Disabled Advocates Demand Better Vaccine Access as They Face Greater Risks of Dying from COVID-19

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TOPICS

Disability Rights

Coronavirus

Vaccination

GUESTS

Alice Wong
disabled activist, founder of the Disability Visibility Project and host of the podcast Disability Visibility.

Rabbi Elliot Kukla
disability activist who offers spiritual care to those who are ill, dying or bereaved at the Bay Area Jewish Healing Center in San Francisco.

LINKS

Alice Wong on Twitter

"Disability Visibility: First-Person Stories from the

Image Credit: Left: Eddie Hernandez; Right: Miki Vargas

As the U.S. death toll from the coronavirus tops 465,000, we speak with two disability rights activists about growing calls to prioritize giving COVID vaccines to people with physical and mental disabilities. Some states, including California, are failing to prioritize vaccines for people with serious physical or developmental disabilities, even though studies show they are up to three times more likely to die from COVID-19. “I use a ventilator to breathe, and I have respiratory failure,” says disabled activist Alice Wong, founder of the Disability Visibility Project and host of the podcast “Disability Visibility.” “If I get the virus, I will not survive. That is a certainty.” We also speak with Rabbi Elliot Kukla, a disability activist who offers spiritual care to those who are ill, dying or bereaved at the Bay Area Jewish Healing Center in San Francisco. “Since the beginning of this

Twenty-First Century"

"Where's the Vaccine for Ableism?"

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pandemic, it's been clear that disabled lives simply don't matter as much," he says.

Transcript

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AMY GOODMAN: This is *Democracy Now!*, democracynow.org, *The Quarantine Report*. I'm Amy Goodman, with Juan González.

As the U.S. death toll from COVID-19 tops 465,000, we look now at the devastating impact the pandemic has had on the disabled. Many states have failed to prioritize giving vaccines to people with serious physical or developmental disabilities, even though studies have shown disabled people are two to three times more likely to die from COVID. California has faced intense criticism for recently switching to a largely age-based vaccine rollout, leaving out many younger disabled residents with serious medical conditions. There is also confusion in many states over what medical conditions qualify for prioritized access to vaccines.

On the international front, the United Nations high commissioner for human rights, Michelle Bachelet, recently appeared on Al Jazeera and spoke out about the pandemic's impact on the disabled.

> **MICHELLE BACHELET:** We know that people living with disabilities, usually they are — they had already inequal conditions, and they are discriminated, and that makes them more likely to be exposed to the virus and less likely to be treated. As you know, in many countries, the biggest amount of people who have died of COVID-19 is people living with disabilities.

AMY GOODMAN: We're joined now by two guests. Joining us from Oakland, California, is Rabbi Elliot Kukla, who offers spiritual care to those who are ill, dying or bereaved at the Bay Area Jewish Healing Center in San Francisco. He is a disability rights activist, working on a book about being

chronically ill in a time of planetary crisis. His recent *New York Times* op-ed was headlined "Where's the Vaccine for Ableism?" Rabbi Kukla is also the first openly transgender person to be ordained by the Reform Jewish seminary, Hebrew Union College–Jewish Institute of Religion in Los Angeles.

And in San Francisco, we're joined by Alice Wong, founder of the Disability Visibility Project, an online community dedicated to creating, sharing and amplifying disability media and culture. Alice Wong is also the host of the podcast *Disability Visibility* and the editor of the new book, *Disability Visibility: First-Person Stories from the Twenty-First Century*, an anthology of essays by people who have disabilities.

We welcome you both to *Democracy Now!* Alice Wong, let's begin with you. I mean, you use an electric wheelchair. You are on a ventilator. But you are not prioritized in California for getting the vaccine?

ALICE WONG: Yes, I am not. Just to explain to people a little bit of what the structure is like in California, they are currently vaccinating people in Phase 1A and 1B, which includes healthcare workers, long-term care residents, people over 65 and essential workers of several sectors. The next step was Phase 1C. That included people under 65 with any disability or health condition, as well as additional essential workers. So, I was supposed to be in Phase 1C.

And the governor, on January 25th, announced that he was moving to an age-based system after Phases 1A and B completed with vaccination. And this is where I lost my bleep, and I got really, really angry. I created a hashtag called #HighRiskCA, because I really need people to understand that young, high-risk people exist, and that when we think about high risk, we often think about older people, people who are in long-term care facilities. But there are a lot of people with disabilities who are chronically ill, higher-weight people people, immunocompromised people, who are in all age groups. And people need to understand the disastrous impact of this change. If you use the hashtag so that we can mobilize and also hold space for one another, because, you know, the bleep is bleepy real.

JUAN GONZÁLEZ: And, Alice Wong, there are some states, such as Oregon, who have included people with intellectual and developmental disabilities of all ages in the vaccine rollout. Could you talk about what's the differences between some states, and which states you think are doing a better job?

ALICE WONG: Well, I think some states are doing a little bit better job. But the question is lists. You know, New York recently announced that they're going to be [inaudible] vaccines for people with disabilities. But there's a lot of questions as to who do they define as high-risk. You know, a lot of states are relying on the CDC's list. And the CDC's list of conditions for groups that are at high risk for COVID-19 is not comprehensive, nor was it even meant to be anything definitive. It leaves out a lot of people with disabilities. And states are using this for their eligibility criteria. And other states are also increasing and adding specific disabilities, as well. So, this leaves a lot of people out, especially people with rare or undiagnosed diseases.

So, you know, for people who want to read more, there's actually a really excellent article, published a few days ago by Liz Bowen in *Scientific American*, that talks about this whole idea of these lists, because, you know, disabled people are clearly heterogeneous, and not everybody has a diagnosis, and not everyone has access to care or a primary care doctor. And a lot of these states that are prioritizing disabled people, they have to actually provide proof and verification. And that kind of gatekeeping is another barrier.

JUAN GONZÁLEZ: Yeah, I'd like to bring Rabbi Elliot Kukla into the conversation. Rabbi, you've suggested that, from the outset, disabled people have been marginalized in response to the pandemic. Could you explain what you see as happening, and also especially what is happening to those who are disabled in long-term care facilities?

RABBI ELLIOT KUKLA: Yeah, thank you for asking about that. A lot of my work is serving people in long-term care, in all sorts of different facilities.

Really, from the beginning of the pandemic, the messaging was, you know, “Don’t worry, the only people who will die or become seriously sick are elders and disabled people and people of higher weight.” So, in other words, we’re really no big loss. You know, “Anyone who is less disposable will be fine, so you shouldn’t worry” was really the — pretty much across the board, was the messaging at the beginning of the pandemic. And that understanding has really led the response to the pandemic, this feeling of being disposable.

Even from the very beginning, before there were even medical shortages, there was a threat of medical rationing to elders and people with disabilities. And the pandemic has really — the epicenter has been long-term care. More than a third of COVID deaths have happened in nursing homes, which has been something that, you know, located in nursing homes, felt like an inevitability to me from the way things were playing out from the beginning, and really unbearable to watch play out.

And a lot of that has to do with so many systemic injustices coming together in this one location, from lack of government oversight to poor infection control to the fact that long-term care, in its very structure, is kind of a pandemic waiting to happen. It’s set up in such a way that because of less and less public funding and more and more need to worry about profits, most long-term care facilities depend on not very well-paid staff, largely of people of color, who are exposed to some of the biggest health risks in society, as we’ve seen. Most of the people who staff nursing homes often don’t have adequate sick leave, are often working multiple jobs to make ends meet, and are in a situation with high turnaround, are often working — often living at home with people who are also in high-risk jobs. And people who are essentially exposed to some of the highest health risks in society due to racism and poverty are in this role of caring up close to the most high-risk people, which is really a position that makes both the staff and the residents, really by design, by the very structure of these institutions and society, disposable, makes both parties disposable. And that’s really systems that are very large, very deep ageism and ableism and racism that’s deep within the structure of how we think about those things in society, and sizeism.

AMY GOODMAN: I'd like to turn to the new Democratic congressmember from New York, Mondaire Jones, speaking on the House floor last week.

> **REP. MONDAIRE JONES:** Now millions of Americans are out of work. And we must remember that it's people with disabilities, people of color, and especially women of color, who have been the hardest hit. As members of Congress, we must do all we can to ensure everyone — and I do mean everyone — can live in dignity. That's why I support the National Apprenticeship Act of 2021, which will create 1 million new apprenticeships. This bill includes the Apprenticeships Access for All Act, which I am proud to have co-authored with my colleague, Congresswoman Alma Adams. This legislation will help remove racist and ableist barriers to employment from our national apprenticeship system, because everyone deserves a good-paying job, no matter your race or your ability.

AMY GOODMAN: So, that's Congressmember Mondaire Jones of New York. Alice Wong, if you could respond to this? And also, if you could take us through your attempt to get a vaccine?

ALICE WONG: Yeah, I'm just so delighted that, you know, the representative just talked about ableism and just named it for what it is. I think a lot of people in the public do not know what ableism is, and if they hear about it, they actually deny that it exists. You know, they just — I've been told by lots of nondisabled people, just like, you know, "You have a parking spot. You have all of these things. You know, you have the ADA. You know, you guys have a lot of perks." And I'm just like, you know, "You don't really understand at all." You know, ableism is systemic. And it's really bound up with hypercapitalism and white supremacy. And I'm really delighted to see more people, especially our elected officials, calling this out and talking about it at the same kind of breadth with racism.

And for me, you know, I've been really nervous, you know? Being a high-risk, disabled person, I have a neuromuscular disability. And I use a ventilator to breathe, and I have respiratory failure, as related with my disability. At this phase, that's — if I get the virus, I will not survive. That is a certainty. So, I have done everything within my power to stay safe. But

again, as with so many people, there's only so much you could do. I have not left my house since March of last year. I tapped out, except one time only in October to get the flu shot. Yet I'm not alone in this. There's so many people in this country and everywhere that are really biding their time and just trying to hang on.

So, you know, when I was in Phase 1C, I thought, "OK, you know, I can just hang on. I know supply is an issue. I know the rollout has been really shaky and not so great in California. But at least I'm prioritized. I'm next in line." But then, you know, the governor made this decision. Phase 1C is completely wiped off of the state's websites, their state vaccination plan. And it's basically a betrayal, you know, a betrayal by the state to the people in Phase 1C, who were told to be patient and to wait our turn. So, I called around. I asked my pharmacist. They don't even have access to the vaccine yet. You know, I'm doing a lot of [inaudible] conversations with people I know. I talk to my doctor. But, you know, there is really no clear idea when I — if I have access.

And I want to also to highlight something that Elliot said in terms of long-term care workers. You know, there are people like me, people with disabilities, living in a community that have attendants that work with them, that help us with our daily needs. This is another layer of risk on top of our disabilities, because it is impossible to social distance. I rely on people to help me get up every day. I am in close contact with them. There is absolutely no way to social distance. And there's a lot of people who — this workforce is absolutely essential. And they, in San Francisco, at least, are getting access to the vaccine. My two attendants, who are my family members, got vaccinated, but yet I have not. And that, to me, is not equity. That, to me, is not justice.

JUAN GONZÁLEZ: Yeah, I'd like to ask Rabbi Kukla — you've noted that although disabled people are a prioritized group in most current vaccine distributions, that, quote, "We often end up at the back of that line, even though we are three times more likely to have chronic conditions that put us at higher risk of dying of COVID-19." From your perspective, how does that happen? How do disabled people end up being pushed to the back of the line?

RABBI ELLIOT KUKLA: I mean, I think it's basically ableism. I think there's basically — since the beginning of this pandemic, it's been clear that disabled lives simply don't matter as much. You know, there was this double message — or maybe it's not a double message, maybe it's very a simple message — that although disabled people have been threatened with medical rationing since the beginning, that although we are considered so high-risk that potentially we can't get medical care if we do get COVID because we might not be savable, at the same time, we're being told that we need to wait for a vaccine, which really is communicating a lack of prioritizing our lives. If we're so high-risk we can't get medical care, but at the same time we are being told that we are not getting a vaccine right away, that double message, or singular message, is one of lack of value.

And that has really continued throughout the pandemic. It hasn't felt so much like hard decisions are being made in terms of weighing hard decisions and sometimes disabled people end up at the bottom, so much as disabled people have been easy to expend with since the beginning of the pandemic in all sorts of places, like when it has come to medical rationing, when it's come to vaccines, and when it's come to the sort of public health messaging that we don't need to worry as much since disabled people, elders, higher-weight people will be the ones to carry the brunt of this virus.

AMY GOODMAN: I was wondering, Alice Wong, if you lived in New York, if you would have better access? Recently, the governor expanded the list of people who are prioritized, actually enumerating issues that people face — for example, if you have cancer, current or in remission, including 9/11-related cancers; chronic kidney disease; pulmonary disease, including but not limited to COPD, asthma, pulmonary fibrosis, cystic fibrosis, 9/11-related pulmonary diseases; intellectual and developmental disabilities, including Down syndrome; heart conditions, including but not limited to heart failure, coronary artery disease, cardiomyopathies or hypertension; immunocompromised state, weakened immune system, including but not limited to solid organ transplant or from blood or bone marrow transplant, immune deficiencies, HIV, use of corticosteroids. And it goes on from there. It's very specific. But even as I'm reading this, I'm wondering: How

do people know this? And how do people even get to vaccine sites? Like, you haven't left home, you said, but for a flu shot once since last March, so you've almost been at home for a year. Would you fall into a category in a different state, where in California you just cannot get to the front of the line?

ALICE WONG: Yeah, I think this is really the real question, right? You know, this is another quotient of ableism, in the sense of: Why do disabled people have to prove or identify or document their disability in order to be prioritized? You know, this is — I understand the need to do that and the need to try to have a list, but it really leaves out a lot of people who are just as highest-risk as I am.

And I think that's the real question, is the people who are in power. And I think earlier, when Elliot was talking about ableism, you know, I think sometimes it's about also a question of power and a question of political representation. You know, who in the Newsom administration, who are major decision-makers, are part of the disability community? You know, this is something that is something that really weighs on my mind, because we're often seen as expendable and disposable because we're just not seen as part of their world or just somebody that is respected just by being themselves.

So, this is one of the things that's so difficult, is the fact that each state, and even each county, is left to kind of have their own kind of lists. And I think this kind of disparity is really unfair. It just troubles me greatly, because I want all of us to live, and I want to live. I want all of us to live. And I think we shouldn't have additional hurdles to just get through the door to say we're high-risk.

AMY GOODMAN: Well, I want to thank you so much for taking this time. Alice Wong is a disability rights activist. She is with the Disability Visibility Project, host of the podcast *Disability Visibility*, editor of the new book, *Disability Visibility: First-Person Stories from the Twenty-First Century*, an anthology of essays. She's speaking through a ventilator and uses an electric wheelchair. We also want to think Rabbi Elliot Kukla, who offers spiritual care to the ill or dying at various centers, including the Bay Area

Jewish Healing Center. He is also chronically ill and a disability activist. We will link to his piece in *The New York Times*, “Where’s the Vaccine for Ableism?”

This is *Democracy Now!* When we come back, most people heard President Biden say that there was a moratorium on deportations, on most deportations. So how is it possible that in the last few days, more than 70 people, more than 20 of them infants and children, were deported to Haiti? Stay with us.

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