POLITICS

Americans With Disabilities Are Terrified

They fear they could be denied lifesaving treatment if they end up in the hospital with COVID-19.

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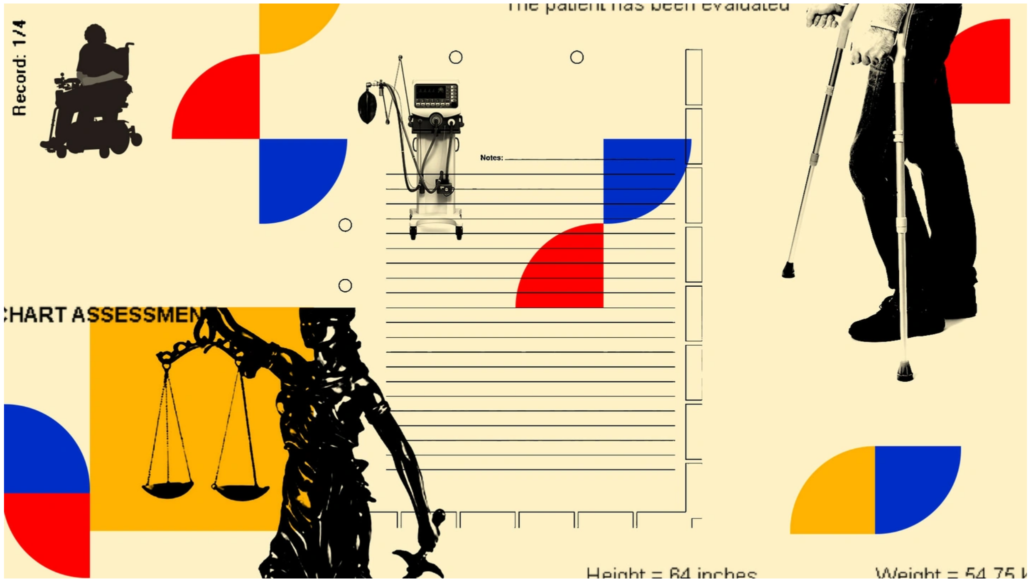

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Many Americans are anxious about contracting the novel coronavirus. Daniel Florio is absolutely terrified.

The 50-year-old lawyer from Maplewood, New Jersey, was born with spinal muscular atrophy, a genetic disorder that makes him unable to walk or use his arms. His disability makes him more vulnerable to the virus than most people, and he's afraid of what will happen if he ends up in the hospital with a serious case. Intubated people cannot speak, and Florio would not be able to use gestures or otherwise communicate with his doctors. Given infection-prevention rules, his caregivers would likely not be allowed to accompany him.

"I would be in an awake coma for weeks," he told me in an interview this week. "The fear of that … it's overwhelming."

But Florio is afraid of something else too: the possibility that, if he contracts the virus, he could be denied lifesaving treatment because of his disability. And like other Americans with disabilities, he worries that could happen not just because of overt discrimination in hospitals, but also because of implicit bias. “People overwhelmingly believe that being disabled implies a worse quality of life than it does,” Florio said. If doctors act on those beliefs—wittingly or not—“what that means in practical terms is that people like us will die.”

As the coronavirus spreads, states may rely on existing best-practice protocols for rationing treatment if they have more coronavirus patients than they do beds and equipment. Some of those protocols stipulate that in such an emergency, people with intellectual or physical disabilities will be deprioritized. The Department of Health and Human Services, in response to formal legal complaints from disability advocacy groups, recently issued guidance that hospitals cannot ration treatment based on disability status. But that’s not enough to ensure that there won’t be discrimination, activists say.

Rationing guidelines in Alabama, Kansas, Tennessee, and Washington State allow doctors to withhold care from people with disabilities in violation of federal law, the advocacy groups argued in complaints filed with HHS last week. Alabama’s Emergency Operations Plan, for example, says that “persons with severe mental retardation” are among those who “may be poor candidates” for lifesaving care if there is a shortage of supplies like ventilators. The Kansas and Tennessee emergency guidelines suggest that people with “advanced neuromuscular disease” might be excluded from receiving critical care. Washington’s guidelines include considerations about a patient’s “baseline functional status,” which involves factors such as physical ability and cognition. Some groups also fear that in certain states, a patient who is seriously ill with COVID-19, the disease caused by the virus, and who regularly uses a personal ventilator could see that ventilator reallocated to another patient.

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The Washington health department told me it’s updating its guidelines to make sure “its original intent of nondiscrimination” is “unequivocally clear,” and a representative for the Kansas health department said it is “reviewing/updating the material to ensure we best meet the needs of all Kansans.” The Alabama health department has replaced its emergency plan, according to a spokesperson, but the new guidelines do not address ventilator-shortage protocols. (Officials at the Tennessee health department did not respond to questions as of press time.)

It's possible that hospitals in some areas of the country will be forced to ration care soon. New York City expects a ventilator shortage after the wave of new patients arriving at hospitals this week, and the New Orleans area is set to run out of machines by tomorrow. The American health-care system has never faced a situation quite like this.

In catastrophic circumstances, doctors should try to save as many lives as possible, says Matt Wynia, the director of the Center for Bioethics and Humanities at the University of Colorado at Anschutz. But equally important is protecting the country's social fabric and preserving confidence in institutions. That can erode when people feel as if the lives of certain citizens are valued more than others. "We need to be able to look back and say we made those decisions in a way that maintains the trust of the community, that maintains social cohesion, and allows us to heal," Wynia says.

That means that when the time to triage comes, medical professionals should not consider a patient's disability status, Wynia says. Ideally, patients would be given preference based on whether and to what extent treatment would help them. "If you have Down syndrome, I don't see why that should matter, unless your Down syndrome comes with a lung condition that makes you less likely to benefit from treatment," he says.

This is what most advocates are arguing, too. People's fitness for treatment should be evaluated on a case-by-case basis. Disability-rights laws, such as the Americans With Disabilities Act, are "all about individual determination," says Shira Wakschlag, the legal director at The Arc, an advocacy organization for people with intellectual disabilities. "A diagnosis is not the whole picture."

When 33-year-old Conrad Reynoldson heard about some of the state protocols, he told me he had "a moment of sinking dread." The Seattle attorney has Duchenne muscular dystrophy, and he's worried that if he becomes seriously ill, his diagnosis could prevent him from getting treatment. "I'm healthy, stable, and I'm contributing to the community," he told me. "I don't want someone looking at my diagnoses and rationing care based on inaccurate assumptions."

Assumptions is an important word here. People with disabilities worry that doctors, nurses, and health-care administrators may not even realize they have biases against disabled people. Research indicates that people without disabilities tend to rate the quality of life of disabled people lower than those people would, says Nancy Berlinger, a research scholar at the Hastings Center, a nonpartisan bioethics-research institute. "We do make snap judgments about whose life seems better than another person's life," Berlinger told me. "Allocation protocols must guard against that."

[Read: Don't believe the COVID-19 models]

The HHS Office for Civil Rights' Saturday guidance assures Americans that the federal government will not tolerate this kind of discrimination, and the office has promised to open investigations into advocacy groups' complaints. "We're concerned that stereotypes about what life is like living with a disability can be improperly used to exclude people from needed care," Roger Severino, the director of the Office for Civil Rights, wrote in the guidance.

But people with disabilities and advocacy groups want states to make clear to the public that they *understand* that guidance by proactively issuing statements and rewriting their emergency procedures immediately. States should indicate that they will not include diagnostic categories at all—not for intellectual and physical disabilities, and also not for diseases, such as COPD, that may make someone more vulnerable to the virus, but are also very treatable. Each diagnosis varies too greatly, they argue, for doctors to make sweeping judgments about any of them. "We want to make sure this message gets to the people who need to hear it in a very timely way," Wakschlag says—so that both doctors and Americans with disabilities are aware of these obligations.

Ultimately, states' protocols show that institutions need to do a much better job of including people with disabilities in emergency-preparedness and other public-health conversations, advocates say. They hope that this moment encourages more conscientious policy making so that in the event of another pandemic, Americans with disabilities won't have to feel quite so uncertain about what the future holds.

It's exhausting to balance the fear of contracting a deadly virus with the fear that the people who are supposed to care for you may not do so, said Florio, who lives in a part of New Jersey that has been hit especially hard by the virus. "The stress that we're under really is a more extreme version of what we already experience," he told me, "in terms of being undervalued by society."

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