**Public Health Post:** What is your…Favorite food?

**Alice Wong:** Last year I had a number of medical crises which left me with the inability to eat by mouth. Since I use a feeding tube for nutrition, I miss my favorite foods so much. Because swallowing is dangerous, I still taste some soft things like ice cream and spit them in a cup so I can at least have some flavor in my life. I love pureed ginger and carrot soup and ice cream. My favorite ice cream flavors are coffee, chocolate, and mango. If folks are interested, they can read an essay I wrote for Eater last year about my love of food.

<https://www.eater.com/23400679/feeding-tube-food-cravings>

Favorite book or author?

I wish I had more time to read, honestly. I do recommend and enjoyed Leah Lakshmi Piepzna-Samarsinha’s [*The Future is Disabled*](https://arsenalpulp.com/Books/T/The-Future-Is-Disabled) and Ed Yong’s [*An Immense World*](https://bookshop.org/p/books/an-immense-world-how-animal-senses-reveal-the-hidden-realms-around-us-ed-yong/17476424?ean=9780593133231), both of which came out last year. Another book that I believe every public health student and professional should read is [*The Viral Underclass: The Human Toll When Inequality and Disease Collide*](https://bookshop.org/p/books/the-viral-underclass-the-human-toll-when-inequality-and-disease-collide-steven-w-thrasher/17086534?ean=9781250796639) by Dr. Steven Thrasher. I love anything by Jane Austen, especially *Persuasion* and *Pride and Prejudice*. And I love graphic novels by Gene Luen Yang such as [*American Born Chinese*](https://bookshop.org/p/books/american-born-chinese-gene-luen-yang/8179780?ean=9781250811899) and [Boxers and Saints](https://bookshop.org/p/books/boxers-saints-boxed-set-gene-luen-yang/12650832?ean=9781596439245).

Favorite movie or actor?

This is a tough one but I love action films and I’ll basically watch anything starring Keanu Reeves, especially the John Wick series.

Favorite animal?

I was born in the year of the tiger, which happens to be [the title of my memoir](https://bookshop.org/p/books/year-of-the-tiger-an-activist-s-life-alice-wong/17818752?ean=9780593315392) and I feel like I have a lot of ferocious feline qualities.

Favorite quote?

“Hope is a discipline.” – Mariame Kaba, co-author of [*Let This Radicalize You*](https://www.haymarketbooks.org/books/1922-let-this-radicalize-you)

*I would like to begin by talking about your work. You have been an activist for many years, working tirelessly for disability justice.* Was this something that came naturally to you? How did you become the activist that you are today?

I’ve written about this before and it still holds true today. I honestly feel like I had no choice but to be an activist because I am a disabled person born in a nondisabled world. It was a means of survival for myself. I had to fight for the basics and advocate for myself at a young age and wish that many marginalized people didn’t have to struggle so much. I don’t even think much of what I did as a younger person was considered activism and it took me a long time to be able to identify as one. I became the activist that I am today by being in community with others, learning, growing, and making lots of mistakes, and understanding that there is no one way to be an activist. I dream of a day where disabled people don’t feel compelled to be an activist or have to advocate so much for themselves because there’s nothing glamorous or idealistic about being one. It’s effin’ hard! Knowing that I am part of a larger movement with other folks keeps me going. Folks can learn more about my origins as an activist in my memoir, [*Year of the Tiger: An Activist's Life*](https://bookshop.org/p/books/year-of-the-tiger-an-activist-s-life-alice-wong/17818752?ean=9780593315392).

What would you say to people who are thinking about becoming more involved in disability activism?

Connect with your community whether it’s on campus, in your local community, or online. You are not alone! Activism can be both big and small actions, it can be about strategy, building with others, sharing your time and wisdom with others. It can be whatever you want it to be as long as you are passionate about something and want to create change.

*This book calls out and unpacks ableism through powerful stories.*What sparked your decision to create this book? Can you talk about the motivations that turned this book from an idea to a reality?

For a long time, most books about disability come from a biomedical model or often filled with inspirational narratives. Many stories about disability continue to be by nondisabled people and often from a white disabled perspective. With *Disability Visibility* I wanted to present a diversity of perspectives and experiences and was very intentional on finding contributors who come from different backgrounds that discuss a variety of issues. I believe every issue is a disability issue so I hope some readers are surprised to discover how climate change, the #MeToo movement, and mass incarceration are disability issues. In this book the majority of the pieces are reprints and I selected them after years of bookmarking and keeping a spreadsheets of essays and articles I absolutely adore, ones that blow my mind and change the way I think such as the first one by Harriet McBryde Johnson.

I knew immediately that Harriet McBryde Johnson’s piece had to go first. This is the one piece I hope a person reads if they pick up this book. I don’t expect everyone to read the whole thing, but I wanted to present Harriet’s piece first which encapsulated so brilliantly what systemic ableism looks like and the real struggle disabled people face existing in the same space as everyone else.

For those of you who read this essay, Harriet had a public conversation slash debate with Peter Singer, a famous philosopher who argued for the infanticide of disabled babies. And here we are today with other academics promoting euthanasia and death such as well known Zeke Emanuel, a doctor and bioethicist, who believes people over 75 have a lesser quality of life and should die by that age. Right now, there are physician assisted suicide laws in various states and countries like Canada. Ableism and ageism are inextricably linked to our capitalist value of productivity. Every person has value and it should not be based on what or how much they can do and whether they earn an income or not. Eugenics is not a relic of the past and I wanted readers to confront this idea with Harriet’s essay.

I also know that I wanted s.e. smith’s beautiful essay at the very end of the book about the magic of disabled spaces. This essay ends the book on a high note centering disabled joy and culture. The disability experience isn’t solely about trauma, stigma, pain, or discrimination. There’s so much more and I thought that would be a nice final note to leave the reader.

How did you decide to organize the book and divide it into the four sections: Being, Becoming, Doing, and Connecting?

All of these stories are impossible to categorize by subject because they are wide-ranging. I decided on larger themes that start from an individual perspective of just being or in the process of becoming to the final category that speaks to connecting to community, relationships, environment, and one another. It’s not a perfect system but I liked the progression of the stories by dividing them into these four sections.

As an editor, figuring out the major thematic categories is a big part of the work. I couldn’t group them by subject because that didn’t make sense so I went with higher level themes that speak to different modes that progressed so I decided on dividing it in four sections: being, becoming, doing, and connecting which felt very organic to me from an individual to a broader community-based level. I was mindful when ordering the pieces that they varied in tone and vibe. I didn’t want a bunch of serious or heavy pieces in a row. So those were some of the considerations when putting the book together.

What was your process to find and collect all the stories that make up this book? Did you have these people and their stories in mind before you put this book together? Or did the stories come together more organically?

Around 2018, I received an email from Catherine Tung, who was an editor at Vintage Books at the time. She asked if I had any interest in editing an anthology and I immediately said yes. I knew exactly what this anthology would be about, first-person essays by disabled writers published in the twenty-first century. I wanted a collection of disabled wisdom from the here and now that cuts across a range of subjects. I did not want to write something about myself because it was important for me to share as many works by disabled people with this opportunity because there simply are not enough stories by us and for us. Things are slowly getting better but we need more of everything because we belong everywhere. My approach to this anthology was to find works that were different in perspective and style but were all political, personal, and powerful. For years I had already been bookmarking and collecting various stories by disabled people so I created a spreadsheet of some of the top favorites being mindful of diversity of topics and perspectives. These are the kinds of stories that move me and I wanted to amplify certain disabled people by including them in this book. And the stories came together through a process of approaching the contributors and many discussions with my editor. I made a few concessions but *Disability Visibility* is precisely what I envisioned it to be.

*There is something for everyone who reads this book. It allows disabled people to be seen and heard, it allows people who practice ableism to be more reflective about moving toward change, and it welcomes people who are new to the disabled community or feeling marginalized within the disabled community.*What changes do you hope will come from people reading this book?

I would like people to feel invigorated, enraged, and motivated. I hope it makes people want to learn more about disability from the perspective of actual disabled people which is why there is a section in the back from additional readings and resources. If this is the first time a reader encounters so many different stories by disabled people, I hope it increases their understanding of ableism and that they want to keep learning and growing.

*As individuals become more familiar with your authorship, your advocacy, and your activism, can you share some of the challenges you have faced at the policy level?* What are some of the structural barriers to your causes that could be mitigated by legislation or legal means? Where do you see or experience the most push-back when making your case to policymakers or others?

In my opinion, non-disabled people only got a small sense of the importance of accessibility during the pandemic when almost everything shut down except for essential workers who had little to no protections at work. A few inroads in a more flexible and accessible world have disappeared which is a real shame such as curbside grocery or library pickup, hybrid and asynchronous remote learning options, online concerts, museum exhibits, and conferences, and Zoom meetings. We can’t go back to normal and we should take the lessons we learned from this pandemic and integrate these options as the standard going forward because there will be future disasters, emergencies, and pandemics. Many of my disabled friends and I find it super ironic that these changes were suddenly possible because non-disabled people have been inconvenienced. If they listened to disabled people, all of us would have been able to adjust to sheltering in place a little more easily while it was still incredibly difficult and stressful for so many.

I fear for this fall and winter with the rising rate of infections and hospitalizations that will be worsened by the divestment in testing and data tracking. In an article by KQED about the new ‘Eris variant’ on [undercounting COVID infections in California](https://www.kqed.org/news/11957790/the-new-covid-eris-variant-and-rising-cases-what-you-need-to-know), where I live, “Why don’t we have firmer numbers on how many people are actually testing positive for COVID right now? Earlier on in the pandemic most people were getting diagnostic PCR tests through official sites, which were then tracked through their laboratory processing and had their numbers reported — the way that the state’s official test positivity rate is still tracked. However, the arrival of widespread antigen tests has now given more people a way to test themselves for COVID at home without having to find a PCR test (albeit in a way that’s different from how a PCR test “detects” the virus.) But while public officials have urged at-home testers to report positive results to their local health authority, very few people still do so. All of this goes some way to explain why the “true” number of people who currently have COVID in 2023 is a very difficult number to report — and why any official number from PCR testing almost certainly represents a big undercount.”

Public health has deteriorated in the last few years with prominent health care professionals, public officials, and policy makers such as Dr. Ashish Jha who has been platformed by the *Boston Globe* and Dr. Leana Wen with the *Washington Post* who continue to minimize the pandemic promote the ideas that long COVID is not a the mass disabling event that it is, that everyone will be fine because vaccines and Plaxlovid exist without acknowledging structural barriers and racial disparities, and that immunocompromised and high-risk are outliers who are inevitable acceptable losses. Just because you may have several comorbidities or be over 65 years old doesn’t mean you deserve harm and adverse outcomes from an infection. High risk people like me have been sidelined and forgotten by the state.

In a Tweet by Dr. Jha on [August 13th of this year](https://twitter.com/ashishkjha/status/1690774099373559808) he gave this advice, “Get treated if infected, Use masks and tests if you wish, And don’t worry about every new variant.” Treatment is not always available or affordable to those most impacted by the pandemic. “If you wish” to get tested erases the fact that testing is no longer free and easily accessible and that people in positions of authority like him find that masks are optional despite the fact that this is an airborne virus that is easily transmissible by asymptomatic people. The condescension of telling the public to not be worried by the [latest EG.5 variant](https://www.kqed.org/news/11957790/the-new-covid-eris-variant-and-rising-cases-what-you-need-to-know) dismisses the valid fear of high risk people who struggle to exist in public spaces without being harassed for masking or requesting accommodations because the current systems in place have abandoned us in a push to return to “normal.”

The pandemic is not over. People need to continue to wear masks in addition to pushing for better air quality and other mitigation efforts instead of focusing on individual responsibility and the “you do you” philosophy. People can still go see Taylor Swift or Beyonce if they take care precautions. And precautions aren’t just for you, they are for everyone. This is what community care is all about. Public health is supposed to address the entire population, not just the ones who are healthy, young, and “productive.”

It disheartens me to see the head of the CDC [maskless in photos on social media](https://twitter.com/ahatlikethat/status/1685661054158696448). The messaging is obvious from the top all the way to the local level: the pandemic is not deadly and just a “summer flu” for “normal” people and f\*ck everyone else because that’s just how hypercapitalism, racism, eugenics, and ableism works.

It pisses me off that medical settings across the country are no longer requiring masks, schools are no longer requiring masks even though they have inadequate ventilation, and that college campuses have similar policies. All of this is intentional. Of all the things to drop that’s related to the pandemic, this one is the most ass backward to me. Even before the pandemic, people with all kinds of infections are entering buildings and medical settings are places where immunocompromised and high risk people also have to enter for their healthcare. And healthcare providers and frontline workers are at risk as well. I don’t understand the rationale behind these decisions and it disturbs me that public health departments across the country are ending other protections. Companies have already started requiring their employees to come back to work in the office full-time or at least four days a week. Universities are requiring the same from their staff and faculty even if they requested remote work as a disability-related accommodation. In some ways these rollbacks can erode disabled people’s right to accommodations which is chilling.

On another policy matter, there is a lack of funding and political commitment in researching long COVID, developing treatments for it, and learning from the significant populations in the disability community who have lived with post-viral illnesses such as POTS, ME/CFS, dysautonomia and other chronic illnesses. [Disabled and sick people have been gaslit](https://www.huffpost.com/entry/doctor-gaslighting-long-covid_n_64bda0fbe4b0229eb5652977) about their lived experiences and the same thing is happening to this growing generation of people with long COVID.

We need more disabled people and people from marginalized communities in public health and all of the health professions. In a essay by [Christine Mitchell for the Disability Visibility Project](https://disabilityvisibilityproject.com/2022/03/07/disabled-people-are-tired-public-health-and-ableism/) “The ongoing rate of COVID cases, hospitalizations, and deaths we are seeing in the US isn’t inevitable; it’s a policy choice…We can choose a different way forward, a way that protects the health of all of us, starting with disabled people, those most at risk of morbidity and mortality, and those who have been historically and structurally marginalized. We must hold our government accountable for the policy choices that have led to the thousands of lives lost to COVID-19 every day in the US. We must create pathways for disabled people to enter the fields of public health and medicine and to help shape the policies that affect us. We must invest in public health research that addresses gaps in data about disabled people so that we *can* create inclusive evidence-based policy towards health equity. We must center disability and racial justice not just in word, but in action. We must continue to wear masks, get vaccinated and boosted, and engage in hard conversations with our families, our friends, and our communities to do the same.”