



## August/September 2020 Book Club

### *Disability Visibility: First-Person Stories from the Twenty-First Century*, edited by Alice Wong

#### **Why Read It**

*Disability Visibility* is an anthology of first-person narratives by disabled people. Editor Alice Wong first started the [Disability Visibility Project](#) in 2014, prior to the twenty-fifth anniversary of the ADA (Americans with Disabilities Act), where she partnered with StoryCorps and recorded oral histories by disabled people—now with 140 oral histories, and an entire online community. This collection is the latest culmination of these efforts, covering the disabled experience in four sections: Being, Belonging, Doing, and Connecting. By reading these stories, knowing that it's not a "Disability 101" primer, you are able to listen and hear what disabled creators and writers are feeling, expressing, and thinking in these uncertain times, and start thinking about your own path to being a better ally and supporter to disabled people.

*The book is available for purchase at any retailer [linked by the publisher](#), at your local library, or via [Bookshare](#) (an ebook library for those with reading barriers).*

#### **Discussion Questions**

- 1) What particular essay or essays really moved you or stayed with you? Why?
- 2) Did this book change how you define "disabled" or "disability"?
  - a) Why or why not? What does it mean to you?
- 3) There are many references to the use of *language* as means of creating harm for the disabled community. For example, the use of the word "accident" for incontinence when it is out of their control. What are ways we can better combat this?
- 4) One of the themes we noticed throughout the book is the idea of help, and the power and control associated with requiring help in some sort of sense. Why do you think we stigmatize certain types of dependency, especially in the case of disabled people needing help, when in fact we are all interdependent?
  - a) Why do we define **help** in only certain ways and not others, and how can we also redefine dependency/independence to be more inclusive and less ableist?

- b) Who should bear the cost of offering help? (One of the essayists, [A.H. Reaume](#), writes that “*Independence is a fairy tale late capitalism tells us in order to shift the responsibility for care and support from community and state to individuals and families.*”)
  - c) How does our privilege empower us to ask for and access help? Who is “entitled” to help and who is not? Why do we rely on individuals to ask for help or force them to have to advocate for themselves? What support networks and systems can be put in place instead?
- 5) What stereotypes does our general society, especially media, create about disabled people, and how do they compare against the narratives shared in this book?
- a) For example, movies like *Me Before You* paints disabled life as unworthy of living; *Wonder Woman* vilifies its disabled characters. One of the essayists talks about how *Shape of Water* sees them as unwanted, un-rapeable. How do these instances “other” disability in order to create a certain distance between “us” and “them”?
- 6) Something that the editor, Alice Wong, talked about in a recent Q&A session about this book is the notion of “acceptable losses”, and how often society will perpetuate the idea that disabled people are acceptable losses. Have you encountered this concept before? If so, how?
- a) How do we reduce harm to disabled people, knowing this idea of “acceptable losses” exists?
  - b) One of the essayists also talks about how we *criminalize* disability, primarily through poverty. How are ways our laws and law enforcement disproportionately hurt disabled people?
- 7) What are our assumptions (as a society) about the choices disabled people should be able to (or not able) to make for themselves?
- a) For example, do we assume that they will want certain things (e.g. to be cured, to *not* want to abort their disabled baby)? How do these assumptions then limit their choices?
  - b) Why do we think we are entitled to make choices for them?
- 8) What is ableism to you? What is saviorism? How do we move beyond ableism but also not into saviorism?

- a) One of the essayists talks about how ableism “kills through isolation” – how do we counter this?
- 9) How do we ensure proper representation of disabled folx within various intersectional movements without tokenizing them?
- 10) What is a “normal”, “full” and/or “worthy” life? How do we reimagine these two definitions? *Who* is able to determine these definitions?
  - a) As one of the essayists posed in the creation of a truly accessible fashion show with audio and visuals integrated into the experience, how do we move beyond compliance to celebrating access?
  - b) One of the essayists mentions how Siri is an assistive technology, but many of us simply see it as a ‘regular’ feature. Are there more technologies like this we can normalize (which helps reduce the cost) and integrate into our work/life?

### **Discussion Summary / Book Analysis**

To book club members, the essays expanded our definitions of what it means to be disabled, particularly in how disabled people describe themselves, how others choose to positively and negatively define them, and what they perceive to be their places in the world and in society. There is so much nuance that is not covered in “mainstream” media, and being disabled is not a monolithic culture or identity, and each disabled person will/can choose to define themselves differently.

The book challenges you to your preconceived notions about disabled people. A key ableist assumption is that all disabled people always want a cure. As [Liz Moore](#) writes in their essay, *I'm Tired of Chasing a Cure*, “How do we feel when abled people start advocating for “cures”--which may come in the form of eliminating our people entirely--rather than when the desire from a cure comes from disabled advocates?”

In the process of understanding *why* we had this assumption, we also talked about disabled people’s sense of autonomy and what choices they are allowed to make--in the same section, *Being*, Harriet McBryde Johnson, described her 2002 conversation with philosopher Peter Singer on disabled and selective infanticide, originally published in the [New York Times Magazine](#). The essay, titled “Unspeakable Conversations,” moved the book club members deeply--in one succinct essay, the author illustrates her own need for assistance with a personal aide, her trying experiences traveling to Princeton for the conversation, and how her own existence and ability to feel happiness are challenged by abled people. Who are abled people to (again) *assume* that disabled people have an inferior quality of life? Relative to who? About her first

encounter with Singer, McBryde Johnson wrote, “I proceed to the heart of my argument: that the presence or absence of a disability doesn’t predict quality of life.”

Another assumption about disabled people and autonomy is that they do not have any autonomy in their lives, when they do—and why are we so quick to define help in certain ways, and not simply recognize the help we are all given in our lives? [Haben Girma](#), the first Deafblind person to graduate from Harvard Law School, concluded in her essay, [Guide dogs don’t lead blind people. We wander as one](#), “But someday the world will recognize that a Deafblind person charts her own path through the unknown. For now, I know it — and so does Mylo. He takes his lead from me.” Why do we assume that Mylo, her guide dog, leads her, when it is she, Girma,, who leads the dog?

When it comes to defining help and care—many of the essays, including Girma’s, stood out to book club members. Why do we most often only define help in terms of resources that are financial and visible? Why is it that we (as a society) don’t automatically provide adequate resources to the disabled? In [Common Cyborg](#), Jilliam Weise described the difficulty of calling herself a “cyborg” and “disabled” when her identity is both—yet she had immense difficulty in finding the right leg for herself, and having to worry if her insurance will approve it. At the same time, the question again comes back to the “cure”—why do we, as abled people, always try to fix disabled people? She is reliant on technology that may or may not suit her, and is conditional to what the marketplace will sell her. The technology disabled people need comes at a great financial cost, even with Medicare assistance—[Jessica Slice](#) estimated that her power chair and van to transport the chair costed nearly \$100,000, but was necessary for her and her family in order for her to be able to enjoy time with her child outside of her home. Why should she have to put such tremendous strain on her family?

Why is it that we define help in such visible terms, such as the technology or need for personal assistants, when in reality, we all are helped in different ways? We discussed at length question 4, from [A.H. Reaume](#)’s key statement about independence. It is easy to glorify individualism, because it is what we have been taught to do (by society and by the economy, due to capitalism). Privilege allows us to receive help more easily, swiftly, and without stigma -- you are less likely to see certain aspects of your identity as a *disability* and simply just something you need. By redefining help and acknowledging as much as possible the ways in which we have been helped, and the privileges we have, and normalizing asking for help (rather than having to beg for it/rely on goodwill from strangers and the community), there is a future possible where help and care can be expected and received from others, intentionally and thoughtfully.

By placing assumptions on disabled people’s quality of life, we overlook (deliberately or unknowingly) the *systemic structures* that make their lives difficult. This is a message that McBryde Johnson presented, and is echoed in many of the essays. In Jeremy Woody’s essay as told to Christie Thompson, [The Isolation of Being Deaf in Prison](#), he describes the complete lack of resources and communications available to him—he was not given a sign language interpreter

for the prison doctor, for mental health services, to communicate with the guards—not even in disciplinary court, where he could not sign “not guilty”. It shocked book club members that such blatant discrimination was legal, even in a prison system that is deeply flawed.

It is impossible to do due justice to the book without mentioning every essay, but to capture some key takeaways: the book deeply challenged the key assumptions of our club members, and made us realize the ways in which our society and our government has failed, oppressed, and marginalized disabled people. Rather than speak for disabled people, we must let them speak for themselves, and give them the opportunity to lead and represent themselves, without being tokenized for ulterior motive and gain. We cannot assume that disabled people have a singular identity of being disabled, as disabled people can be found/should be included in every movement that exists.

We also [should not romanticize strength](#) in “conquering” or “overcoming a disability,” as many sought to do after Chadwick Boseman’s death last month. Instead, how can we create a culture where disabled people can disclose publicly their disability, without fear of their industries or society rejecting them? ***As we dream of a new “normal” after COVID-19, what is a new normal that can be more inclusive, and normalize accessible features so that disabled people do not have to constantly advocate for their needs and ability to exist? How can we proactively support disability justice, rather than just ensure we are no longer ableist?***

### **Behavior Changes + Action Items**

- Support diverse voices and publications, such as [Wear Your Voice](#) (features an entire section on ableism, plus feminism, LGBTQIA+, race, and more)
- Continue to engage with the [Disability Visibility Project](#) via social media, the podcast and the blog
- Support and inform yourself through some of the [organizations listed by the National Center on Disability and Journalism](#) (also has a helpful style guide and best journalistic practices)
- Support disabled creators ([link to shops run by disabled creators](#)), disability justice performance artists such as [Sins Invalid](#), or [on youtube](#), following [disabled models](#)
- Understand and remove ableist language from your vocabulary **as a first step:** [glossary and alternatives](#) by [Lydia X.Z. Brown](#)

### **Additional resources (podcasts, articles, book recommendations)**

- [1A Radio Show: The Americans With Disabilities Act At 30](#) 45 min segment with [Alice Wong](#), [Judy Heumann](#), [Britney Wilson](#)
- [Book review of Hearing Happiness: Deafness Cures in History by Jaipreet Viridi and Design Justice: Community-Led Practices to Build the Worlds We Need by Sasha Costanza-Chock and Disability Visibility: First-Person Stories from the Twenty-First Century Edited by Alice Wong - The](#) book review of two other book to read
- More on ADA at 30: [https://www.adaanniversary.org/findings\\_purpose](https://www.adaanniversary.org/findings_purpose)

- [What is Disability Justice? Some Resources to Get You Started](#) by Civil Liberties and Public Policy
- [28 Movies, Books, TV Shows \(and More\) That Explore Disability Culture](#)
- [My Child Has a Disability. What Will Her Education Be Like This Year?](#) by [Nicole Chung](#)
- Refinery29's [Voices of Disability](#)