

Resources for Disability and Culture

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Books Related to Disability, Culture, & Social Justice

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Readings for diversity and social justice. Adams M, Blumenfeld WJ, Castanede R, Hackman HW, Peters L, Zuniga X, editors. New York, NY: Routledge; 2000.

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Journal Articles Related to Disability, Culture, &/or Social Justice

1. Eddey, G. E., Robey, K. L. (2005). Considering the culture of disability in cultural competence education. *Acad Med*, 80(7): 706-712.
2. Galvin, R. (2003). The paradox of disability culture: the need to combine versus the imperative to let go. *Disability & Society*, 18(5), 675-790.
3. Gilson, S. F., Depoy, E. (2000). Multiculturalism and disability: A critical perspective. *Disability & Society*, 15(2) 207-218.
4. Jones, K. E., Itamar, E. T. (1997). Making our offices universally accessible: Guidelines for physicians. *Can Med Assoc*, 156(5) 647-655.
5. Keilhofner, G. (2005). Rethinking disability and what to do about it: Disability studies and its implications for Occupational Therapy. *AJOT*, 59(5) 487-496.
6. Kirschner, K. L., Breslin, M. L., Iezzoni, L. I. (2007). Structural impairments that limit access to health care for patients with disabilities. *JAMA*, 297(100), 1121-1125.
7. Melville, C. (2005). Discrimination and health inequalities experienced by disabled people. *Medical Education*, 39, 122-126.
8. Mercer, S., Dieppe, P., Chambers, R., MacDonald, R. (2003). Equality for people with disabilities in medicine. *BMJ*, 327(7420) 882-228.
9. Neri, M, Kroll, T. (2003). Understanding the consequences of access barriers to health care: Experiences of adults with disabilities. *Disability and Rehabilitation*, 25(2), 85-96.

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12. Peters, S. (2000). Is there a disability culture? A syncretisation of three possible world views. *Disability & Society*, 15(4), 583-601.
13. Taylor, R. R. (2005). Can the social model explain all of disability experience? Perspectives of persons with Chronic Fatigue Syndrome. *AJOT*, 59(5) 497-506.
14. Wainapel, S. F. (1999). A clash of cultures: Reflections of a physician with a disability. *Lancet*, 354(9180), 763.

Disability-Related Web Links of Interest to Health Professionals

1. [The Americans with Disabilities Act Home Page](#) is the official government website regarding the law and interpretations of it.
2. [Americans With Disabilities Act Technical Assistance](#) is the national network of ADA Centers. This site gives access to the Disability and Business Technical Assistance Centers (DBTACs) which provide information, materials, technical assistance, and training on the ADA.
3. [Association of University Centers on Disabilities](#) (AUCD) is a membership organization which promotes and supports the national network of university centers on disabilities. It also includes Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Programs and Developmental Disabilities Research Centers (DDRC).
4. [Center for Universal Design](#) (CUD) is a national information, technical assistance, and research center that evaluates, develops, and promotes accessible and universal design in housing, commercial and public facilities, outdoor environments, and products. Our mission is to improve environments and products through design innovation, research, education and design assistance.
5. [Centers for Disease Control, Disability and Health](#) (CDCDH) is part of the National Center for Birth Defects and Developmental Disabilities at the CDC. Disability and Health supports several programs, projects, and activities aimed at maintaining and improving the health of families, adults, and children living with disabilities.
6. [Centers for Medicare and Medicaid Services](#) (CMS) has ten field offices based on the agency's key lines of business: Medicare health plans, Medicare financial management, Medicare fee for service operations, Medicaid and children's health,

survey & certification and quality improvement. The intent of this structure is to improve performance through uniform issue management, consistent communication and leadership focused on achieving the agency's strategic action plan.

7. [**Consortium for Citizens with Disabilities**](#) is a coalition of approximately 100 national disability organizations working together to advocate for national public policy that ensures the self determination, independence, empowerment, integration, and inclusion of children and adults with disabilities in all aspects of society.
8. [**Department of Health and Human Services**](#) (DHHS) is the United States government's principal agency for protecting the health of all Americans and providing essential human services, especially for those who are least able to help themselves.
9. [**Department of Health and Human Services Administration on Developmental Disabilities**](#) funds the Consortium of Developmental Disabilities Councils (CDDC), National Association of Developmental Disabilities Council (NADDC), National Association of Protection and Advocacy Systems (NAPAS), and the American Association of University Affiliated Programs (AAUAP). The Administration on Developmental Disabilities (ADD) is the U.S. Government organization responsible for implementation of the Developmental Disabilities Assistance and Bill of Rights Act of 2000, known as the DD Act. ADD, its staff and programs, are part of the [**Administration for Children and Families**](#), of the U.S. Department of Health and Human Services.
10. [**Disability Research Institute**](#) resource of online information. The website is categorized into: institutions that conduct disability research and offer academic programs related to disability and rehab; publications; listservs and electronic newsletters, statistical and data sources; conferences and events; major disability related organizations, and major disability Meta Sites.
11. [**Healthy People 2010 \(and 2020\)**](#) challenges individuals, communities, and professionals to take specific steps to ensure that good health, as well as long life, are enjoyed by all. The Healthy People 2010 plan includes health objectives for people with disabilities.
12. [**IDEA partnership**](#) is dedicated to improving outcomes for students and youth with disabilities by joining state agencies and stakeholders through shared work and learning.
13. [**Interagency Committee on Disability Research**](#) (ICDR) collects input from stakeholders to inform planning; identifies emerging research areas; assesses gaps and duplications in existing research; and makes recommendations to strengthen the federal research agenda.

14. [Job Accommodations Network](#) (JAN) is a resource supported by the US Department of Labor. It provides an extensive list of reasonable accommodations for people with disabilities under the ADA. The site contains a brief description of a diagnosis/illness/disability followed by a list of potential accommodations for that condition. This is an excellent resource for people considering employment.
15. [Learning Disabilities Online](#) (LDOonline) is the world's leading web site on learning disabilities and ADHD, serving more than 200,000 parents, teachers, and other professionals each month.
16. [Museum of Disability](#) is an online virtual museum which allows you to “walk through” exhibits on topics such as the history of disability, medicine, social and policy issues.
17. [National Rehabilitation Information Center](#) (NARIC) is funded by the National Institute on Disability and Rehabilitation Research (NIDRR), the center collects and disseminates the results of federally funded research projects. The site features five searchable and browsable databases of current research, current literature, historical literature, NIDRR-funded literature and the NARIC knowledge base.
18. [National Center for the Dissemination of Disability Research](#) (NIDDR) focuses on knowledge translation (KT) of NIDRR-sponsored research and development results into evidence-based instruments and systematic reviews. NIDDR is developing systems for applying rigorous standards of evidence in describing, assessing, and disseminating research and development outcomes. The center is involved in research activities, demonstration activities, dissemination and utilization activities and technical assistance and has in-depth information on 386 NIDRR-funded projects.
19. [National Council on Disability](#) (NCD) provides advice to the President, Congress, and executive branch agencies to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities, regardless of the nature or 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. NCD has been a valuable contributor in promoting successful disability policies in many arenas, including education, transportation, homeland security, emergency preparedness, international disability rights, employment, foster youth with disabilities, vocational rehabilitation, livable communities, and crime victims with disabilities.
20. [National Institute on Disability and Rehabilitation Research](#) (NIDRR) Through this Institute, the United States Department of Education’s Office of Special Education and Rehabilitative Services (OSERS) conducts comprehensive and coordinated programs of research and related activities to maximize the full inclusion, social integration, employment, and independent living of disabled individuals of all ages.

21. [Office of Civil Rights, US Department of Education](#) (OCR) offers information about Section 504 and ADA as they relate to the education of people with disabilities at all levels. An excellent resource on the laws governing access and accommodations.
22. [Office of Disability Employment Policy for the Department of Labor](#) (ODEP)
Formerly called the President's Committee on Employment of People with Disabilities. The mission of ODEP, under the leadership of an Assistant Secretary, will be to bring a heightened and permanent long-term focus to the goal of increasing employment of persons with disabilities.
23. [Office of Disability, Aging and Long-Term Care Policy](#) (DALCPT)
DALCPT is in the Office of the Assistant Secretary for Planning and Evaluation within the U.S. Department of Health and Human Services. DALCPT is charged with developing, analyzing, evaluating and coordinating HHS policies and programs which support the independence, productivity, health and long-term care needs of children, working age adults and older persons with disabilities.
24. [Office of Special Education Programs](#) (OSEP)
A division of the United States Department of Education's OSERS, this office administers programs and projects relating to the free appropriate public education of all children, youth and adults with disabilities, from birth through age 21.
25. [Office of Special Education and Rehabilitative Services](#) (OSERS)
The office within the United States Department of Education responsible for funding programs that assist in educating children with special needs (OSEP), providing for the rehabilitation of youth and adults with disabilities (RSA), and supporting research to improve the lives of individuals with disabilities (NIDRR).
26. [Rehabilitation Services Administration](#) (RSA)
A division of the United States Department of Education's OSERS, the RSA oversees programs that help individuals with physical or mental disabilities to obtain employment through the provision of such supports as counseling, medical and psychological services, job training, and other individualized services.
27. [Social Security and Supplemental Security Income Disability Programs](#) are the largest of several Federal programs that provide assistance to people with disabilities. While these two programs are different in many ways, both are administered by the Social Security Administration and only individuals who have a disability and meet medical criteria may qualify for benefits under either program.
28. [US Census Bureau – Information on Disability](#) Professionals can join the Census Disability Data Users group list, which serves as a forum for people to communicate their ideas, comments, research, and analysis on disability data collected at the Census Bureau. It will also serve as a way for the Census Bureau to communicate to users any new or upcoming releases, provide programming help,

and/or inform users of continuing research on disability data collection methods as well as any papers to be presented at conferences on disability. We encourage users to share their ideas, participate in discussions, ask questions, and provide suggestions.

Resources of Interest to People with Disabilities & Health Professionals

1. [Abledata](#) provides objective information about assistive technology products and rehabilitation equipment available from domestic and international sources. Although ABLEDATA does not sell any products, they provide information about companies that do.
2. [American Association of People with Disabilities](#) (AAPD) is the largest national, nonprofit cross-disability member organization in the US. It hosts the Justice for All (JFA) listserv and newsletter through which information about public policy affecting people with disabilities is disseminated.
3. [DisabilityInfo.gov](#) is a federal, interagency web portal for people with disabilities, their families, employers, service providers, and other community members including information about civil rights, education, employment, housing, health, income support, technology, transportation, and community life.
4. [Institute on Disability Culture](#) is a website established in 1994 to promote pride in the history, activities, and cultural identity of individuals with disabilities throughout the world. The purpose of this site is to provide information about disability culture and to share examples of the disability culture. There are links to multiple other disability related organizations.
5. [The Ragged Edge](#) is an online disability rights magazine. It was originally started as The Disability Rag was around for 16 years. Contains thousands of current and archived articles.
6. [Disability Resources, Inc.](#) is a nonprofit 501(c)(3) organization established to promote and improve awareness, availability and accessibility of information that can help people with disabilities live, learn, love, work and play independently. They serve thousands of individuals with disabilities through a multidisciplinary network of service providers and consumers. In order to reach as many people with disabilities as cost effectively as possible, we target our services and publications to libraries, disability organizations, independent living centers, rehabilitation facilities, educational institutions, and health and social service providers.
7. [DisabilityInfo.gov](#) provides quick and easy access to comprehensive information about disability programs, services, laws and benefits. You can begin your search by visiting any one of the nine subject areas at the top of the home page. To find disability resources in a particular state just click on the Find State and Local Resources map located in each of these subject areas.

8. [Disability Rights Advocates](#) (DRA) is a non-profit law firm dedicated to protecting and advancing the civil rights of people with disabilities. DRA advocates for disability rights through high-impact litigation as well as research and education. There is no charge to clients for services provided.
9. [Easter Seals](#) – National, non-profit agency providing low or no cost services, resources, and information to enhance the lives of people with disabilities.
10. [National Council for Support of Disability Issues](#) is a non-profit group whose mission is to help advance public attitudes, awareness, respect, consideration and advance the success of people with all types of disabilities.
11. [Social vs. Medical Model of Disability](#) This is a beta site for self-directed training on the social vs. medical models of disability. It is fun, interesting and informative for stakeholders from different backgrounds, at different levels of understanding.
12. [YouTube – Miller Chat](#) offers videos such as, “How to Talk to Persons with Disabilities PC Style” and “Myths, Stereotypes, and Perceptions.”

Memoirs Written by Persons with Disabilities, their Friends or Family Members

1. Albom, M. (1997). [Tuesdays with Morrie](#). New York: Doubleday.
A journalist's interviews an older man who has been his college professor to learn of his experiences while dying from ALS.
2. Bauby, J. D. (1997). [The Diving Bell and the Butterfly](#). New York: Random House Books. Very moving account of Locked-in Syndrome. This is the story of a French magazine editor who sustains a CVA and becomes unable to speak or move.
3. Beck, M. (1999). [Expecting Adam](#). New York: Random House. This is the story of a woman who is a candidate for a PhD from Harvard. She tells the story of her pregnancy and life as a mother of a child with Down syndrome.
4. Coughlin, R. (1993). [Grieving: A Love Story](#). New York: Random Books. A widow tells the story of her husband's death from cancer.
5. Fadiman, A. (1998). [The Spirit Catches You and You Fall Down](#). NY: Farrar, Straus, & Giroux. This is an account of Hmong culture, illness, and the customs used to achieve health or avoid illness.
6. Galli, R. (2000). [Rescuing Jeffrey](#). Chapel Hill, NC: Algonquin Books.
A father writes the story of his reaction to his son's SCI that resulted from a diving accident. The story takes place during the acute care period of recovery.

7. Grealey, L. (1994). [*Autobiography of a Face*](#). Boston, MA: Houghton Mifflin. After undergoing five years of treatment for cancer, a young woman is left with facial disfigurement and subsequent reconstructive surgeries.
8. Hockenberry, J. (1995). [*Moving Violations*](#). New York: Hyperion. A news reporter who sustained a spinal cord injury describes his experiences of re-entry into the world of journalism after his injury.
9. Hornbacher, M. (1998). [*Wasted: A Memoir of Anorexia and Bulimia*](#). New York: Harper Perennial. This is a story about a young woman with anorexia and bulimia.
10. Hornbacher, M. (2008). [*Madness: A Bipolar Life*](#). New York: Houghton-Mifflin Books. By the author of *Wasted*, this memoir captures Hornbacher's realization and struggle to manage her diagnosis of Bipolar Disorder.
11. Jamison, K. (1995). [*An Unquiet Mind*](#). New York: Alfred A Knopf. A renowned psychologist describes living with Bipolar Disorder.
12. Lydon, J. (1997). [*Daughter of the Queen of Sheba*](#). Boston, MA: Houghton Mifflin. NPR reporter writes a memoir of growing up with a mother who is mentally ill.
13. Manning, M. (1996). [*Undercurrents: A Life Beneath the Surface*](#). San Francisco: Harper. This is a story about a female psychologist who has a diagnosis of depression.
14. McCrum, R. (1999). [*My Year Off: Recovering Life After Stroke*](#). New York: Broadway Books. This is the story of a man who had a severe stroke at the age of 42. It illustrates the importance of having the love and commitment of another person to assist in recovery.
15. Osborn, C. (2000). [*Over My Head*](#). Kansas City, MO: Andrew McMeel Publishing. A doctor tells her own story of living with the effects of a head injury.
16. Rollin, B. (2000). [*First you Cry*](#). New York: Harper Collins. A New York journalist who has breast cancer and a mastectomy describes her response to illness and recovery.
17. Parker, S. (2002). [*Tumbling After*](#). New York: Crown Publishers. This is the account of the wife of a man with C4 quadriplegia, an injury sustained in a biking accident.

18. Rose, L. (1995). [*Show Me the Way to Go Home*](#). Forest Knolls, CA: Elder Books.
This book is written by an engineer who develops Alzheimer's disease. He describes the losses he experiences over time.
19. Simon, C. (1997). [*Mad House*](#). New York: Penguin. A Boston Globe reporter describes growing up in a family with two siblings who have schizophrenia.