

***SOC 2053: Sociology of Disability:***  
***What's Available in Open Access Resources?***

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*SOC 2053: Sociology of Disability* examines a wide range of issues, from defining disability and the words we use to talk about it, to disability identity and experience; disability history, culture, and rights movements in the US and abroad; images of disability in popular culture; the intersection of disability with race, gender, class, and sexuality; and disability in the context of different social institutions such as the criminal justice system, education, and the healthcare system. I typically do not teach this course using a text, but rather bring together a wide variety of resources such as academic articles, reports, advocacy organization websites, documentaries, news stories, and more to capture the breadth and depth of the issues. Alongside these materials, I assign a book length memoir, carefully chosen to tie in to many of the semester's topics. This serves as a common thread to help unify the course, as individual chapters relate to themes addressed at different points but from the common vantage point of an author who the students come to know over the semester. It is memoirs of this type that I review in the following bibliography, with an eye to identifying suitable open access resources to fulfill this role in my course.

There are numerous engaging and informative memoirs about disability experience, a important subset of which are written by family members discussing parenting a disabled child, or their experiences as the partner, sibling or child of someone with a disability. Here, I have chosen to focus on works representing the voices of people with disabilities themselves, examining publications of the last 15 years or so.

*The Disabled Teacher: A Memoir of an Interrupted Pedagogical Career, a Life with a Chronic Illness, and an Encounter with Real Barriers to Inclusive Education*

Dorothy M. Bossman, University of Nebraska-Lincoln Digital Commons, 2015

<https://digitalcommons.unl.edu/teachlearnstudent/53/>

As a teacher, I struggled to maintain my pedagogical values during my time in secondary schools. As someone who remained a teacher while pursuing a Ph.D., I became a double outsider whose presence in two spheres of education exposed the divide between them. At the same time as these developments, I developed multiple sclerosis, which progressed over my ten years in the classroom. The profound experiences of adjusting to life with a disease and learning to cope with physical disability impacted my practice, research interests, and identity. For some readers, this work stands as an example of a memoir within the genre of “literature of the personal catastrophe” (Mairs, 1994), but for others the writing will be interpreted as “a love letter to teachers” (Ayers, 1993). Ultimately, the project is a criticism of the mechanism of public education, “to challenge traditional educational ideology” (Giroux, 1988, p. xxx), with particular focus on the systematic edging out of committed teachers and the disrespect for the wisdom most relevant for constructing curriculum and preparing young people for their lives. (from author-provided abstract)

This text is actually a dissertation, but presented in a somewhat non-traditional format (for a dissertation, that is) and written in accessible and engaging prose. It touches on the joys of teaching, the methodology of autoethnography, and the difficult reality of illness forcing a change in direction professionally and academically. I enjoyed reading this work, and Bossman’s astute analysis of trends within education resonated with me. “Chapter 11: Literature Review 3 (Literature Review for a Personal Crisis)” provides an overview of many central texts and issues in the disability literature, grounding them in the author’s own personal situation and questions about how to live as a person with a disability, find community, assert her rights, and make meaning of difficult experiences presented by her illness. This section could potentially serve as an introduction to the myriad issues our course covers. “Chapter 12: A Disabled Woman” speaks to the writer’s identity as a woman with a disability. “Chapter 15: What My Kind Has to Offer” chronicles how the author’s awareness of disability and the need for broad social inclusion has changed as a result of her illness; she addresses not only physical environments but societal attitudes and representations of disability in popular culture.

## *One Little Finger*

Malini Chib, Sage Publications Pvt. Ltd. 2011 (EBSCO Ebook Academic Collection, AN 354919, unl copies)

'The birth was hugely traumatic, and the pediatrician in charge kept repeating to himself, 'It was a mistake...I should have carried out a caesarean...lets see if she survives...I am not sure if she will survive...at the most 72 hours.' I Survived! ...This is the story of Malini's search for independence and identity, and her zeal to live a full, meaningful life despite lifelong disability. ... She recounts her experiences from childhood to adulthood, her struggles with motor skills and speech, managing day-to-day activities, and the apathy and indifference of people towards her and others who are disabled. She educates herself, learns to type with her little finger and speak through the Lightwriter. Finally, she works through unfavourable social systems and attitudes to get a career as an event manager. (Adapted from source)

Chib's narrative is written in direct prose and chronicles not only her own struggles to realize and have her own potential recognized as a woman with cerebral palsy, but the fits and starts of the nascent Indian movement for inclusive education. With relatives in both London and India, Chib's family moves back and forth over the years, and she is exposed to differing attitudes toward and approaches to the treatment and education of children with disabilities. She was one of four students with multiple disabilities to "integrate" Indian higher education by pursuing a degree at a prestigious college alongside her non-disabled peers. Chib describes the revelations she experienced during a late 1980s trip to Berkeley, CA, birthplace of the Independent Living Movement and where accessibility and self-determination are taken for granted. In the latter half of the book, she chronicles her growing independence and increasing understanding of the socially constructed and political nature of her disability experience, leading to her direct involvement in and spearheading of the nascent Indian Disability Rights Movement. While the personal narrative provides many touchpoints for discussion of various larger disability-related themes, more context on the institutions, places, and events at times would be helpful.

## *A Body, Undone: Living On After Great Pain*

Christina Crosby, New York University Press, 2016 (EBSCO Ebook Academic Collection, AN 1084158, unl copies)

A compelling account of recreating a life through writing, memory, and desire. In the early evening on October 1, 2003, Christina Crosby was [paralyzed in a bicycle accident]. She was a respected senior professor of English who had celebrated her fiftieth birthday a month before. ... In *A Body, Undone*, Crosby puts into words a broken body that seems beyond the reach of language and understanding. She writes about a body shot through with neurological pain,

disoriented in time and space, incapacitated by paralysis and deadened sensation. To address this foreign body, she calls upon the readerly pleasures of narrative, critical feminist and queer thinking, and the concentrated language of lyric poetry. Working with these resources, she recalls her 1950s tomboy ways in small-town, rural Pennsylvania, and records growing into the 1970s through radical feminism and the affirmations of gay liberation. Deeply unsentimental, Crosby communicates in unflinching prose the experience of "diving into the wreck" of her body to acknowledge grief, and loss, but also to recognize the beauty, fragility, and dependencies of all human bodies. (adapted from source)

The writing is overall accessible, though in some places lower division undergraduates might need more support to appreciate the nuances of the text. Chapter 5, "Caring at the Cash Nexus" provides a look at the contrasts in life experience between Crosby and one of the working-class women who has provided her in-home care for many years. Chapter 7, "Masculine, Feminine, or Fourth of July" addresses the author's thoughts on her gender identity and presentation, pre- and post-accident.

### *Visceral: Essays on Illness Not as Metaphor*

Maia Dolphin-Krute, 2017

<https://library.oapen.org/bitstream/handle/20.500.12657/25444/1004651.pdf?sequence=1>

*Visceral: Essays on Illness Not as Metaphor* .... to the extent that it is a memoir, is a record not of illness but of the research project being sick became. While rooted firmly in critical disability and queer practices, the use of personal narratives opens these approaches up to new ways of writing the body—ultimately a body that is at once theoretical and unavoidably physical. A body where everything is visceral, so theory must be too. From the gothic networks of healthcare bureaucracy and hospital philanthropy to the proliferation of wellness media, off-label usage of drugs, and running off to live a life with, these essays move fluidly through theoretical and physical anger, curiosity and surprise. (adapted from source)

This is a beautifully written and provocative book, and one that touches on many issues of disability that we address in class, including definitions of disability; how disability is constructed—in interpersonal relations, within the medical system, and in relation to a person's self-concept; disability history; disability rights; the intersection of disability and gender (among other aspects of experience); disability and work; and more. The writing often takes the form of a series of philosophical musings, rather than a straightforward narrative. As such, it would be a more difficult choice as a unifying text for a sociology course, but I could see using smaller excerpts in discussion with appropriate background and contextualization.

## *Out of Joint : A Private & Public Story of Arthritis*

Mary Lowenthal Felstiner, University of Nebraska Press, 2005 (EBSCO Ebook Academic Collection, AN 135770, unl copies)

Felstiner characterizes her chronicle as “tracing a private timeline and splicing it into a public one” (p. xiii) as a way to heal and better understand a disease that affects fully one third of Americans (p. xii). This is C. Wright Mills’s “sociological imagination” at its best. She examines how arthritis has been treated, in the broadest sense of the term, throughout history and notes some great contrasts with her initially very private, medicalized experience today. Later, she chronicles her changing experience of the social aspects of disability, as her attempts to “pass” and minimize her impairments in light of stigma and shame evolve and give way to an understanding of her right to access, a sense of community, and common purpose with others. Felstiner also addresses the gender dynamics of medical research and funding that have left arthritis disproportionately understudied even as it affects in some form one-third of women between the ages of forty-five and sixty-four, and more than half of women over sixty-five (p. 101). The writing is very accessible and engaging. It would be wonderful to see an updated version of this book addressing her experience in light of recent trends in gender and medical research, treatment for RA, and changes in the disability rights landscape after 30-plus years of the ADA.

## *A Certain Loneliness: A Memoir*

Sandra Gail Lambert, University of Nebraska Press, 2018 (EBSCO Ebook Academic Collection, AN 1845061, unl copies)

After contracting polio as a child, Sandra Gail Lambert progressed from braces and crutches to a manual wheelchair to a power wheelchair—but loneliness has remained a constant, from the wild claustrophobia of a child in body casts to just yesterday, trapped at home, gasping from pain. *A Certain Loneliness* is a meditative and engaging memoir-in-essays that explores the intersection of disability, queerness, and female desire with frankness and humor. Lambert presents the adventures of flourishing within a world of uncertain tomorrows: kayaking alone through swamps with alligators; negotiating planes, trains, and ski lifts; scoring free drugs from dangerous men; getting trapped in a too-deep snow drift without crutches. *A Certain Loneliness* is literature of the body, palpable and present, in which Lambert's lifelong struggle with isolation and independence—complete with tiresome frustrations, slapstick moments, and grand triumphs—are wound up in the long history of humanity's relationship to the natural world. (from source)

Lambert’s writing is engaging—I read her memoir in one sitting; her chapters are written as short vignettes that weave back and forth across time and place. In recounting events and

reflecting on their meaning, she also addresses larger questions of human experience such as intimacy, forging human connection, and being in the moment, especially as regards her beloved forays into nature, often in a kayak. While Lambert does address the accessibility of homes and public accommodations, attitudes of the public and of professionals, and describes an ADAPT-organized protest, her focus throughout is more on interpersonal relationships than social structural issues. Nevertheless, her lessons about living with disability are nuanced and have deep resonance beyond what C. Wright Mills would term the realm of “personal troubles”.

### *The Art of Being Deaf : A Memoir*

Donna McDonald, Washington, DC : Gallaudet University Press, 2014 (EBSCO Ebook Academic Collection, AN 1179842, unl copies)

Concerned about aspects of her romantic relationships, Donna McDonald consulted with a psychologist who asked, “Your hearing loss must have had a big impact on you?” At age 45, with a successful career in social work policy, McDonald took umbrage at the question. Then, she realized that she never had addressed the personal barrier she had constructed between her deaf-self and her hearing persona. In *The Art of Being Deaf*, she describes her long, arduous pursuit of finding out exactly who she was. Born in 1950s Australia, McDonald was placed in an oral deaf school when she was five. There, she was trained to communicate only in spoken English. Afterwards, she attended mainstream schools where she excelled with speechreading and hard work. Her determination led to achievements that proved her to be “the deaf girl that had made good.” Yet, despite her constant focus on fitting in the hearing world, McDonald soon realized that she missed her deaf schoolmates and desired to explore her closed-off feelings about being deaf. When she reconnected with her friends, one urged her to write about her experiences to tell all about “the Forgotten Generation, the orally-raised deaf kids that no one wants to talk about.” In writing her memoir, McDonald did learn to reconcile her deaf-self with her “hearing-deaf” persona, and she realized that the art of being deaf is the art of life, the art of love. (from source)

McDonald deftly addresses how the time in which she grew up shaped attitudes toward deafness (including those of her family and, ultimately, herself), available resources, and the actions individuals chose. She touches on key topics such as whether deafness is a disability, what it means to “pass” as hearing, the varieties of deaf/Deaf identity and experience and who gets to speak as a deaf/Deaf person, debates about oral education versus signing, and more. Her quest to understand herself and her own experiences are an attempt to put them in the larger social context; her fine description of most every part of this exploration is embedded in the interactions, settings, and relationships that support this project.

## *Fuckhead*

David Rawson, Punctum Books, 2013

<https://library.oapen.org/bitstream/handle/20.500.12657/25569/1004526.pdf?sequence=1>

What is a fuckhead? David Rawson's *Fuckhead* is a surreal exploration of the literature, film, nature and expectations of disability, and of fuckheads in literature and film. Part lyric essay, part fictional memoir, Rawson's work tells the story of an unnamed narrator whose familial relationships are defined by his VATER syndrome. Abused by his mother and stripped of a voice by his brother's need to be Tom Cruise via *Rain Man*, he sets out into a universe of literary tropes. ... But in accumulating characters with disabilities as widely diverse as Darth Vader, Benjy of Faulkner's *The Sound and the Fury*, and the TV sitcom *Community*'s Abed Nadir, Rawson movingly, and with wry humor, articulates the assumptions and clichés faced by persons with disabilities, all the while creating a new family with his unlikely gathering of "fuckheads." (adapted from source)

As the title suggests, the author approaches disability—in general and specifically, his own—with a good dose of irreverence. This is not simply attitude, however, and the writing is not, as might be suspected from the title, profanity-laced. Rather, Rawson's irreverence is a tool for engaging with a disability that leaves little room for tiptoeing around the physicality and immediacy of bodily functions. This work speaks to how disability is defined, disability identity and stigma, and disability in popular culture. It is probably too heavy on the literary criticism for my lower-division sociology class, but selections on disability and family or Rawson's thoughts on disability and community would be welcome additions to discussion on those topics.

## *The Center Cannot Hold: My Journey Through Madness*

Ellyn Saks, Hyperion, 2007

[http://www.brainm.com/software/pubs/brain/The\\_center\\_cannot\\_hold.pdf](http://www.brainm.com/software/pubs/brain/The_center_cannot_hold.pdf)

Ellyn Saks is a success by any measure: She's an endowed professor at the prestigious University of Southern California Gould School of Law. She has managed to achieve this in spite of being diagnosed as schizophrenic and given a "grave" prognosis—and suffering the effects of her illness throughout her life. Saks was only eight, and living an otherwise idyllic childhood in sunny 1960s Miami, when her first symptoms appeared in the form of obsessions and night terrors. But it was not until she reached Oxford University as a Marshall Scholar that her first full-blown episode, complete with voices in her head and terrifying suicidal fantasies, forced her into a psychiatric hospital. Saks would later attend Yale Law School where one night, during her first term, she had a breakdown that left her singing on the roof of the law school library at midnight. She was taken to the emergency room, force-fed antipsychotic medication, and tied

hand-and-foot to the cold metal of a hospital bed. She spent the next five months in a psychiatric ward. So began Saks's long war with her own internal demons and the equally powerful forces of stigma. (from book jacket)

This book is accessible and allows the reader to understand Saks's experience, both internally and in its effects on her relationships with others. Additional contextualization would be useful to help understand the connections between her biography and the larger societal forces that shape it, as Saks does not provide a lot of background on the issues she addresses. One such example is the hint at larger patterns regarding standards of care (or lack thereof), as she mentions that hundreds of patients die as result of physical restraint (p. 149). She does, however, discuss her legal advocacy for individuals with mental illness, which provides a window into rights and recourse for those failed by systems of "care".

### *Sounds Like Home: Growing Up Black and Deaf in the South*

Mary Herring Wright, Gallaudet University Press, 2019/1999 (EBSCO Ebook Academic Collection, AN 2259211, unl copies)

20th Anniversary Edition features a new introduction by scholars Joseph Hill and Carolyn McCaskill [in which they discuss the significance of this work in relation to their project documenting Black American Sign Language]. Mary Herring Wright's memoir adds an important dimension to the current literature in that it is a story by and about an African American deaf child. The author recounts her experiences growing up as a deaf person in Iron Mine, North Carolina, from the 1920s through the 1940s. Her story is unique and historically significant because it provides valuable descriptive information about the faculty and staff of the North Carolina school for Black deaf and blind students from the perspective of a student as well as a student teacher. In addition, this engrossing narrative contains details about the curriculum, which included a week-long Black History celebration where students learned about important Blacks such as Madame Walker, Paul Laurence Dunbar, and George Washington Carver. (adapted from source)

Wright's memoir provides insight into how hierarchies related to hearing loss, use of speech, and facility with lipreading among the deaf students intersect with other social divisions to shape peer relationships at the school and teacher-student dynamics. She also describes how, due to her love of reading, she spent many hours in the school library and there befriended her blind peers. Used as a place of punishment for deaf students and commonly referred to as "jail", the library was where blind students learned to read and write Braille and where they taught Wright the tactile letters. All together, Wright's telling is a rich and nuanced narrative not only for the texture of daily life it provides but also for the larger historical backdrop against which her story unfolds.