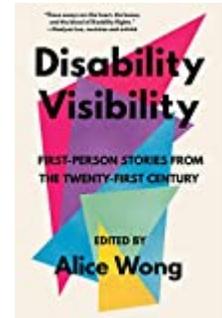


**Alice Wong, ed.** *Disability Visibility: First-Person Stories from the Twenty-First Century*. New York: Vintage Books, 2020. xxii + 309 pp. \$16.95, paper, ISBN 978-1-984899-42-2.



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*Disability Visibility: First-Person Stories from the Twenty-First Century* is part of the larger Disability Visibility Project led by Alice Wong in partnership with StoryCorps, a national oral history organization. What began as a “one-year campaign” to record disabled people’s oral histories and archive them at the Library of Congress has grown into a multimedia movement (p. xvii). The Disability Visibility Project had approximately 140 oral histories on record with StoryCorps at the time Vintage published *Disability Visibility* in 2020. Wong admits that the project has “always been a one-woman operation,” but, she notes, “this doesn’t mean I do everything alone.” Collaborating and partnering with other disabled people is what makes the Disability Visibility Project thrive. The relationships forged through the project and the book bring Wong “epic, Marie Kondo-level joy.” Wong writes that what she has “always been hoping to accomplish is the creation of community” (p. xviii). With both *Disability Visibility* and the larger project of which it is a part, Wong is succeeding in achieving her goal.

*Disability Visibility* is a collection of thirty-seven first-person accounts of what it means to be disabled in an ableist world and of what it feels like to be part of a broad, and growing, disability community and of disability rights and justice movements. Most of the book’s entries are only a few pages. They range from the poetic to the pragmatic. They are all politicized in their own way. The essays in part 4 are more overtly political. Contributors identify as women and men, as queer and non-binary, as black, as Asian, as white, or as some mix of racial-ethno-religious backgrounds. Some have been disabled all or most of their lives, others only for a few years. Authors identify as living with the effects of brain injuries, tumors, chronic illnesses, cerebral palsy, and spina bifida. A few identify as Deaf, deaf, blind, deaf/blind, or simply, and quite powerfully, as disabled.

As Wong notes at the outset, these are twenty-first-century disabled voices. Contributors are at ease using such words as “Crouzon syndrome,” “congenital idiopathic nystagmus,” “fibromyalgia,” “Ehlers-Danlos syndrome,” “dysautonomia,” “mul-

tiple sclerosis (MS),” “spasmodic dysphonia,” “lipomyelomeningocele spinal bifida,” “bipolar,” and “myalgic encephalomyelitis” (p. 263). Some contributors write about “having” cerebral palsy or a “rare genetic disorder.” Others lament loss and value recovery. A few refer to people as “able” and “able-bodied.” One writer calls the day she began taking psychiatric medication “one of the greatest days of [her] life” (p. 187). It seems from this collection of essays that the days when, as an act of solidarity and as a conscious disavowal of the “medical model,” we would limit our referential range to “disabled” and “non-disabled” are behind us. As Leah Lakshmi Piepzna-Samarasinha declares, we have “succeeded in getting more people to buy into being disabled” over the last thirty years and it has engendered a shift in focus and priorities of the most active among us (pp. 259-60). Our fight no longer seems to be with the medical gaze. We have moved from institutions, rehab centers, and doctor’s offices to “a million weird little groups and actions and projects”; from occupying federal buildings and lying in the streets, to using Facebook, Instagram and Twitter; from disability rights to disability justice (p. 260).

These essays suggest that the time may have arrived when in our academic and activist work we can begin to think of medicine as something other than a villain. Yet these essays also reveal that it is not the time to dissolve the divide between the fight for disability justice and the growing power and reach of a global medical-pharmaceutical industry. Every person on the planet should have access to reliable, efficient, effective, and informed health care when they need it. This does not mean, however, that disabled people must have their “activities of daily living” medicalized and made part of a “rehabilitation” plan. Our trips to the movie theater and the grocery store, our friendships, and our sex lives should not be scheduled and supervised by Medicaid Service Coordinators, nurses, physicians, and support staff (unless we request their presence). *Disability Visibility* provides a vision for some of the ways so-

ciety can be restructured so that we all have access to the things, and the care, that we want and need without exposing ourselves to the damaging, and sometimes deadly, effects of living a marginalized and medicalized life.

The essays gathered in *Disability Visibility* are at once deeply social and communal, and intensely and intimately personal. Nearly all of the contributors write about the importance of love and relationships, and what some call “interdependence,” in forging and sustaining life—in thriving in a brutally ableist world. At the same time, each of the authors contemplates their own embodied life. They write about self-catheterization and incontinence; about trauma, fatigue, and overstimulation; about lying in bed for days, weeks, and even months; and about having their limbs moved by other people, or getting dressed or positioned in their chair, or having their ass wiped by someone who is there to help them. More than one author talks about the importance of having—and creating—clothes that fit disabled bodies properly. Contributors write about “brilliant disabled” brains, disabled poetics, and disabled praxis, about making “something disabled and wonderful out of the disabled knowledge our bodies and minds know” (pp. 153, 258). As more than one author notes, disability affects “every moment of our lives” (p. 152). Bearing witness to the ways disability shapes what we do, who we are, and how we think, these beautifully and lovingly crafted essays bring the limits of the “social model” into stark relief. Although none of the authors explicitly address the “social model,” the cumulative effect of this volume is a powerful unveiling of all of the benefits of thinking about more than just the external forces that constrain us. Perhaps more important, *Disability Visibility* pushes beyond an irreverent and romanticized rendering of all of the wonderful possibilities disability engenders to get to the gritty, and sometimes shitty, realities of disabled people’s everyday lives. As Britney Wilson’s essay on using paratransit in New York City reveals, we cannot afford to abandon structural and

systemic change, but we must reenvision that change from a more radically embodied disability perspective. The essays in this volume show us that disability justice is social justice.

There are many wonderful affirming and provocative moments in *Disability Visibility*, but one particularly troubling passage has stuck with me. In her essay, Piepzna-Samarasinha writes, “I’m never eager for any disabled person to die, but I gotta say, if the old racist parts of white disability studies and disability rights die out—and they will—we will have an opportunity. Right now, the old Disability Rights guard is angry at disability justice people because ... we aren’t racist and we’re not just focused on policy work.... What happens if we can take over the Centers for Independent Living, the disability studies programs—or make something entirely new and different?” (pp. 259-60). Now, in the midst of the disproportionate lived realities of COVID-19 and the divisive politics of the Trump administration, is not the time to be heralding the death of disabled people. When I think of an old guard in the fight for rights and justice, I think of Martin Luther King Jr. and Malcolm X, of Bayard Rustin and A. Philip Randolph, of Sojourner Truth and Ida B. Wells, of Cesar Chavez, Angela Davis, and Shirley Chisholm. I think of Stonewall. I think of the hundreds of thousands of disabled people forced to survive and ultimately die in institutions. I think of people like Judy Heumann and Ed Roberts, who had to fight just to go to school with their friends and neighbors. I think of the nine black teenagers who walked into the high school in Little Rock in 1957. I think of the Section 504 sit-ins, and the Black Panthers, who provided hot meals to the disabled folks in San Francisco so that they could persist in what became the longest occupation of a federal building in US history. I think of places like Warm Springs, the campus of the University of Illinois, and Berkeley, where people were able to come together to form friendships and build a movement. I think of kids dragging themselves up the Capitol steps because they wanted Congress to pass the Americans with Disabilities

Act. I think of the activists in ADAPT (American Disabled for Attended Programs Today) who got out of their chairs and laid on the ground in front of buses, or crawled up the bus steps. I think of the policy changes that were required to close the hundreds of “snake pits” throughout the country and to send disabled kids to school. And I think of the policy changes that will be needed to end the police murder of disabled people of color and to free the tens of thousands of people (mostly people of color) with developmental disabilities and mental health problems incarcerated in jails and prisons. We cannot have justice without rights, and we cannot have rights without changes in policy. The dominance of white (and I would add elite heteronormative) disability studies must end; there has been every indication over the last decade and a half that it is ending. We do not need to wish for the death of our disabled elders, or of anyone else, to make that happen.

Stacey Milbern, in her essay, has offered an alternative way to think about the past and those who have come before us. She writes that she thinks about “crip ancestorship” often (p. 268). Her ancestors are “disabled people who lived looking out of institution windows, wanting so much more for themselves.” She believes that our disabled ancestors “laugh, cry, hurt, rage, celebrate with us.” Most important, she believes that our ancestors “learn as we are learning, just as we learn from them.” Milbern writes that “We grow knowledge and movements with them. We crip futurism with them. We demand and entice the world to change the way things have always been done, with them. We change ourselves with them. They learn through us. When we become ancestors, we will also continue to learn” (p. 269). We all live and learn together.

*Disability Visibility* is a barometer, a bellwether and a beacon. Each of its entries reveal in beautifully rendered prose and poetry a measure of our current climate. Taken collectively, the essays show us where we need to go. Wong’s curatorial

brilliance is a welcomed guiding force. A hope that I hold for the next volume is a deeper engagement with more ordinary disabled folks. Wong culled thirty-two of the thirty-seven essays included in *Disability Visibility* from other sources. The contributors to this volume are professional writers, research scientists, university professors, medical doctors, Ivy League educated lawyers, and presidential appointees. One writer was named “Person of the Year” and another a “Top 30 Thinker Under 30.” One writer spent one hundred thousand dollars on a “chair and the van to transport it” (p. 131). Some of the authors included in this volume are able to live their lives on “crip time” without worry of losing an hourly wage. It is delightful to see disabled people reach such heights of relevance and influence, but we also need to hear from those folks who do not have nearly as impressive credentials. This is something of which Wong and her contributors are well aware. Most of the contributors are mindful of their own privilege, and Wong writes that while the recently achieved visibility of disabled people is “exciting and important, it is not enough.” She encourages us to “*expect more.*” “*We all deserve more,*” she writes. Wong demands that there must be “depth, range, nuance to disability representation” (p. xxi).

*Disability Visibility* provides readers with depth, range, and nuance in its rendering of disabled lives. It pushes us into our future. It should become essential reading for anyone involved in social justice movements.

If there is additional discussion of this review, you may access it through the network, at <https://networks.h-net.org/h-disability>

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