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BOOK REVIEW

How to be disabled in a pandemic

By Mara Mills, Harris Kornstein, Faye Gibsurg, and Rayna Rapp, Durham, North Carolina: New York University Press. 2025. 392 pp.

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How to Be Disabled in a Pandemic, edited by Mara Mills, Harris Kornstein, Faye Ginsburg, and Rayna Rapp (hereafter Mills et al.), is a polyvocal yet intensely-local, documentary yet future-imagining, and timely yet historically-expansive view of the early years of the COVID-19 pandemic in New York City. Its contributors, many of whom first convened in a documentation project called the "Disability Covid Chronicles" that met regularly via Zoom at the height of the city's shelter-in-place order, represent a wide swath of what Mills et al. call—after the work of Cassandra Hartblay (2020)—"disability expertise."[1] That is, their knowledge is constructed both "*as* and *with*" people with disabilities, including "autistic adults, people living with chronic illness, blind accessibility experts, Black pregnant people experiencing mental health challenges, people with mobility impairments, adults with intellectual and developmental disabilities and their supporters, anti-racist activists, and incarcerated and unhoused disabled people" (11–12). Given the grinding ableism of higher ed spaces, it is still rare for any academic collection to collectively lay claim to the authors' disabled identities; also unusual, many of the essays could be seen as examples of what is now being referred to commonly as "autotheory" (Borstoff & Cooppan, 2025).[2] For these reasons alone the volume is a unique contribution to medical anthropology and cultural studies more broadly. But in addition to the disability expertise of each author, what emerges from the collection is a robust picture of a complex social phenomenon, what Mills et al. call "the disability dialectic" (4).

The dialectic they describe is the simultaneous fear and hope of people with disabilities navigating a hostile world made more complex by the arrival of a highly contagious pathogen. It is the provocation of what contributors Faye Ginsburg and Rayna Rapp describe as "both existential dilemmas and unexpected catalysts for creativity" (168). At the same time that "crisis standards of care guidelines" saw the quiet part of eugenics spoken out loud in hospitals (as described in Mara Mills' chapter on New York State Ventilator Allocation Guidelines), people living with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) felt like pandemic conditions gave them new opportunities for socializing (Kornstein and Rogers), and blind New Yorkers experienced increased awareness about basic access measures online (Coklyat and Fleet). Palpable anxiety and joy about what will happen in various futures—tomorrow, decades from now—throb between the lines of the entire collection.

[Correction added on November 21, 2025 after first online publication: In the title of this article, the publisher name was changed from Duke University Press to New York University Press.]

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For medical anthropology in particular, *How to Be Disabled in a Pandemic* is a watershed in that the chapters deal with medical questions, structures, and personnel in the same frame as disability *without* medicalizing disability itself. A look at the volume bookends makes the point clearly: an introduction by Pulitzer-Prize-winning science writer Ed Yong, who is known for his ability to translate complicated medical research for more general audiences, and a coda by well-known disability activist Judy Heumann (depicted in the film "Crip Camp," released in 2022 and discussed by several of the authors)—who crystallized resistance to the medicalization of disability, with its singular insistence upon "cure," in her famous refusal to see herself as "sick."[3] If at some point the medical model of disability, which focuses on impairment and its amelioration, and the social model of disability, which stresses the way that people with disabilities are excluded from full participation in built environments and social life, may have seemed at odds, *How to Be Disabled in a Pandemic* reflects and helps to create a new political world for health and healing. This is a world in which suffering—pain, impairment, disease—can be addressed as the subject of justice pursuits, but disability is not imagined only as illness in need of cure, erasure, or improvement.

While it is hard to survey such a far-reaching publication, representing different disciplines, methods, and subject positions, the editors usefully identify three patterns that run across the chapters. (While the patterns emerge and are brought to bear in the specific constellations of New York City, their wider implications are obvious). First, many chapters describe a "hierarchy of disability vulnerability" (Mills et al., 6), with pre-extant vulnerabilities such as incarceration (Bordelli, Thomas, and Brown), residence in group-care settings (Ginsburg and Rapp), lack of housing (Bhaman), and anti-Blackness (Mbonde) all being exacerbated under pandemic conditions. Second, disability and discourses of "care" were also used to justify greater surveillance and population management, such as in the allocation of ventilators to those judged to have higher quality of life (Mills) or the violent detention of undocumented residents (Salyer). Third, in many cases authors saw examples of what Mills et al. call "crip pandemic cultural production." This refers to everything from daily techniques for getting by to bed-bound imagination to dramatic public artworks (Kornstein and Rogers; Watlington; Mbonde; Mohapatra, Sharma, Ngyuen, and Kuo), usually rooted in notions of crip joy and connection.

Those teaching courses in medical anthropology, disability justice, abolition, Covid-19, or the rise of 21st-century fascism in the United States will find this volume useful for discussion. The prose is consistently accessible and contextualized in both deep study and experiential knowledge; students will undoubtedly appreciate these materials.

It is, of course, impossible to read this volume in the final quarter of 2025 without the benefit of hindsight, knowing that many of the fears it conveys are being realized. Anxiety has grown, and hope can seem rare. I would suggest that this volume encourages us to remember the myriad ways community and beauty are made in the face of danger.

Not long after the publication of *How to Be Disabled in a Pandemic*, I found myself in the Musée national Picasso-Paris, limping through an exhibit called "Degenerate Art: Modern Art on Trial Under the Nazis." Comprised of works from the infamous 1937 Nazi exhibition "Entartete Kunst" (translated as "Degenerate Art"), which toured Germany to "prove" that modern art represented the decline of national culture, and set against press clippings and biographical materials about the artists (not just Pablo Picasso, but also Paul Klee, Vincent Van Gogh, Vassily Kandinsky, and many others), the show stunned, overwhelmed, and terrified its contemporary audience.[4] As I sat to catch my breath, I realized that most viewers were probably not viewing "degeneracy" through a disability lens, as I was. But of course, the eugenic mathematics of those deemed "unfit"—people with disabilities being at the top of the list—was an essential piece of Nazi rhetoric.

And the art was fighting back.

Surrealist and modernist works were challenging (parts of) the status quo and standing up to fascism; they were cripping the triumphant able-bodied march of history, much like those creative New Yorkers who wrote and spoke with the contributors to this volume.

Given that Mills et al. relate in the Introduction that "a primary motivation of this project has been to archive ephemeral evidence of this important [crip] cultural work, much of which circulates widely but informally" (8), I suggest that even if that had been the *only* aim, to archive artistic "ephemeral evidence" is itself important, even radical, and worth publishing and reading. Putting *How to Be Disabled in a Pandemic* on my shelf, I think of the words of Egyptian surrealist artists, written first in Arabic, then translated into French and printed on the Picasso Museum wall: "O [people] of art, [people] of letters! Let us take up the challenge together! We stand absolutely as one with this degenerate art. In it resides all hopes of the future."[5]

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ENDNOTES

[1] Hartblay, Cassabdra. 2020. "Disability Expertise: Claiming Disability Anthropology." *Current Anthropology 61*(S21): S26–S36.

[2] Brostoff, A., and Vilashini Cooppan, eds. 2025. Autotheories. Cambridge: MIT Press.

[3] Newnham, Nicole, and James LeBrecht (Directors). 2020. "Crip Camp: A Disability Revolution [Film]." Higher Ground Productions; Netflix.

[4] Information about the exhibit: https://www.museepicassoparis.fr/en/degenerate-art-modern-art-trial-under-nazis

[5] You can read about the Egyptian surrealist movement here: https://www.tate.org.uk/art/art-terms/s/surrealism/a-brief-guide-to-egyptian-surrealism