

PEOPLE WITH DISABILITIES ARE AFRAID THEY WILL BE DENIED HEALTHCARE BECAUSE OF CORONAVIRUS

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Margaret Breihan relies on the nursing assistants who visit six mornings a week to help her shower, dress and tidy up her Silver Spring, Maryland, apartment.

Breihan, 31, who has cerebral palsy, is mostly self-reliant and does everything from shop to cook from her electric wheelchair but she has limited mobility and struggles with daily tasks like pulling clothes out of a dryer or showering.

Sheltering in her apartment for the past two weeks amid the coronavirus outbreak, she lives in daily dread of one day finding out the help can no longer visit. One of her helpers lives with a daughter who is a nurse at a local hospital, deepening her concern for infection.

"I keep waiting every morning for the phone call that the agency is withdrawing its assistance," said Breihan, who is pursuing a master's degree in social work at Catholic University of America in Washington, D.C. "It hasn't happened, thank God. But it's a scary prospect, I won't lie."

People with disabilities and chronic health conditions are some of the most vulnerable groups during the coronavirus crisis, though often overlooked in the national debate, according to advocates. The virus has infected more than 69,000 Americans and led to nearly more than 1,000 U.S. deaths, according to a site run by Johns Hopkins University.

On Wednesday, 27 U.S. representatives and five senators sent a letter to the Department of Health and Human Services, or HHS, and U.S. Attorney General William Barr, urging them to issue guidance to state agencies to protect people with disabilities from being discriminated against during the outbreak. U.S. Rep. Chris Smith, R-NJ, led the effort.

A \$2 trillion relief bill passed by the Senate earmarks some relief for those with disabilities, such as \$85 million for centers for assisted living, but has a long way to go to protect the most vulnerable, U.S. Bob Casey, D-PA, said.

"If you have a disability, your daily life is often a series of struggles to begin with," said Casey, who has advocated for more assistance for the elderly and people with disabilities during the outbreak. "Those challenges that they face are now that much greater. We have to try to be responsive to that."

One of the concerns is whether people with disabilities will be sidelined for healthcare as medical equipment such as ventilators and hospital beds become increasingly scarce, said Ari Ne'eman, visiting scholar at the Lurie Institute for Disability Policy at Brandeis University in Massachusetts.

A number of states, including Utah, Tennessee and Alabama, have emergency contingency plans that direct hospitals not to provide medical equipment, such as ventilators, to people with certain intellectual and cognitive disabilities, should that equipment become scarce, he said.

On Tuesday, several groups, including the Center for Public Representation and the Alabama Disabilities Advocacy Program, [filed a complaint](#) with HHS's Office of Civil Rights, alleging the Alabama Department of Public Health's Emergency Operations Plan violates federal disability rights law, including the Americans with Disabilities Act (ADA), according to the complaint.

"There are very severe concerns that disabled people are going to be sent to the back of the line when accessing healthcare equipment such as ventilators," Ne'eman said.

Signed into law 30 years ago this July by former president George H.W. Bush, [the ADA](#) is the signature civil rights law for people of disabilities, prohibiting discrimination in all areas of public life, including jobs, schools and transportation.

As hospitals and the federal government reach crisis levels because of the pandemic, advocates are closely watching to see whether the ADA is adhered to, Ne'eman said.

"What we're really going to see determined here is whether this country really meant it when they passed the ADA 30 years ago, that they passed it as a civil right and not as an act of charity," he said. "You can do away with charity when times are tough. You cannot do away with civil rights."

The National Disability Institute hosted two webinars this week to explain developments and field questions regarding disabilities and the coronavirus. The online sessions drew more than 1,500 attendees.

One of the voiced concerns was that health care providers were not going to be able to continue making home visits as the outbreak deepened, said Michael Morris, the institute's founder and senior strategic adviser. With no home care, states could turn to grouping those with severe disabilities in state-run facilities -- a trend advocates have worked hard to reverse over the past three decades, he said.

There's also fear that hospitals will classify people with disabilities and chronic illnesses as a lower priority for healthcare -- a fear Morris said he's experienced firsthand. As a person battling cancer, Morris had been going to a Washington-area hospital once a month for chemotherapy and had investigative surgery every three months, he said. The hospital recently told him they're suspending his treatment to redirect doctors and space to coronavirus victims.

"This story is playing out by the thousands across the country," Morris said. "People with disabilities and chronic health conditions are incredibly afraid of the rationing of healthcare."

As the pandemic took hold in the U.S., Breihan began prepping. Her classes at Catholic University went online so she was able to continue with those. Her mother brought her cash and

friends volunteered to deliver groceries. In case her helpers stop coming, she bought a "reacher-grabber" through Amazon.com that allows her to pull laundry out of the dryer. She plans to struggle through sponge baths.

Breihan's greater concern is what happens if she gets infected. Drive-through testing sites won't help her or thousands like her, she said, since she doesn't drive. If some day she needs emergency healthcare, she hopes she doesn't wind up low on the list of priorities.

"I do my best to contribute to our society," Breihan said. "Just because I live a life that might be different from yours, doesn't mean my life isn't valuable and worth saving and worth protecting."

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