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The Coronavirus Crisis

Many try to return to normal from COVID, but disabled people face a different reality

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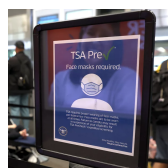
A selfie of Beth Kenny (foreground), their wife Adina (middle), and their child Vyla sitting in their backyard in Alameda, Calif. Since the lifting of COVID safety measures, Kenny and their family have had to pull back from indoor activities, and they struggle to explain why to Vyla.

Beth Kenny

Beth Kenny is immunocompromised but found a routine that worked for their family during the pandemic, leaning into safe protocols to protect themselves from COVID-19.

Kenny's wife could pick up the groceries, and social distancing measures and vaccines allowed their family to do activities together outside safely. And the precautions helped Kenny's wife safely ride the bus and go to the library with their child Vyla without putting their family's health at risk.

The sense of safety the routine provided them during all this time came to an end in February, when the mask mandate for indoor spaces ended in their home state of California.



NATIONAL

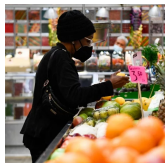
DOJ asks federal appeals court to reverse order lifting travel mask mandate

Now, nearly the entire country has lifted COVID-19 safety precautions such as mask mandates on buses and airplanes and in restaurants and other indoor settings.

Safety precautions have been rescinded as many try to return to a sense of pre-pandemic normalcy. But the reality of disabled and immunocompromised people remains forgotten, causing them to feel left behind and further pushed out of society, disability advocates say.

Kenny and their family used to be able to participate safely in both indoor and outdoor activities when the mask mandates were in place. Eventually, it became apparent that swim lessons were needed for Vyla, who has autism.

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IA

What Does 'Return to Normal' Mean For The Immunocompromised?

Due to the COVID protocols that were in place at the facility and in other places within their community, Kenny's wife was able to take Vyla to her swim lessons, go to the library, and ride the bus throughout town. They even found an outdoor preschool that allowed Vyla to safely continue her education.

Now, their family is locked inside once again, and Kenny struggles to explain the reality to their child.

"The damage that it's caused to my family is [that] my child is having nightmares about my death," Kenny told NPR over Zoom. "This started after mask mandates were removed because we really had to pull back from a lot of activities, and explaining why we had to do that is scary for a 4-year-old to have to take on."

How COVID is measured makes it difficult for immunocompromised people to assess risks

Back in March, Jay Justice had been invited to speak on accessibility at the Game Developers Conference (GDC), an annual event for video game developers. Justice is director of LGBT HQ, a group that supports queer writers, artists, creators and

developers in comics and gaming.

Traveling from her home in the Bronx to San Francisco for the event as an immunocompromised person was only feasible because of the mask mandates on planes. This was not long before U.S. airlines announced that masks would not be required for travel.



Jay Justice is seen in her hotel room while at the Game Developers Conference in San Francisco in March. Justice says the hotel room was the only place she felt safe without a mask during the visit.

Jay Justice

Fifty-seven percent of disabled people believe that masks should be required on public transportation and 64% think masks should be required on planes, according to a survey of likely voters conducted in April by Data For Progress, a progressive think tank and political advocacy group. However, mask mandates have been lifted on various forms of transportation and in other parts of society amid court rulings and declining cases reported by the Center for Disease Control and Prevention.

In March, the CDC began determining COVID-19 community levels based on new hospital COVID admissions and the percentage of beds occupied by COVID patients. But hospitalization data is a lagging indicator of how much COVID-19 is spreading in the community. Matthew Cortland, a senior fellow at Data for Progress, notes that when someone gets COVID-19, it doesn't cause them to become sick immediately, and they may spread it to other people before they're symptomatic or become sick enough to require hospitalization.



COMICS: TEACHING IN THE PANDEMIC

COMIC: How A Teacher Tackled Pandemic Fears For His Students With Disabilities

"If you're using that hospital data for your public health interventions, you're always going to be behind the curve, you're always going to be playing catch-up. And with a disease like COVID that can spread so easily and rapidly, that means if you're behind the curve, there's going to be uncontrolled spread," Cortland tells NPR.

Cortland points out that public transit is a vital lifeline for disabled and immunocompromised people, as it connects them to doctors, grocery stores, and other aspects of society. But because of the new way COVID-19 levels are measured, along with the lifting of mask mandates, disabled and immunocompromised people say they feel it's too risky to safely go out.



CONSIDER THIS FROM NPR

As Masks Come Off, Immunocompromised Americans Feel Left Behind

That applies to even a seemingly simple task. For instance, since getting back from the convention in San Francisco Justice hasn't been able to go to her storage unit to put her stuff from the trip away because of how quickly the mandates had been lifted.

"All we're really asking for is for a masking policy that will allow us to be able to go to the store, to go to the doctor, go get the mail, without risking [our health]," Justice said. "One-way masking does not work, and no one seems to care outside of our community because they don't see you as someone who needs to be protected. They see you as someone who's just on borrowed time as it is."



Jay Justice says she could have only traveled to the Game Developers Conference as an immunocompromised person because of the mask mandates on planes at the time.

Jay Justice

The GDC conference offered a hybrid format including remote video access, but Justice said she ended up attending in person because of the lack of opportunities that would follow if she didn't. She said that when you hold multiple marginalized identities, people already don't see you as a hiring opportunity.

"It is absolutely demoralizing to feel like if I hadn't risked my health, I wouldn't have had the opportunities that I've gotten. I preach constantly, that you have value outside of capitalism, but it is so hard to push against the constant reinforcement that we don't," Justice said.

"I easily could have gotten COVID and died at GDC," she added. "I don't want to die for capitalism. But at the same time, my actions have to reinforce the issue, because if I don't, how am I gonna pay for my medication?"

Disability advocates say putting the economy first cuts the odds of renewing COVID safety measures

Disability rights advocate Imani Barbarin said economic pressures — including the push to get people to return to their offices — are contributing to the constantly changing COVID policies.

She notes that with the decades of exponential growth in the economy, many don't care about people being expendable tools for labor.

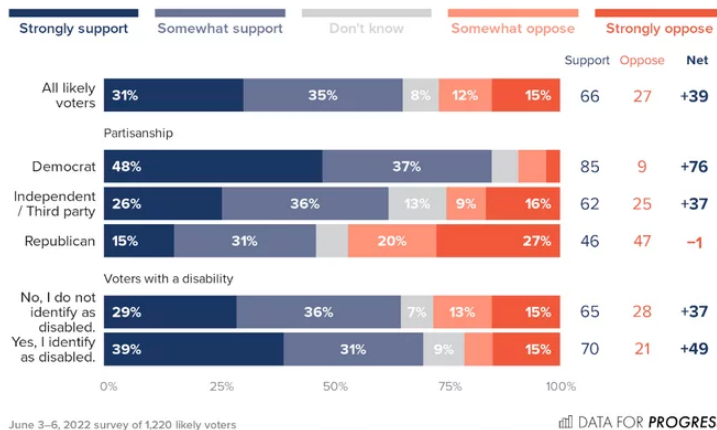
"Even if you think of bodies and people as machines for labor, you have to set the time aside for maintenance. And as a society, we don't want to do that," Barbarin told NPR over Zoom.

"We want to keep chugging along [and] return to normal. We can't keep treating people like this and expect progress and continuous upward trends in economics and economic policy, if you don't take care of people first," she said.

Cortland says that to break this cycle of back-and-forth policies and actually stop the spread of COVID, people need to keep wearing N95 masks and invest in indoor air filtration. Additionally, they said that Congress or states should allocate money for wastewater data monitoring, which can provide more accurate data on COVID-19 community levels.

Voters Support COVID-19 Air Safety Certifications

Would you support or oppose a proposal to create COVID-19 safety certifications for public buildings? The certifications would be posted outside of stores and offices that have made improvements to indoor air quality, such as indoor ventilation and air filtration upgrades.



On a Zoom call, Matthew Cortland discusses a Data for Progress survey on voter support for air quality certifications for public buildings.

Matthew Cortland

"When you pursue pandemic policies that keep people like me — people with chronic illness and disabilities and who are immunocompromised — safe, you protect everyone because if we're safe, everyone is safe," Cortland said. "We do not need to be locked into this cycle of preventable suffering and death."

People within the disability community, such as Kenny, have actively worked to break the cycle and advocate for the return of COVID safety policies. Kenny is a member of Senior and Disability Action (SDA), a San Francisco-based organization that mobilizes and educates seniors and disabled people to fight for individual rights and social justice. This year, Kenny said that SDA has been meeting with public health officials and transit health officials to push for mask requirements.



SHOTS - HEALTH NEWS

Here's why you might still want to wear masks on public transport

Currently, AC Transit, a Bay Area public transit agency, has a mask requirement in place, but Kenny wonders how long it will remain. On June 25, Alameda County undid indoor mask requirements despite still being in the "high risk" category as defined by the CDC. Although some officials have been receptive to SDA's work and goal of reinstating mask mandates, Kenny said that many who have the power to change these policies are resistant.

Barbarin says that the frequently changes in messaging of COVID mitigation policies has resulted in people thinking that it's all a personal choice. Public health has become about personal responsibility, Kenny said, and that benefits the people who have the most resources.

"I think there is an understanding that seniors and high-risk folks are being lost to the virus, and there is an acceptance of that," Kenny said. "But I think people don't want to look too hard at it, and maybe they're losing the thread that they're just one COVID infection away from being in my shoes, and being as disposable as people with preexisting conditions are under the current COVID policies."

Disabled people say they are being disregarded even as their numbers grow due to long COVID

The number of disabled people in the U.S. is predicted to increase as more people get infected with the virus.

According to a recent study released by the CDC, one in five adults under the age of 65 who had COVID are experiencing at least one health condition that could be considered long COVID.

As the number of people who have been infected with SARS-CoV-2 increases, so will the number of survivors suffering from post-COVID conditions. "I'm proud to be a

person with disabilities. But I don't want to see our numbers growing so fast," Kenny said.



SHOTS - HEALTH NEWS

People With Intellectual Disabilities Are Often Overlooked In Pandemic Response

Barbarin said she believes this loop of loosening and reinstating COVID policies will continue until the most privileged communities feel the effects. "I don't really think we're gonna get to a place where we're more steadfast in our COVID mitigation unless the majority of the most privileged people are impacted by COVID and by these policies ... because our system is built to protect some and let others die," she said.

This issue has been brought back into light, especially with disabled people wanting to take part in protests regarding bodily autonomy. With the overturn of *Roe v. Wade*, the disability community has vocalized the ways that the Supreme Court decision will impact their community. However, without mask and social distancing requirements those who are immunocompromised and disabled can't safely attend the protests.

"I just want everyone to be safe," Justice said. "But I know that the world is moving on without the sense of safety, the United States has moved on and does not provide safety for anybody. It feels like an uphill battle constantly fighting for someone, anyone to care."

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