TITLE:

Disability Information for Students and Professionals

ACCESS INFORMATION:

http://www.abilityinfo.com/

This web site seeks to be a one-stop resource for students from around the world who wish to support and work with individuals with disabilities. This site also is intended for professionals within the field to continue in their knowledge. Includes daily news, job postings, a bulletin board area, more than 250 links, and live chat.

TITLE:

Canadian Centre on Disability Studies

SPONSOR:

University of Manitoba Winnipeg, Manitoba

ACCESS INFORMATION:

http://www.escape.ca/~ccds/

The Canadian Centre on Disability Studies is a consumer-directed, university-affiliated centre involved in research and education on disability issues. The CCDS is committed to fostering a spirit of collaboration between the disability and academic communities and other interested parties on initiatives of mutual interest and benefit nationally and internationally. They are also the sponsor for the Disability Studies Web Ring.

TITLE:

Disability-Research Discussion List

SPONSOR:

Disability Research Unit, University of Leeds

ACCESS INFORMATION:

You can join the list by sending the following message to mailbase@mailbase.ac.uk: join disability-research your name

This is an international e-mail discussion list administered at the DRU by Mark Priestley. The list (started in December 1994) is the largest of its kind in the world, and provides a forum for discussion on all aspects of disability research--both theoretical and practical.

The list is intended for all those interested in research as it affects disabled people both in the UK and internationally. It provides a forum for the exchange of ideas, information and news, particularly among researchers working within a social model of disability.

The list provides an opportunity for researchers, students and disabled people to share their ideas, experiences and research findings. It is also an excellent place to ask questions or seek information.