The New Paradigm of Disability

A Bibliography on AboutDisability.com

It has been forty 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, & Relationships, 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 interlibrary loan through most libraries to borrow

them. Amazon.com, Abebooks.com, and other on-line sources for used books are possibilities, as well.

This bibliography is updated regularly.

I. 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.

Too Late to Die Young, Nearly True Tales from a Life (2006) Johnson, Harriet McBryde

Wonderful storytelling that also illuminates disability culture and policy.

What Psychotherapists Should Know About Disability (1999) Olkin, Rhoda

A useful overview of disability that is valuable for anyone involved with disability issues.

II. 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 (1983) 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. (republished)

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)

Why I Burned My Book and Other Essays on Disability (2003) Longmore, Paul K.

At last, the cogent, clear, and ground-breaking work of Paul Longmore is collected in one book.

III. Family, Children, & Relationships

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.

IV. 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 atwww.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)

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.

V. 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 from an insider's perspective.

Too Late to Die Young: Mostly True Stories from a Life (2005) Johnson, Harriet McBryde

Wonderful stories from an activist who shows the complex world of disability and creating change.

Waist High in the World: A Life Among the Nondisabled (1998) Mairs, Nancy

Essays on living with a disability in an illogical world.

VI. 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)

VII. 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.

(http://www.independentliving.org/radio/index.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 atwww.thestrengthcoach.com/archive.html)

VIII. 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. (VHSclosed captioned)

Finding Nemo (2003) Stanton, Andrew

A family animation from Pixar that had its disability plot ignored in reviews and advertising. The scene when one disabled character, Gill, mentors another, the title character Nemo, is unprecedented. for one disabled character mentoring another.

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.

Murderball (2005) Rubin, Henry Alex

Finally, a movie that got critics to see disability not as a tragedy but as an opportunity. The movie show the ruby players' competitiveness and occasional obnoxiousness is a result of their personalities not their disability experiences.

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)

The Sessions (2012) Lewin, Ben

Mark O'Brien makes another movie appearance, this time as a wonderful, direct, and ground-breaking fictionalized version of his oftreprinted article "On Seeing a Sex Surrogate."

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)

IX. 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)

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. National Organization on Disability,

(http://www.nod.org/index.cfm?fuseaction=Page.viewPage&PageID= 1302)

Disability History Dateline , Longmore, Paul, San Francisco State University

An extensive, searchable database of events in disability history. Institute on Disability.

(http://bss.sfsu.edu/disability/dateline.html)

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.jiscmail.ac.uk/cgi-bin/wa.exe?S1=disability-research

Disability Social History, Dias, Steve & Chadwick, Pat, A window into the untold disability history. (www.disabilityhistory.org)

Disability World Duncan, Barbara & Berman-Bieler, Rosangela A now defunct 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. The archives are still available. (http://www.disabilityworld.org/)

DS-HUM List, Gill, Mike, University of Maryland

A list-serv discussing disability in the humanities. To subscribe fill out the form.

Archives are available to subscribers.

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 with the following in the body of the message:

subscribe justice

Archives are available at: http://www.jfanow.org/jfanow/

X. Publications

The Mouth, Voice of the Disability Nation, Lucy Gwin Ed. Mixing news, humor, and attitude, The Mouth covered the struggles for disability identity and freedom. While no longer published it is still available online.(http://www.mouthmag.com)

New Mobility, Disability Culture and Lifestyle, Tim Gilmer 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, Mary Johnson Ed.,

This magazine (formerly the *Disability Rag*) had been where the disability rights community found its news, argued its policies, and celebrated its successes. Also, no longer published, it too is archived online. Avocado Press PO Box 145 Louisville, KY 40201. (http://www.ragged-edge-mag.com/)

XI. Videos

Able to Laugh (1993) Dougan, Michael J., Fanlight Productions (use search box),

Six disabled comics are featured interpreting the disability experience.

Breathing Lessons: The Life and Times of Mark O'Brien (1996) Yu, Jessica, Fanlight Productions (use search box),

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)

The Collector of Bedford Street (2002) Elliott, Alice, New Day Films An engaging example of how community support and resources made it possible for Larry Selman, a man with an intellectual deficit, to remain in his neighborhood.

Disability Culture Rap: Disability Identity and Culture (2000) Wade, Cheryl Marie & Smith, Jerry, Tools for Change

Cheryl Marie 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)

Freedom Machines (2005) Stobie, Jamie, New Day Films
A broad look at people with disabilities in the work force and how technology, mostly high tech, makes independence possible. The realities of inadequate funding and civil rights issues are also shown. There is an accompanying Web site, Freedom Machines.

If I Can't Do It... (1998) Brock, Walter, Fanlight Productions (use search box),

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.

Lives Worth Living: The Great Fight for Disability Rights, Neudel, Eric, ITVS

An essential video that tells the story of the modern day Disability Rights Movement and the passage of the ADA. Shown on PBS, it has a companion website.

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. out of print

Storm Reading (1996) Marcus, Neil

Written and performed by Neil Marcus, this one man show (with two aides) shows the expressiveness of his atypical body and intellect. out of print

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 (use search box),

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 (use search box), 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 (use search box),

One man's search for his new disability identity. Many of the leading disability activists are profiled. (Closed or open captioned)

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