

H-Net Reviews

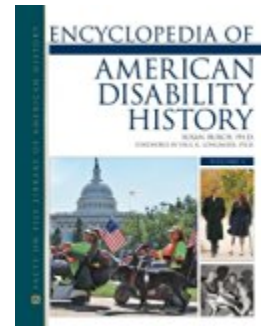
in the Humanities & Social Sciences

Susan Burch, ed. *Encyclopedia of American Disability History*. 3 volumes. New York: Facts On File, 2009. 1200 pp. \$295.00 (cloth), ISBN 978-0-8160-7030-5.

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As American as Disability History?

The three-volume compendium *Encyclopedia of American Disability History*, edited by Susan Burch, contains over 750 entries and original texts that document disability as a constant and multicolored thread in the tapestry of U.S. history. Taken together, the entries in these volumes offer five main arguments: 1) in the history of the United States, disability has been, and remains, much more than a singular medico-scientific category; 2) the social roles of people with disabilities in families, communities, and local economies have shifted across different periods of U.S. history; 3) people with disabilities in the United States have been agentic for at least two centuries, engaging in various forms of collective action; 4) the history of systematic exclusion of people with disabilities in the United States can be articulated and analyzed as a shared experience of erasure and oppression; and 5) different groups of people with disabilities in the United States have experienced unique forms of conflict and resistance, resulting in multiple, intersecting histories of disability. *Encyclopedia of American Disability History* serves as both an important reference text and a fertile source of brief but powerful readings for courses in disability studies, history, and/or culture.

Over 350 authors contributed entries for this compilation, including established scholars, graduate students, officials in federal, state, and local government, and community leaders and social activists. This multidisciplinary chorus of voices addresses both how people with disabilities have shaped U.S. history and how U.S.

history has been organized around various chronologically situated constructions of disability. The first volume includes a foreword by the late Paul Longmore, professor of history, activist, and leader, instrumental in the founding of both the H-Disability listserv and the Disability History Association. Also in this volume there is an introduction by the editor and an impressive twenty-four page chronology of disability history in the United States. The timeline begins in 1624 with the identification of Mara Buck, born in Jamestown, Virginia, in 1611, as the first colonial-born English child to be described as “very Dull” (what we now would refer to as having an intellectual or developmental disability) and concludes with the U.S. Supreme Court’s 2009 dismissal of a class action lawsuit brought by the Vietnamese Victims Association against the companies that manufactured Agent Orange. In addition to illustrating disability as a consistent local and national concern from the era of European colonialism forward, this chronology recasts the multiple (re)negotiations between people and social institutions as central political struggles for personhood and recognition fought by, with, and for people with disabilities in the United States.

A particularly useful feature of *Encyclopedia of American Disability History* is the organization of the volumes’ content around twelve entries that the editor describes as “anchor entries.” These anchor entries are broad concepts that encompass and relate to a large number of the other entries. Examples include: activism and advocacy, disability art and artistic expression, law and policy, and sci-

ence and technology. For each anchor entry, the authors weave together people, places, events, ideas, and groups into a web that captures specific angles of the history of disability in the United States. Any and all of these twelve entries could serve as framing documents for conversations about disability in any social science discipline or in specific courses on disability studies, history, and/or culture. Unfortunately, there is nothing to delineate these entries as special. Aside from one sentence in the introduction and the increased length of these entries, they appear nonchalantly in their appropriate alphabetical order, with no change in font, size, or format and no special demarcation in the index. Without prior knowledge of their existence, they could easily remain undiscovered.

Across the entries in *Encyclopedia of American Disability History*, the authors both balance the languages of “then” with those of “now” and portray disagreements and controversies in their depictions of American disability history. For example, the entries on cognitive and intellectual disability and developmental disability use quotation marks to place terms in their historical context (“idiot,” “simpleton,” “imbecile,” “feeble-minded,” “moron,” and “mental retardation”) and to differentiate them from current language. Furthermore, the complexity of highly charged social issues like cochlear implants and physician-assisted suicide is represented through the depiction of multiple perspectives. The authors describe the various groups that advocate for or oppose these actions, capturing the desires that drive these groups and the historical antecedents that structure these motivations as well.

Despite the expansiveness of these volumes, two important lacunae remain. First, uneven attention is paid to the systematic and institutionalized forms of discrimination and exclusion as both unique mechanisms and as interlocking systems of oppression that magnify disadvantage. While ableism is rightfully afforded its own entry and ageism is treated as part of an entry on age and ageism, classism, racism, sexism, and heterosexism do not receive their own entries or any mention in the index. To be fair, there are excellent entries on race, eugenics, poverty, gender, feminist disability studies, intersexuality, and queer disability studies. However, these do not accurately address the social production of disability in the context of social structures, or the social distribution of access to supports as a result of these structures. And while African Americans, Hispanics, and Native Americans have their own entries in the index, Asian Americans do not. Moreover, without an entry on intersectionality (Patricia Hill Collins, 1990), understanding

the relationships between these institutionalized forms of exclusion and how they shape unique positionalities is lost. Also missing from these volumes is an entry focused specifically on critical theory—although it is referenced in some entries—as a method to outline the ways in which disability is marshaled and elided in the production of cultural texts.

The second gap in the topics addressed across these volumes is centered around issues of legislation, policy, and access to services, supports, and care. There are certainly many entries on key pieces of legislation (e.g., the Architectural Barriers Act, the Americans with Disabilities Act, the Individuals with Disabilities Education Act) and social policies and programs (e.g., Medicare, Medicaid, long-term care); however, there are important historical developments that receive short shrift in the encyclopedia. For example, social insurance is a significant concept for understanding the principles of the Social Security program in the United States and the distinction between social insurance and means-tested (or needs-based) programs is not addressed. Additionally, over the last three decades, the politics of “long-term care” have developed considerably and for many groups of people with disabilities “long-term services and supports” (LTSS) has become the preferred term. This historical shift seems to go unacknowledged in *Encyclopedia of American Disability History*. Similarly, while there are entries for both institutionalization and deinstitutionalization, personal assistance services, home- and community-based services, and related concepts such as consumer-directed and/or consumer-managed services are virtually absent throughout the text. Similarly, the CLASS Act and the Community Choice Act (and earlier incarnations in the form of the Medicaid Community-based Attendant Services and Supports Act [MiCASSA] first introduced in 1996) are missing as entries or in the index. This is particularly disappointing since parts of these bills were incorporated into the Patient Protection and Affordable Care Act. There is no expectation that policy developments occurring within one year of the publication date (2009) would be reflected in this edition. However, the multiple, significant policy changes that have occurred since *Olmstead v. L.C.* (1999) deserve mention.

Encyclopedia of American Disability History is an important collection, filled with knowledge about the often previously unidentified role of disability and people with disabilities in the history of the United States. This three-volume set will quickly become a mainstay on the desks of academics and policymakers alike. Despite

omissions in some key areas of struggle and triumph for people with disabilities, this text represents a historical milestone unto itself—for people with disabilities, for the field of disability history, and for the field of U.S. history which can no longer (if it ever could) claim that there is no source of information on American disability history.

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