

# **The New Paradigm of Disability**

## **A Bibliography**

**September 30, 2000**

This bibliography was developed by an *ad hoc* task group of the President's Committee on the Employment of People with Disabilities, Subcommittee on Communications.

Contributors:

Anthony Tusler, Editor, Betsy Bayha, Elaine F. Brodey  
Steven E. Brown, Melanie Fry, Tari Susan Hartman  
Edward J. Heaton, Kathlene McCarthy-Barnett  
Zara Buggs Taylor, Greg Smith, Linda Walls

# The New Paradigm of Disability

## A Bibliography

It has been thirty years since the beginning of the contemporary Independent Living Movement. It was a time when the previously separate groups of people with disabilities began to collectively fight for the respect, and demand the civil rights, enjoyed by mainstream America. There are now the first generation of laws protecting the rights of disabled people. Access to employment, Transportation, education, and public accommodations is now mandated by Federal law for disabled people. More than ever people with disabilities are participating in American life. But, the mainstream media barely recognizes that disability is an inherent, integral, and inevitable component of the human experience. Nor do newspapers, television, and movies portray the role that society plays in marginalizing and stereotyping disabled people. More often the antiquated myths and stereotypes about people with disabilities are the norm.

From disabled activists using civil disobedience for social justice to university professors with disabilities researching and teaching disability studies, a new, clearly articulated analysis of the disability paradigm has emerged and is taking root throughout the nation and around the world. This new perspective on the human condition needs to be integrated into mainstream media. Following on the successful Disability Messenger project of the President's Committee on Employment of People with Disabilities this bibliography is intended as a catalyst to further articulate, amplify, and promote this new perspective of disability to allies, potential allies, academics, and policy makers and the media. This bibliography is further demonstration of the power of a community defining itself and articulating its members own collective and individual identity.

## Description

This is an annotated bibliography of books organized by categories: Community/Culture, Disability Studies, Family, Children, & Sexuality, History, Identity, Policy/Civil Rights, Children/Young Adults, and separate categories for Radio, Movies, WWW (Internet), Publications and Videos. The list is a compilation of recommendations from a diverse group of disability scholars and activists and other bibliographies. All of the entries illustrate an authentic view of disability using the new paradigm. Included is disability experience, identity, pride, passion, intellect, and community as we define it. The focus is on disability in the United States, but it also includes international perspectives. Far too many of the books are no longer in print. Larger university libraries have many of these books in their collections. Also, you can use inter-library loan through most libraries to borrow them. Bibliofind.com and other on-line sources for used books are possibilities, as well. This bibliography is updated regularly. It will be formally updated on a semi-annual basis. The next formal version will be posted by July 1, 2001.

## **Community/Culture**

*ABC Clio Companion to the Disability Rights Movement (ABC-Clio Companions to Key Issues in American History and Life)* (1997) Pelka, Fred Short entries on everything to do with the Disability Rights Movement.

*What Psychotherapists Should Know About Disability* (1999) Olkin, Rhoda A useful overview of disability that is valuable for anyone involved with disability issues.

## **Disability Studies**

*Claiming Disability: Knowledge and Identity (Cultural Front Series)* (1998) Linton, Simi, A strong overview of the "construction" of disability and the resulting ramifications.

*Disability Is Not Measles: New Research Paradigms in Disability* (1994) Rioux, Marcia H. & Bach, Michael A collection of essays on disability and statistical analysis that reveals how false stereotypes pollute much disability research.

*Missing Pieces: A Chronicle of Living with a Disability* (1982) Zola, I. K., A wonderful combination of personal disability discovery and sociological analysis. Considered by many disabled people as a key to understanding the personal and the political. (Out of print)

*Pride Against Prejudice: Transforming Attitudes to Disability* (1991) Morris, Jenny An accessible and pioneering study of the way that people are disabled by society. Includes discussion of the role of cultural representation and social barriers, and the problems with feminist research on community care. (out of print)

## **Family, Children, & Sexuality**

*Enabling Romance : A Guide to Love, Sex, and Relationships for the Disabled and the People Who Care About Them* (1992) Kroll, Ken One of the few books on sexuality and disability. (out of print)

*Past Due: A Story of Disability, Pregnancy, and Birth* (1990) Finger, Anne Well-written exploration of disability, pregnancy, and reproductive rights.

*Question of David: A Disabled Mother's Journey Through Adoption, Family, and Life, The* (1999) Jacobson, Denise Sherer An intimate, honest portrayal of a woman with a significant disability as she grapples with the lifelong issues of self-worth, sexuality, family value, relationships, and motherhood.

## History

*Beyond Affliction* (1998) Block, Laurie A detailed, fascinating, radio documentary on the history of disability in the United States. (Available on tape and excerpts on RealAudio at [www.npr.org/programs/disability](http://www.npr.org/programs/disability))

*By Trust Betrayed: Patients, Physicians and the License to Kill in the Third Reich* (1990) Gallagher, Hugh Gallagher documents the history of the German T-4 project which killed 200,000 disabled people in the name of eugenics during the Third Reich.

*Disabled State, The* (1984) Stone, D. A. Valuable for its historical perspective on the formation of disability social construct and its affect on US government policy.

*FDR's Splendid Deception, FDR Memorial Edition* (1998) Gallagher, H. How FDR was changed by disability, the lengths he used to conceal it, and the legacy of the "cured cripple." Gallagher argues that FDR's social consciousness is a direct result of his disability experiences.

*History of Disability (Corporealities)* (1982) Stiker, Henri-Jacques & Sayers, William (Translator) The welcome English translation of this European perspective on the historical basis for disability.

*Last Civil Rights Movement: Disabled Peoples' International, The* (1989) Driedger, D. One of the first books on disability rights and self-determination. Has a strong international and Canadian perspective. (out of print)

*New Disability History: American Perspectives*, forthcoming, Umansky, Lauri & Longmore, Paul K. This much anticipated historical view of disability in the US is edited by one of the foremost disability scholars, Paul Longmore.

*No Pity: People with Disabilities Forging a New Civil Rights Movement* (1993) Shapiro, Joseph P. Probably the most accessible accounting of the contemporary disability rights movement, although from a "great men" perspective.

*When The Mind Hears: A History of the Deaf* (1984) Lane, Harlan. The key text on the Deaf and their history.

## Identity

*Body, Remember: a Memoir* (1997) Fries, Kenny. The intertwining identities of being Jewish, disabled, and gay are the subject of this memoir.

*Count Us In: Growing Up with Down Syndrome* (1994) Kingsley, Jason And Mitchell Levitz. First person account of exceeding society's expectations by two friends.

*Don't Worry, He Won't Get Far On Foot: The Autobiography of a Dangerous Man* (1989) Callahan, J. Dark humor about spinal cord injury and addiction. The final three chapters outline the difficulties and frustrations of living on government disability support.

*Moving Violations: War Zones, Wheelchairs, and Declarations of Independence* (1995) Hockenberry, John. Another first-person account of life from a wheelchair. Hockenberry's insight, humor, candor, and fascinating career raise this text to the next level.

*Nobody Nowhere: The Extraordinary Autobiography of an Autistic* (1992) Williams, Donna. First person account of autism that has helped change how we regard people with autism.

*Planet of the Blind* (1998) Kuusisto, Stephen Kuusisto writes about his struggle to deny his disability and his eventual understanding and accommodation to it.

*Seeing Voices; A Journey Into the World of the Deaf* (1990), Sacks, Oliver. An exploration of the culture, politics, and neurology of American Sign Language and its place in the Deaf community.

*Staring Back: The Disability Experience from the Inside Out* (1998) Fries, Kenny. Valuable compilation of contemporary disability writings.

*Waist High in the World: A Life Among the Nondisabled* (1998) Mairs, Nancy, Essays on living with a disability in an illogical world.

## **Policy/Civil Rights**

*Disability Politics: Understanding Our Past, Changing Our Future* (1996) Campbell, Jane & Oliver, Michael. An accessible account, drawing on the perspectives of British disabled activists on the rise of the civil rights movement in UK, summarizing the history and the issues.

*Exploring Disability Policy* (1999) Barnes, Colin; Mercer, Geof; & Shakespeare, Tom, An undergraduate text reviewing the sociology of disability, which will be of interest to a general audience. Clear, comprehensive and the best place for any academic or student to start reading.

*Nothing About Us Without Us: Disability Oppression and Empowerment* (1998) Charlton, James. First American text to document and synthesize the growth of the disability rights movement.

*People with Disabilities Explain It All For You: Your Guide to the Public Accommodations Requirements of the Americans With Disabilities Act* (1992) Johnson, Mary & the Editors of the Disability Rag An insider's view of the Americans with Disabilities Act, capturing the spirit and intent of the law. (out of print)

*Ragged Edge: The Disability Experience from the Pages of the First Fifteen Years of The Disability Rag*, Shaw, Barrett. The Disability Rag has been the voice for the politicized disability community. All of the key issues of the past fifteen years are debated in these pages.

*Unexpected Minority, Handicapped Children in America, The* (1980) Gliedman, J. & Roth, W. A significant turning point in disability studies that still has powerful insights about the disability experience. (out of print)

## **Children & Young Adults**

Thank you to Chris Saad of Chris' Corner: Books for Kids & Teens in Philadelphia, PA for her recommendations.

*ABC for You and Me, Girnis, Meg* (2000) preschool  
*Alex, the Kid with AIDS, Girard* (1993) primary  
*The Crazy Horse Electric Game, Crutcher, Chris* (1991) high school  
*Deenie, Blume, Judy* (1983) middle school  
*Extraordinary Friends, Rogers, Fred* (2000) primary  
*From Anna, Little, Jean* (1991) upper elementary  
*Invincible Summer, Ferris, Jean* (1991) high school  
*Izzy, Willy-Nilly, Voigt, Cynthia* (1995) high school  
*Kathy's Hats, Krishner, Trudy* (1992) primary  
*The Seeing Stick, Yolen, Jane* (1977) upper elementary (out of print)  
*Someone Special Just Like You, Brown, Tricia* (1984) preschool  
*Summer of the Swans, Byars, Betsy* (1997) upper elementary

## **Radio**

*Disability Radio Worldwide*, Parker, Jean. A truly international perspective on disability. International on short-wave frequencies 6975, 15050 and 21460, Mondays at 19:00 UTC, Fridays at 17:00 UTC and Saturdays at 22:00 UTC, each with a second broadcast eight hours later. ([www.independentliving.org/radio/index2.html](http://www.independentliving.org/radio/index2.html))

*On a Roll Radio*, Smith, Greg, Contemporary issues in disability that does not shy away from the controversial or un-hip. (Available on RealAudio at [www.onarollradio.com](http://www.onarollradio.com))

## **Movies**

*Color of Paradise, Rang-e khoda* (1999) Majidi, Majid. An insider's view of a blind, Iranian boy's life including a residential school for the blind. (English sub-titles)

*Coming Home* (1978) Ashby, Hal. Still controversial twenty years later for its portrayal of the effects of the Viet Nam conflict on veterans, their families, and society. A good insider view of rehabilitation and living as a wheelchair user. (VHS-closed captioned)

*Freaks* (1932) Browning, Tod. Pauline Kael, the New Yorker's long-time critic, described the actors as "creatures" who used their "physical deformity for ...horror" but this movie's portrayal of disability community and reaction to exploitation is remarkably powerful and affirming.

*Gaby, A True Story* (1987) Mandoki, Luis. A remarkably straight forward look at coming of age for a young woman with CP in Mexico. Gaby's loves, flirtations, and crushes are artfully explored.

*Genghis Blues* (1999) Belic, Roko A documentary of San Francisco bluesman, Paul Pena's search for fellow throat singers in China. Pena's blindness is central to the beginning of the story, but ultimately is peripheral.

*My Left Foot* (1989) Sheridan, Jim. Daniel Day Lewis brings Christie Brown's autobiography to life with a savage intensity fueled by Day Lewis experience of staying in character throughout the course of filming. (DVD & VHS-closed captioned, & VHS Spanish captioned)

*Pelswick* (2000) Callahan, John. Disabled, acerbic, non-PC, cartoonist John Callahan's amusing depiction of a wheelchair-using eight grader is over-the-top, but somehow realistic. Nickelodeon, Saturdays 6 P.M. (ET) & 7:30 A.M. (ET).

*Waterdance, The* (1992) Jimenez, Neal & Steinberg, Michael. An accurate portrayal of the grief, shock, and loss that often comes with a new spinal cord injury while in a rehab hospital. (VHS-closed captioned)

## **World Wide Web & Internet**

*Art, Disability & Expression Exhibit of VSA arts* (1999) Moore, Stephanie & Jeffries, Chris. This on-line exhibit shows some of the best examples of the vital artistic, political, and cultural expression of the disability community. Caution, there are many high definition images on the site, so downloads might be lengthy. (<http://www.vsarts.org/gallery/exhibits/disability/index.html>)

*Beyond Affliction* (1998) Block, Laurie, The companion web site to the four hour disability history radio program on NPR. The site contains excellent primary source material. ([www.npr.org/programs/disability](http://www.npr.org/programs/disability))

*Assistive Technology* (2001) Williams, John W. Pragmatic and realistic about the advantages and disadvantages of technology for disabled people, William's columns highlights computers and other electronic devices. Go to Business Weeks Technology page and look under Assistive Technology. Archived at the National Organization on Disability at <http://www.nod.org/jwarchive.html>.

*Disability Policy*, Mazrui, Jamal and Pierce, Kelly, DIMENET A moderated list that provides members with policy, government, and legal documents and articles on emerging issues in the disability community. Subscribe by sending to: [Majordomo@trip.tripil.com](mailto:Majordomo@trip.tripil.com) the following command in the body of your e-mail message: subscribe dpolicy Archives are at: <http://www.dimenet.com/dpolicy>

*Disability-Research Discussion List*, Priestly, Mark, University of Leeds Based in the United Kingdom with a world wide focus this list focuses on disability research, both

theoretical and practical from a social model perspective. To join e-mail to: JISCMail@JISCMail.ac.uk: with the following message: join disability-research your name Past messages are available in a searchable archive at <http://www.leeds.ac.uk/disability-studies/>

*Disability Social History*, Dias, Steve & Chadwick, Pat, A window into the untold disability history. ([www.disabilityhistory.org](http://www.disabilityhistory.org))

*Disability World* Duncan, Barbara & Berman-Bieler, Rosangela. A bimonthly web zine in English and Spanish focusing on an international perspective of independent living and disability. It has a strong arts and culture section plus international politics with a distinct point of view. (<http://www.disabilityworld.org/>)

*DS-HUM Listproc*, Holmes, Martha Stoddard, Georgetown University A list-serv discussing disability in the humanities. To subscribe to DS-HUM, send a message in the following format to [listproc@listproc.georgetown.edu](mailto:listproc@listproc.georgetown.edu) subscribe ds-hum Yourfirstname Yourlastname More information is available at: <http://www.georgetown.edu/crossroads/interests/ds-hum/index.html>

*Interdisciplinary Bibliography on Disability in the Humanities*, Doug Baynton Works within the humanities (rather than social sciences) that explore disability. (<http://www.georgetown.edu/crossroads/interests/ds-hum/ds-bib.html>)

*JFA E-mail Network*, Fay, Fred, Justice for All. An electronic newsletter with the latest news, legislative alerts, and current problems in the disability community. To subscribe send a message to: [majordomo@jfanow.org](mailto:majordomo@jfanow.org) with the following in the body of the message: subscribe justice Archives are available at: <http://www.jfanow.org/cgi/getin.pl?1R>

*Manifesto*, Brown, Steven E., Institute on Disability Culture. An electronic newsletter of thoughts, news, and information on disability. To subscribe send a message to: [majordomo@tripil.com](mailto:majordomo@tripil.com) the following command in the body of your e-mail message: subscribe disculture Searchable archives are at: <http://www.acils.com/disculture/>

## **Publications**

*The Mouth, Voice of the Disability Nation*, Gwin, Lucy Ed. Mixing news, humor, and attitude, The Mouth covers the struggles for disability identity and freedom. (<http://www.mouthmag.com/subform.htm>)

*New Mobility, Disability Culture and Lifestyle*, Corbet, Barry Ed. This glossy, lifestyle magazine has equipment reviews, sex and relationship advice, profiles, and the arts. P.O. Box 220, Horsham, PA 19044 (<http://www.newmobility.com/>)

*Ragged Edge*, Johnson, Mary Ed., This magazine (formerly the Disability Rag) has been where the disability rights community has found its news, argued its policies, and



celebrated its successes. Avocado Press PO Box 145 Louisville, KY 40201.  
(<http://www.ragged-edge-mag.com/>)

## Videos

*Able to Laugh* (1993) Dougan, Michael J., Fanlight Productions, Six disabled comics are featured interpreting the disability experience.

*Breathing Lessons: The Life and Times of Mark O'Brien* (1996) Yu, Jessica, Fanlight Productions. The Academy Award winning documentary of the late disability poet and author Mark O'Brien. Mark's passionate and incisive poems are highlighted. (Open captioned)

*Disability Culture Rap: Disability Identity and Culture* (2000) Wade, Cheryl Marie & Smith, Jerry, Tools for Change Wade's expanded version of her ground-breaking and celebratory "Disability Culture Rap" paired with images from disability history and the disability rights movement. Includes facilitator's manual. (Closed captioned)

*If I Can't Do It...* (1998) Brock, Walter, Fanlight Productions. This is an unflinching portrait of a complex and cantankerous disabled man, Arthur Campbell, as he pushes for independence and an equal slice of the American pie.

*King Gimp* (2000) Hadary, Susan Hannah, HBO. An extensive look at the commitment, passion, and struggles of a disabled artist. An Academy Award winner.

*My Country: The Civil Rights Movement That Created the Americans with Disabilities Act*, Ward & Associates, Program Development Associates. A powerful video on the parallels between the Disability Rights Movement and the African American civil rights struggle of the 1960s.

*Storm Reading* (1996) Marcus, Neil, Access Theater Written and performed by Neil Marcus, this one man show (with two aides) shows the expressiveness of his atypical body and intellect.

*Tell Them I'm a Mermaid* (1983) Daley, E., & Kaplan, C., Embassy Telecommunications, 1901 Avenue of the Stars, Los Angeles, CA 90067. A documentary of Victoria Lewis' ground breaking theatrical troupe exploring disabled and women's identity.

*Twitch and Shout, a New Day film*, Chiten, Lauren, Fanlight Productions. Humor and gritty reality highlight this documentary on people living with Tourette's.

*Vital Signs: Crip Culture Talks Back* (1995) Mitchell, David T. and Snyder, Sharon L., Fanlight Productions Disability culture is highlighted by some its prime exponents. Theater, monologues, humor, and stories help to illustrate disability pride and culture. (Open captioned)

*When Billy Broke His Head...and Other Tales of Wonder* (1994) Golfus, Billy and Simpson, David E., Fanlight Productions One man's search for his new disability identity. Many of the leading disability activists are profiled. (Closed or open captioned)