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'It Just Burns Me Up': Disability Activist Alice Wong Reminds California This Pandemic Is Far From Over

LISTEN

By Ariella Markowitz, Sasha Khokha May 23, 2020

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Alice Wong, a San Francisco-based disability rights activist and the host of the Disability Visibility podcast, said she was dismayed to find out about the state's new vaccine prioritization plan. *(Eddie Hernandez Photography)*

Alice Wong is an influential disability rights activist, media maker and podcaster who hosts the podcast Disability/Visibility from her home in San Francisco.

Here are some highlights from her recent conversation with California Report Magazine host Sasha Khokha.

Comments have been edited for brevity and clarity.

What's most troubling about the COVID-19 pandemic:

Seeing so many people go outside and really, absolutely not social distancing, not wearing masks. It just burns me up, the way people are so ready to be over the pandemic. I don't think we're anywhere close to it. They're going to actually create more infections and subsequently more deaths.

"We've learned how to make do with living in a world that's rather hostile and never designed for us in the first place. There's a lot of lessons and insight that disabled folks have to share."

—Alice Wong, disability rights activist

They're still advising high-risk people like myself to just stay at home. I feel like this sets up this very unfair dynamic where the burden of staying safe and healthy falls upon those who are the most marginalized and the most impacted. It's going to create additional complications, consequences that all of us are going to suffer.

On her recent Vox essay, "I'm Disabled and I need a ventilator to live. Am I expendable during this pandemic?"

It doesn't surprise me that state guidelines or health systems would say, "We have only this many ventilators or this many staff or resources. You know, we really need to think about who are the most likely to benefit." Any sort of calculus about who's the most worthy often takes into account issues about quality of life. I do know that people see me with my wheelchair, with my ventilator on, and they just can't imagine living this way. Some people just straight up feel like this kind of life is a life not worth living. These kinds of attitudes end up really excluding and discriminating against folks like me.

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How the pandemic has highlighted the importance of accessibility:

I think it's bittersweet. It's wonderful that people are suddenly realizing, "Oh, you know, we should make this concert live streaming!" That working from home should be more flexible, or learning from home. Realizing and seeing how access really does benefit everyone.

But I also feel some concern, and also some irritation, because disabled people have been advocating for this kind of thing for 30 years after the passage of the Americans With Disabilities Act. There's still this idea that requesting accommodations and advocating for them is somehow asking for something extra, some unfair advantage. These kinds of adaptations should absolutely remain and become a part of the default in the ways we organize and the ways we connect as people.

The importance of caregivers:

For a lot of us, like myself, it's basically impossible to social distance and isolate ourselves. I can't get out of bed without help. If I'm infected or if my [caregiver] is infected, there's really no way to protect myself from exposure.

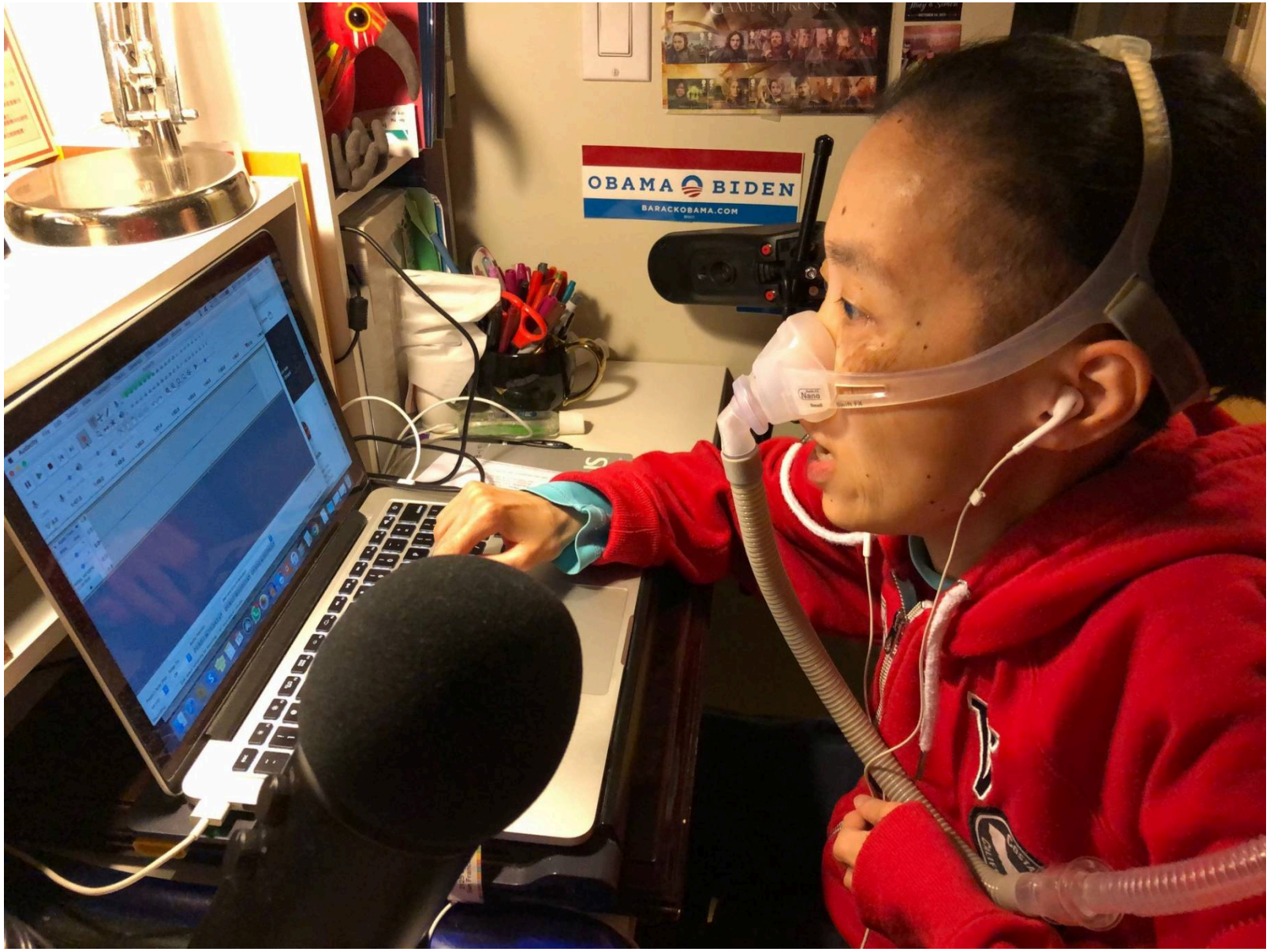
"It's so troubling to see people so ready to get the economy jump-started and just relaxing everything, while so many people are dying behind closed doors. I don't understand why there isn't more outrage over these deaths."

—Alice Wong, disability rights activist

I want the people who help me to have all the protections, equipment and everything they need. This is a workforce that's under the category of "essential workers," but they truly aren't valued in our society in terms of caregiving. This is a very gendered profession where so many of the workers are women of color or immigrants. I'd like to see an increase in wages and benefits for this workforce. Access to protective gear for anyone that does this kind of work, [including] family caregivers.

One thing that's really distressing to me is the number of workers and people living at nursing homes and other long-term care facilities all over California and nationally that are dying and infected with COVID-19.

It's so troubling to see people so ready to get the economy jump-started and just relaxing everything, while so many people are dying behind closed doors. I don't understand why there isn't more outrage over these deaths, because these systems, these institutions are broken. This a really important time to think about, to rethink, about why these systems exist and to really question them.



Disability rights activist Alice Wong podcasting at her desk at home. *(Eddie Hernandez Photography)*

What she's hearing from her podcast listeners:

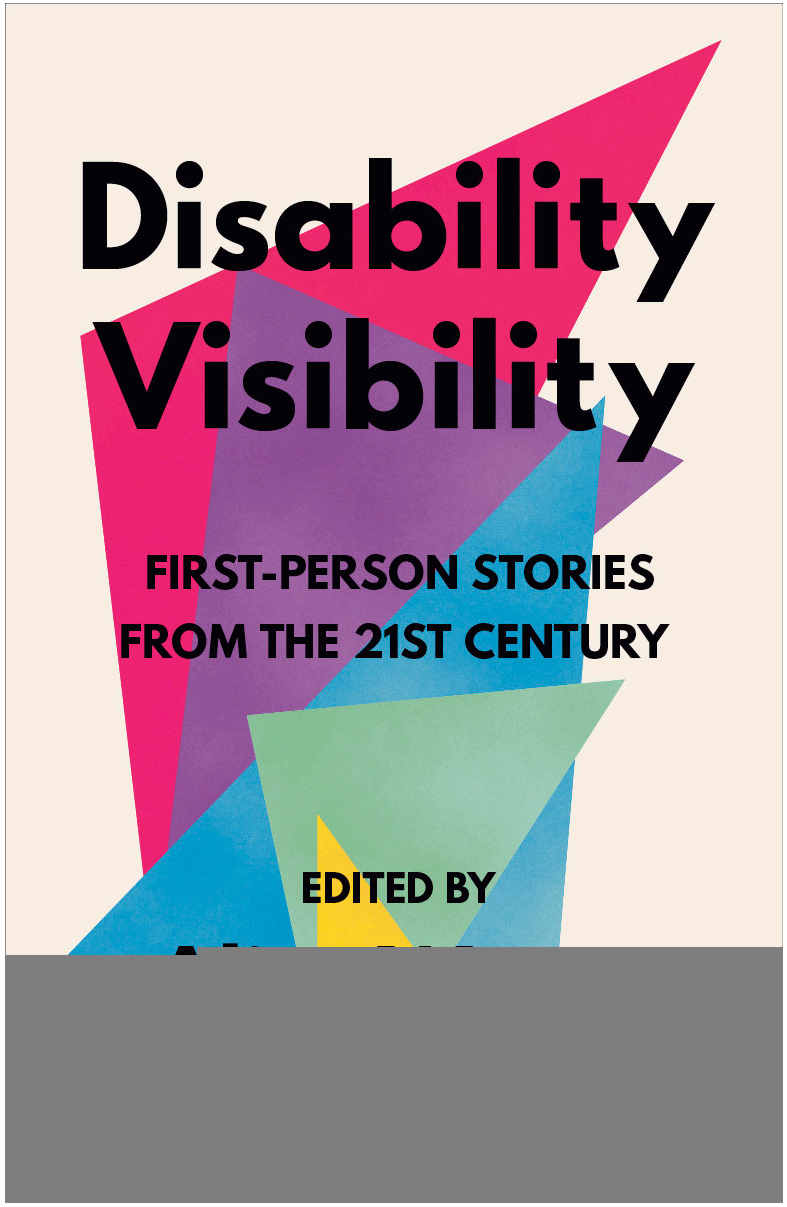
We really need more stories and perspectives by the people who are most impacted by this pandemic. I'm talking about multiply-marginalized people, like black, disabled, chronically ill folks. Because we can't separate the racism and the ableism

and classism from this experience. This wasn't the first crisis that disabled folks faced. This is just one of a long kind of arc. We've learned how to make do with living in a world that's rather hostile and never designed for us in the first place. There's a lot of lessons and insight that disabled folks have to share.

What it would take to build an inclusive future:

I think the future could look so different. I think so much of what's happened during the pandemic and the flaws in the structures and systems we have are basically a failure of imagination. What if we designed ways that people could be integrated into society with the supports and services in place so they have as much autonomy as possible? This kind of work is already happening. By communities of color, queer communities, disabled communities, in the way that we provide mutual aid and care for one another.

There's such an opportunity to kind of take these lessons and scale it up so that we really can have people living the lives that they want. I feel like that's absolutely possible. But it's just it's a matter of a culture shift and political will.



Alice Wong's book, "Disability/Visibility: First Person Stories for the 21st Century," comes out in June 2020. *(Courtesy of Alice Wong)*

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