

California's Vaccine Rollout Presents Barriers for Disabled People

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WRITER'S COMMENT: During an 1892 speech, investigative journalist Ida B. Wells said that "the way to right wrongs is to turn the light of truth upon them." By exposing the lies that white Southerners told to justify lynchings of Black people after the Civil War, Wells' work embodies her words. In Sasha Abramsky's UWP 104C course, we learned that journalism, at its best, shines this "light of truth" on the injustices of our time. For our feature story assignment, Sasha asked us to report on the life and times of California during the COVID-19 pandemic. In January, the state pivoted away from its initial phased vaccine rollout to a speedier age-based approach, deprioritizing eligibility for disabled and immunocompromised people younger than sixty-five years old. As disabled Californians found community online through hashtags like #HighRiskCA, I was drawn to their stories. My reporting follows the difficulties encountered by high-risk Californians during this time, examines where the state fell short, and seeks to answer questions about how we build a healthier future for disabled people. On multiple occasions, Sasha brought his extraordinary eye for impactful journalism to our conversations—I extend my gratitude to him for his guidance throughout this project.

INSTRUCTOR'S COMMENT: In teaching my journalism students, I always hope that they will, in doing their reporting and writing, come to see the complexities and nuances of the stories that they are weaving. Some of my students manage this, others struggle. In Daniel's case, from his first writing assignments, I knew that he was a born journalist. His skill at telling a story, and at weaving complexity and also color into

his narrative stood out. In choosing to tell the stories of a particular group of people—disabled Californians—and the obstacles they faced in getting vaccines during the early days of the vaccine rollout, Daniel brought both an eye and an ear for detail to his work. He used quotes and voice to powerful effect, and ended up with a journalism narrative that, frankly, stunned me with its sophistication. I am delighted that this piece has been chosen for Prized Writing, and I look forward to following Daniel's writing career over the coming years...

—Sasha Abramsky, University Writing Program

It was Gillian Ladd's forty-eighth birthday when she received news in January that she would have to wait months to become eligible for a COVID-19 vaccine in California. For Ladd, the news was "crushing."¹⁹

Ladd has lived with brittle diabetes—characterized by sharp swings in blood sugar levels—for the last forty-two years following an early childhood diagnosis. In 2010, the toll of the disease kickstarted a process of kidney failure that made her a transplant candidate. Eight years later, she received a rare simultaneous pancreas and kidney transplant, and she has been on immunosuppressive medication in the years since.

These conditions make Ladd higher risk for serious complications were she to become infected with COVID-19.²⁴

Within hours of the news, Ladd reached out to her transplant center, which had "no advice" for her. She also inquired with the San Francisco Department of Public Health, which said that they were essentially "powerless" and could not make exceptions for high-risk disabled people.

Ladd's search for help then led her to the California Department of Public Health. She "never heard anything back" after writing to Dr. Tomás Aragón, the department's director.

"It's terrifying to breathe the air, and then to be told that I wasn't worth figuring out by the governor, by the health department? That was very distressing to me," Ladd said. "I've never felt so disposable in my life."

The state's early tiered framework for vaccine rollout initially included at-risk disabled people in phase 1C.⁷ But in late January, amid growing criticism about a slow start during the first six weeks of vaccine distribution, state officials pivoted, announcing a significant expansion

of eligibility to educators, food service employees, first responders, and Californians over sixty-five years of age.^{14, 25} Absent from the state's new policy on eligibility were California's estimated five million disabled residents under sixty-five.¹²

This shift to an age-based system for vaccine eligibility “will allow us to scale up much more quickly and get vaccines to impacted communities much more expeditiously,” Gov. Gavin Newsom said during a January 25 press conference.⁹

While the amended eligibility was meant to broaden the scope of vaccine recipients with respect to racial and economic equity, it left high-risk disabled Californians under sixty-five on their own to figure out when, where, and how they would be able to get a vaccine.

The next day, Yolanda Richardson, secretary of the California Government Operations Agency, explained the decision. “We want to make sure that nothing slows down the administration of vaccine other than the pace with which vaccine arrives in the state,” said Sec. Richardson. “We’re going to do that by balancing safety, speed, and equity while scaling up to meet the level of vaccine needed in the state.”⁵

The response to this announcement from the disabled community was swift. Alice Wong, a disabled activist from San Francisco who has spinal muscular atrophy, posted a call to action on YouTube within days. “Age is not the only factor in determining risk,” Wong said. “This decision by the Newsom administration is an act of violence and erasure toward groups disproportionately impacted by the pandemic. It is racist, classist, and ableist.”³⁵

Subsequent advocacy efforts through online platforms, including #HighRiskCA on Twitter and other social media sites, have highlighted inconsistencies and inequities in the vaccine rollout. In their shared struggles, many disabled Californians like Ladd have found community with others online while they cannot gather in person.

“I’ve never been in such great risk to go outside that I haven’t been able to demonstrate or show up on somebody’s doorstep or be active,” Ladd said. “I’m an activist at heart.”¹⁹

Since late November, the state’s Community Vaccine Advisory Committee has been working on ensuring equitable access to COVID-19 vaccines.⁸ But as California and other states have raced to vaccinate their residents at record pace, specific communities, including disabled people, have seen lower rates of vaccination.

Taking steps to reduce inequity, the governor's office worked with over twenty philanthropic foundations to fund the Together Toward Health initiative, a project managed by the Public Health Institute. The program has committed over \$23 million to community based organizations, which naturally adapted their outreach and networks to pandemic efforts because they were "already trusted" in their communities, said Sue Watson, the initiative's director.³⁰

The state provided vaccine access codes to hundreds of these community groups to schedule priority appointments for their vulnerable populations. But these codes were intended mostly for the state's low-income, Latino, and Black residents, and confusion spread throughout disabled communities about whether the codes applied to them.

"It was very unclear who they were intended for. And so, there was a sense of, like, who's supposed to be using these?" said Jessica Lehman, executive director of Senior and Disability Action, a disability rights organization based in San Francisco. "There were a bunch of disabled people who used the codes to sign up for appointments" which were later cancelled because they "didn't meet the criteria," Lehman said.²⁰

In February, reports that healthy and affluent residents were misusing these shared codes surfaced in San Francisco³ and Los Angeles,³⁴ and the governor replaced the group codes with individual ones²⁹ shortly thereafter to prevent linecutting. Ladd, who received the vaccine using an equity code that was "not intended" for her, found these missteps frustrating.

"What I have contended since I learned that there were equity codes was why the hell weren't the organ transplant recipients given that code?" Ladd said, adding that it is "easy enough" for the state "to contact the major medical centers and say, 'Hey, here's a code for your highest risk patients. Send it out to them.'"¹⁹

Advocates say that outreach to disabled individuals has not adequately met the needs of this community. Instead, millions of disabled and older Californians have relied on family caregivers²³ to care for their pandemic needs and to advocate for vaccine access.²² Kenny Strohmaier, a disabled resident of Redwood City, lives with his sister, Karen, who has cared for him for over two decades.²⁸ Diagnosed in early childhood with a neurodevelopmental disability that impacted his movement, balance, and learning, Kenny has adapted well to various physical and social challenges throughout life. More recently, however, Kenny has begun aging at a rapid rate, resulting in significant health complications.

During the pandemic, Karen’s concerns for her brother’s health have been heightened due to his underlying conditions. Kenny was born with two kidneys, but one of them failed him in adulthood. In 2017, he underwent four kidney surgeries in five days and suffered a similar relapse in 2019. Even though Kenny’s impaired kidney function and other disabilities are high-risk conditions, Karen said his nephrologist refused to make the vaccine available to Kenny in early 2021 until he was eligible. At sixty-four, Kenny was just one year short of the state’s age requirement for vaccine eligibility.

“I wasn’t okay with that answer, so I climbed the medical ladder of his other doctors,” Karen said. To no avail, she continued to seek support from the appropriate medical contacts.

With the help of physician friends who were aware of their situation, Kenny and Karen received a chance call in late January that leftover shots were available that same day at the Ravenswood Family Health Center vaccine clinic in East Palo Alto. “We raced there right away. I was honest that he wasn’t sixty-five and the shot was for him,” Karen said. “They took both of us and put Kenny at the front of the line, no questions asked.”

In part, the clinic was organized to meet vaccine equity goals for the economically disadvantaged communities of San Mateo County. This type of collaboration—where local counties, nurses, fire departments, and other organizations work together to identify and fulfill the community’s needs—is the main goal of the Public Health Institute’s Together Toward Health initiative.

If not for the clinic, Kenny and Karen would have had to wait until March or April to receive their vaccine shots. Their story represents an early success, but wider access to vaccine eligibility was still weeks away for a majority of the state’s disabled population.

With support from disability rights groups, high-risk Californians scored a collective victory on February 12, with an announcement from state officials that eligibility would be expanded in mid-March to those with any underlying health conditions²⁴ that elevate their risk of COVID-19 complications.¹⁶

For many disabled people who had been left in limbo for weeks, the updated eligibility was welcomed with relief. The March 15 date for expanded eligibility has since come and gone, and optimistic vaccination stories have populated the online feeds of many disability rights groups.

But for some disabled people, the challenges continue. The websites of many public health departments are inaccessible to blind

or visually impaired people who use screen readers,³¹ which violates the Rehabilitation Act of 1973¹⁵ and the Americans with Disabilities Act of 1990.²⁶ And the social media feeds of many government agencies are missing alternative text² or video captions¹⁰ that allow blind or deaf people the same access to information as abled people.²¹

“This is one of the challenges of having fifty-eight counties and all these different local folks that are trying to stand up something that has a much bigger public interface than anything they’ve ever done,” said Andy Imparato, executive director of Disability Rights California.¹⁷

In addition to these web accessibility issues, transportation to and from a vaccination site presents a barrier for some disabled people, said Imparato, who also serves on California’s vaccine advisory committee. “There’s an effort on the part of the state right now to try to get the vaccine to people where they are. But that’s going to take time,” Imparato said.

In May, the state announced a partnership with Healthy Future California, the University of California, Los Angeles, and seventy community based organizations to take vaccination efforts door-to-door.²⁷ Canvassers are bringing mobile vaccinations to underserved communities to boost the state’s vaccination numbers. Many organizations have also taken up the mantle to provide mobile clinics to rural communities, and President Joe Biden has followed suit at the federal level with his own “community corps.”³²

The biggest barriers to these efforts are money, people power, and the logistics of keeping the shots at their required temperatures throughout the day, experts say.

“That doesn’t change the fact that it needed to be done, and that the state had to find ways to do it,” said Silvia Yee, a senior staff attorney at Disability Rights Education and Defense Fund. For the most part, local authorities were managing these efforts on their own while the state looked to “one big contractor,” which was not necessarily ideal, Yee said.³⁶

Carolyn, mother to Kristin, a twenty-eight-year-old disabled woman, knows that the state can “do better” at bringing vaccines to disabled people. At five years of age, Kristin was full of energy and life, and her family could never have imagined that complications during a surgery to remove a brain tumor would leave Kristin blind, nonverbal, and unable to walk without assistance. Kristin later developed scoliosis and was diagnosed with dystonia, a serious neurological disorder characterized by painful muscle spasms and a loss of muscle control. In the twenty-four

years since her surgery, Kristin has persevered through multiple physical, social, and educational hurdles but remains very limited in her ability to navigate the world without full-time care. With the support of her family, Kristin continues to live at home with her parents, who serve as full-time guardians and advocates.¹¹

Kristin's disabilities are severe, which qualifies her for care through California's regional centers for people with developmental disabilities.⁶ Despite Carolyn's advocacy, Kristin waited alongside most high-risk Californians for months to receive her vaccine shot. Finally, on April 13, weeks after California opened up shots to disabled people, Kristin was vaccinated at a CVS—a thirty minute drive from her home.

"If she would have had some sort of adverse reaction, it would have been a nightmare," Carolyn said. "People shopping all around there, and then you're going to have somebody with a disability laying on the floor in the middle of a CVS, right?"¹¹

Like Ladd, who struggled to find solutions from her doctors and government officials, Carolyn was disappointed by the lack of outreach from medical institutions. "It's really easy to pick out the people that have severe disabilities [since childhood] because they're all, in California, run through the regional centers," Carolyn said, adding that disabled people should have received their "location preference" for vaccinations in a timely manner.

Even with these challenges, Carolyn emphasizes that "financial means" and involvement as an advocate "makes a huge difference." "So many people with disabilities don't come from [a place] of having economic means, people that can advocate for them, and education," Carolyn said.

These factors, along with inequities in access to nutritious food, health care, and safe environments, are what public health experts call social determinants of health. During the pandemic, reliable access to a computer and the Internet also affected how accessible a vaccine appointment might be.

Understanding how these social determinants of health have impacted disabled people during the COVID-19 pandemic is crucial to improving access and equity in the future. To do this, disability advocates need consistent data, said Imperato,¹⁷ who has worked on this issue as a member of the Biden administration's COVID-19 health equity task force.³³ "The lack of data was an equity issue. And then, [the] CDC and others were using that lack of data as a reason not to prioritize people

for life-saving vaccines, so I felt like they were punishing people for something that wasn't their fault," Imparato said.¹⁷

After advocating at several meetings of the state's vaccine advisory committee for data that takes a closer look at vaccine access, Denny Chan, a senior staff attorney at Justice in Aging, noticed a gap in access for older adults. He says that some other states have done a "better job" of providing data, and organizations can use this information to more effectively inform equitable strategies that close gaps in access.¹³

Many disabled advocates, like Imparato, are hopeful about the future of health access.

"We have generational opportunities to improve equity for people with disabilities," Imparato said, adding that issues with data, research, and federal resources need to be addressed as "we think about how a culture of public health needs to be more disability-competent." Imparato continued, "I'm hopeful that a lot of the leaders in public health now realize that they need to have more knowledge and more relationships around disability."¹⁷

At Johns Hopkins School of Medicine, a team of researchers is working to fill these gaps in data and research by studying the immune response of organ transplant recipients, who take immunosuppressant medications for life, to two doses of a COVID-19 vaccine. The study, which was recently published in the *Journal of the American Medical Association*, enrolled 658 organ transplant recipients.¹⁸ More than 45 percent of the study's participants had little or no immunity to COVID-19 following full vaccination.⁴

For transplant recipients like Gillian Ladd, these concerns about immunity are long lasting, even after full vaccination. She worries about staying safe as California inches toward its planned June 15 reopening before reaching herd immunity levels. "It really seems that we're a tiny little iota of the disability community that is still not receiving equity," Ladd said.¹⁹ "A complete lack of acknowledgement makes it feel very clear that not only am I not a priority, but that I have no value. And that there's no respect for what I've gone through medically, and there's no respect for what somebody else has given up and lost in order for me to still be alive and have a second chance."

"And it feels like a slap in the face, all while I'm afraid to breathe."

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