

Book Review

Alice Wong, (ed.), *Disability Visibility: First-Person Stories from the Twenty-First Century*, New York, N.Y.: Vintage Books, 2020, pp.309, \$16.95 (paperback)

Reviewed by Victoria M. Rodríguez-Roldán

Alice Wong is one of the nation's foremost disability advocates. Among her achievements are the development of the Disability Visibility Project and the creation of the popular hashtag #CripTheVote on Twitter. She has now edited two anthologies, the first one being *Resistance and Hope: Essays from Disabled People*. Her second anthology is the subject of this book review, *Disability Visibility: First-Person Stories from the Twenty-First Century*.¹ In it, she offers something frequently absent from how we discuss disability: voices from disabled people themselves. By definition, anyone who does this (with the masterful choice of authors that Wong makes) is doing something refreshing and even revolutionary. All in all, Wong gives us an essay-based recounting of the past of the early disability justice movement, as well as many examples of disabled life in the current moment.

The collection offers a broad range of disabled perspective, but it is thoughtfully and intentionally edited. The book is divided into four sections: being, belonging, doing, and connecting. Taken together, they are the stages of building a disabled community from the inside of a person outward to the networks they organize.

Wong is emphatic about telling the story of a disabled community outside the mainstream narrative of disability. An issue that lives at the core of Wong's editing of the anthology is that she comes to it with a vision focused on disability *justice* and not disability *rights*. The "rights" perspective, which is older, focuses on the idea that the movement is just about securing legal rights for our community and, in the eyes of justice activists, fails to articulate how systemic oppression has led to injustices that exist beyond the basic laws. Disability justice, by contrast, acknowledges the intersection of marginalized identities within the disability community and how they work together to keep those with multiple marginalized identities oppressed and at the margins of

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1 *DISABILITY VISIBILITY: FIRST-PERSON STORIES FROM THE TWENTY-FIRST CENTURY* (Alice Wong ed., 2020).

society.² Its goal is not legal but liberatory, and it insists that the liberation of disabled people is inextricably intertwined with an end to racism, capitalism and other forms of oppression.

In my personal experience as a neurodiverse trans woman of color, the disability movement can be extremely pale, stale and male. Far too often organizations and efforts are led by white men, who continue to rest on achievements from the prior century and have not given space for newer voices to hold positions of leadership. Therefore, one of the first things to strike me about this anthology is the diversity of the authors. Jen Deerinwater, an Indigenous chronically ill activist, speaks from their perspective as to how being Indigenous has affected the ableism they experience and the intersection between the genocide of Indigenous peoples and ableism. TL, a deaf/hard-of-hearing and autistic activist who specializes in prison abolition, narrates their experience with what grief and remembrance look like when you live at the margins that society relegates us to as disabled people. Maysoun Zayid, known for her comedy and art, tells us about her lived experience as a Muslim disabled person with cerebral palsy. All in all, it is a list of diverse and accomplished and amazing activists, and it doesn't rely on the "same old-same old" usual list of suspects that is frequent in books and events about disability.³

An additional common thread that unites all the narratives told in the book is that they portray the complexity of the human experience without engaging in any form of self-pity. Indeed, as self-advocates we eschew the idea of being seen as objects of pity, but rather insist on being recognized as full-fledged humans who enjoy and are capable of great lives. As the stories portray, the only thing "wrong" about having a disability is society's ableism and lack of accessibility and opportunity for disabled people.

This lack of self-pity is such a strong through-line that some unfamiliar with disability could well come out with the wrong idea: The stories that portray resilience and refusing to go quietly into the good night may be misread as what the activist Stella Young termed "inspiration porn," a kind of feel-good story of disabled success, produced mostly for the benefit of an able-bodied audience. As an activist and colleague to many of these authors myself, I would say that this impression couldn't be further from the truth. Instead, the essays show the way that activists have been fighting ableism their whole lives, since well before they even considered themselves activists. If these stories inspire

2 See *What is Disability Justice?*, SINS INVALID (June 16, 2020), <https://www.sinsinvalid.org/news-1/2020/6/16/what-is-disability-justice> (offering the following tenets of "[a] disability justice framework": "[a]ll bodies are unique and essential"; "[a]ll bodies have strengths and needs that must be met"; "[w]e are powerful, not despite the complexities of our bodies, but because of them": "[a]ll bodies are confined by ability, race, gender, sexuality, class, nation state, religion, and more, and we cannot separate them"); Talila "T.L." Lewis, *Disability Justice Is an Essential Part of Abolishing Police and Prisons*, LEVEL (Oct. 7, 2020), <https://level.medium.com/disability-justice-is-an-essential-part-of-abolishing-police-and-prisons-2b4a019b5730>.

3 Carrie Basas, *Disability Rights So White: Disability and Racial Justice*, FAKEEQUITY (Mar. 8, 2018), <https://fakeequity.com/2018/03/08/disability-rights-so-white-disability-and-racial-justice/> (on the topic of racism and whiteness in disability rights organizations).

readers, it cannot be because they show disabled people triumphing over their disabilities and happily winning the privileges of the nondisabled, but instead because the disabled authors make clear their right to exist in the world as themselves, without having to change the essence of who they are for a world that insists on defining them against their will.

The essay with which Wong chose to lead the volume beautifully encapsulates these themes: The late Harriet McBryde Johnson, a well-known disability rights attorney from South Carolina who had a neuromuscular disability, discusses her conversations and debates with the moral philosopher Peter Singer of Princeton University. Within the disability community, Singer is well known for advocating that parents should have the option to kill disabled children when they're babies. His logic even extends to elderly people whose minds have ceased to properly "function" (at least by abled people's standards). In Singer's ideal world, someone with the physical disabilities that Johnson had would have been killed as a child. The disabled should not exist, according to him.⁴

Johnson describes how, despite Singer's advocacy that effectively says she's better off dead and has no place in the world, he turns out to be perfectly capable of having an ongoing friendly debate about the topic while treating her politely.⁵ This creates significant cognitive dissonance for her, as well as the broader disabled community she is a part of back home. Memorably, she tells us that a friend of hers compared Singer to how Nazi SS officers would often be doting fathers or loving husbands.⁶ That relationship with Peter Singer in many ways captures both the banality of evil (to borrow from Hannah Arendt, who coined the term to explain the Nazis who could otherwise be "good people" but still guilty of genocide)⁷ of eugenics and ableism and the emotional sacrifices disability activists often have to make.

Here, Johnson's essay resonated with me, and I'm sure resonated with many disability justice activists. We often realize from painful experience that ableist people never hate you or me in particular or want you or me dead specifically, but instead "those" nameless "other" people. As I have frequently been told when discussing society's hatred of people with psychiatric disabilities such as myself, they see me as one of the "good ones" who takes her meds and is presentable in society. This cognitive dissonance is similar to that seen in other

4 A deeper critique of both Singer's stances and Johnson's work can be found in Johnson's memoir, *Too Late To Die Young*. HARRIET MCBRYDE JOHNSON, *TOO LATE TO DIE YOUNG: NEARLY TRUE TALES FROM A LIFE* (2005). The debates with Singer were also the subject of a play titled *The Thrill*, from 2013. See Donal O'Connor, *Strength of Judith Thompson's new play The Thrill is asking provocative, complex questions*, THE BEACON HERALD (Aug. 14, 2003), <https://www.stratfordbeaconherald.com/2013/08/14/strength-of-judith-thompsons-new-play-the-thrill-is-asking-provocative-complex-questions>.

5 DISABILITY VISIBILITY, *supra* note 1, at 3.

6 *Id.* at 23.

7 HANNAH ARENDT, *EICHMANN IN JERUSALEM: A REPORT ON THE BANALITY OF EVIL* (1963).

types of prejudice. For example, the person who hates LGBTQ people will just as gleefully excuse mentally the lesbian cousin who gets him Christmas presents as not meaning her, just the ones who flaunt identity. The racist will try to justify police profiling of Black people at the same time as he has Black co-workers with whom he loves having lunch and of whom he thinks highly. That cognitive dissonance is the one of which Johnson is on the receiving end during her debates with Singer.

Ultimately, what Johnson shows in the essay is how easy it was for Singer to debate intellectually whether people like Johnson should get to exist when it's not his life at stake. To him, it is just a theory and the intellectual discourse is stimulating and fun. To those of us who end up dead or institutionalized when his views are turned into culture and policy, it is a terrifying matter of life and death. The emotional sacrifice that we frequently have to make as activists and members of marginalized communities is to be forced to debate our own existence and lives with people who hold power but for whom it is just an abstract intellectual exercise. Although Johnson passed away in 2008, her experience with people like Peter Singer is one that resonates deeply with me and that reminds me of many debates and discussions I've had. It particularly brings back memories of lobbying with congressional staffers against the curtailing of civil liberties of the mentally ill, and the ability with which they were able to debate whether people with mental health disabilities such as myself should be forced into treatment or be at the mercy of others. For me, a disabled person with bipolar disorder, it means a major difference in quality of life. For them it is an abstract issue to debate, which has no impact on them. By making concrete the realities of multiple disabled experiences, Wong, like Johnson, deprives the reader of an abstract version of disability and forces them to contend with the real impacts of ableism.

Another essay that left a powerful impact on me was Maysoon Zayid's work on her experiences with being a religious Muslim, and her relationship to Islam as someone with multiple disabilities.⁸ For example, in Ramadan it is customary for Muslims to fast during the daytime. However, people who for health reasons cannot do so are exempted from the rule. Notwithstanding this exemption, Zayid fasted during the holy month for the first few years of her adulthood, despite its being so much harder for her, until eventually she was unable to do so. This experience, which helped her be more proud and embracing of her disability and her religious beliefs, resonated with me because of my own Judaism, and the memories of my father not fasting during Yom Kippur because of his own health issues, and the example that set out for me. In Judaism, at least, the logic behind exempting those who cannot fast from the commandment is that you shall live by the commandments, and not die by them—the preservation of life is more important. Seeing this similar experience in another religious tradition was special for me and, once again, showed the intersection of disability with other facets of identity.

8 *DISABILITY VISIBILITY*, *supra* note 1, at 36.

There are many other essays throughout the book, more than this review can adequately cover. The collection contains Talia Lewis's eulogy to their partner, Ki'tay D. Davidson, a 22-year-old disability activist who in Lewis's words was a great activist and a dear loved one.⁹ This essay, which is so heartfelt it moved me to tears, weaves social justice and disability liberation with mourning and grief.

One resonant idea from this segment is this, on "Ki'tay's ability to sit with and *actively* love oppressors and those who were violent toward him and marginalized communities—most often solely because they do not adhere to that which has been deemed 'normal.'" This "truly set him apart." "He could breathe life and love into even *those* people within mere moments of making their acquaintance. This is what makes him special—reminiscent of what some here may call a prophet; others, a wise man; others still, a light or sage." This ability to love all and breathe life into the world makes me wish I had met Ki'tay and sets him as an example for all of us to follow.

Other essays that will likely resonate with many readers include Keshia Scott's piece on embracing asexuality as a disabled person.¹⁰ This one is essential for anyone who works with disability, because our society so often refuses to sexualize or acknowledge that the disabled usually have a sexual identity. It will also be resonant for those who fall within the LGBTQ umbrella, as asexuality is frequently erased even within queerness. There are parallels between how asexuality and disability are perceived: Both are seen by many through the lens of there being a "problem" or something "wrong" with the person.

Jessica Slice's experience as a parent with a disability is another obligatory read because of another stereotypical image that society often has of people with disabilities: that their disabilities mean that they couldn't be good parents. Disabled people often have to fight for the right to have and raise their children, and those of us with intellectual, developmental and mental health disabilities still face calls for sterilization and guardianship. Slice's essay challenges that perception with firsthand accounts of her experience.

For similar reasons, I enjoyed the essay on the isolation of being deaf in prison, by Jeremy Woody as told to Christie Thompson.¹¹ By including this viewpoint, a poignant story of isolation and suffering, Wong centers directly the most marginalized and least popular within our community: the incarcerated. The story of mass incarceration in the past few decades, particularly as it affects marginalized minorities, is a uniquely American story that is essential to understanding our darker instincts as a nation. This essay makes sure we don't forget that when discussing disability.

9 *Id.* at 28.

10 *Id.* at 121.

11 *Id.* at 59.

Another favorite of mine is the essay by Jen Deerinwater, who writes on the experiences of chronically ill and disabled Indigenous people in America.¹² They discuss their own experience of growing up disabled and Indigenous in Oklahoma and their objections to the term “Native American,” as well as their experience of anti-native racism in the healthcare system, often being addressed with slurs or asked invasive questions about their ethnicity while in hospitals. They also discuss in-depth the service of the Indian Health Service, in their words rated as “the worst healthcare provider in America,” with an allocation of funding of less than \$1,300 per person served. There is a reason the essay is called “The Erasure of Indigenous People in Chronic Illness.”

In addition to personal essays, the volume also contains manifestoes and political essays about contemporary issues of concern to the disabled community. Rebecca Cokley discusses abortion and how access to it is a crucial disability justice issue.¹³ The Harriet Tubman Collective’s essay describes their organization’s vision for Black lives.¹⁴ New Yorkers and those familiar with one of my favorite cities will also enjoy Britney Wilson’s essay on the fight for access and dignity in the New York City’s Paratransit system, and the famously inaccessible subway system.¹⁵

It is almost impossible to fully write on the scope of the book, because the essays and their authors are so diverse. Wong successfully captured, in the course of her anthology, the true breadth and multifaceted diversity of the disability community and brought it to light in a single, easily readable volume. All in all, when I put down the Kindle after finishing *Disability Visibility*, I felt that I had read a special book. When the next generations of historians are researching what this movement did during this day and age, this book will be as much a must-read as it is now.

To conclude, I’d say that this book is also an essential read for the legal profession, such as lawyers, attorneys, law students, judges, and professors. In our profession, it is essential that we center the most marginalized among us and understand the full breadth of who comprises the people whose rights we are supposed to protect and guard. This includes the disability community.

12 *Id.* at 47.

13 *Id.* at 159.

14 *Id.* at 236.

15 *Id.* at 205.