

## The Coronavirus Crisis

# One Man's COVID-19 Death Raises The Worst Fears Of Many People With Disabilities

July 31, 2020 · 3:29 PM ET  
Heard on Morning Edition



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Melissa Hickson says no one asked her husband, Michael, shown here with stepdaughter Mia, if he wanted to keep getting treatment. "He would say: 'I want to live. I love my family and my children ... that's the reason for the three years I have fought to survive,'" she says.

*Melissa Hickson*

What Melissa Hickson says happened to her husband — and what the hospital says — are in conflict.

But this much is for sure: Michael Hickson, a 46-year old quadriplegic who'd contracted COVID-19, died at St. David's South Austin Medical Center in Austin, Texas, on June 11 after the hospital ended treatment for him and moved him from the intensive care unit to hospice care.

Melissa Hickson says her husband was denied potentially lifesaving treatment because doctors at the hospital made a decision based on their biases that, because of his disabilities, Michael Hickson had a low quality of life.

The hospital says it acted based on the man's dire medical prognosis and that it would have been pointless and cruel to give him invasive treatment.

Michael Hickson's death has become a cause among many with disabilities, an emblem of a medical system that they believe views their lives as having less value, even before a pandemic put doctors and hospitals under stress.

And now Hickson's death may get the scrutiny of a federal civil rights office.

ADAPT of Texas, a disability rights group in Austin, sent a complaint on July 24 to the federal Office for Civil Rights at the Department of Health and Human Services. And on Friday, the National Council on Independent Living filed a similar complaint to ask the Office for Civil Rights to open an investigation into Hickson's death.

"In Mr. Hickson's case, the issue is not abstract," the complaint says. "The treating professional for Mr. Hickson made a discriminatory determination that, due to his disabilities, Mr. Hickson's life would not be supported."

In addition to those formal complaints, two members of the U.S. House of Representatives from Texas expressed alarm. Rep. Chip Roy, a Republican, called the circumstances around Hickson's death "highly troubling." And Rep. Joaquin Castro, a Democrat, said Hickson's death "should be immediately investigated."

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#### THE CORONAVIRUS CRISIS

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#### THE CORONAVIRUS CRISIS

COVID-19 Infections And Deaths Are Higher Among Those With Intellectual Disabilities

Since the start of the pandemic, the federal civil rights office has kept an eye on health care rationing. Specifically, it has warned states, doctors and hospitals that they can't place elderly and disabled people at the back of the line for care for COVID-19.

"We're concerned that stereotypes about what life is like living with a disability can be improperly used to exclude people from needed care," said Roger Severino, the Office for Civil Rights director, on March 28 as he announced guidelines for states and medical providers.

To do so, he warned, would violate laws — including the Americans with Disabilities Act and the Affordable Care Act — that guarantee the disabled and older people will not face discrimination when they need medical care.

Since then, Severino's office has investigated multiple states that put out plans for limiting care and has announced settlements with four of those states.

But those plans were simply guidelines, telling medical providers what, theoretically, they could do in case they faced the need to triage care.

Much harder to determine is what actually takes place on the front lines of medical care, especially when hospitals are overwhelmed and doctors are forced to make quick decisions.

Melissa Hickson says she believes she saw proof that her husband was denied care because of his disability. (Hickson says she thinks her husband may have been dismissed as a Black man, too, but "the main reason was because of his disabilities.")

On June 5, Hickson went to see her husband in the ICU at St. David's South Austin Medical Center.

Michael Hickson was a quadriplegic who'd been diagnosed with COVID-19. Now he had pneumonia. A BiPap machine, a kind of ventilator that people often use in their own homes, was pushing air into his lungs to help him breathe.

Through the mask, he answered her questions with short answers. Would you like me to get you a Long Island iced tea, she joked. Yes, he said with a smile. Will you pray with me? Yes.

She asked him "to keep it in your mind: You will live and not die. You will live." She asked him to repeat the words with her and she saw, under the mask of the breathing device, his lips move as he repeated it with her.

She called the kids on the phone — their five teenage children — for a FaceTime conversation. They told their Dad what they were up to. The 16-year-old was excited she was going to get her driver's license.

Hickson with his five children.

*Melissa Hickson*

"They chattered. Very chattery," she recalls with a laugh. "And so I could see him just kind of shaking his head" and smiling.

That was June 5. One morning, three years earlier, Michael Hickson, a Morehouse College graduate who was an auto insurance claims estimator, went into sudden cardiac arrest as he was driving his wife to work. Blood stopped flowing to his brain and other organs. Sudden cardiac arrest is often fatal, but paramedics arrived and performed extensive CPR. He survived. But the temporary loss of oxygen to his brain left him with significant disabilities — an anoxic brain injury, blindness and quadriplegia.

He could no longer walk. He had trouble talking.

Melissa Hickson posted YouTube videos of him in the years after his injuries: singing Happy Birthday to his daughter from his hospital bed, joking with his kids, getting physical therapy, bobbing his head as he listens to music. He seems to have difficulty speaking and moving, but he is aware and involved.

Still, Melissa Hickson says, the years since the accident were difficult for her husband. He'd moved from hospital to nursing home to back home — and then back to more hospitals and nursing homes.

That day at St. David's hospital, on June 5, the medical staff had something to tell Melissa Hickson. They were going to stop treating her husband. And move him from the ICU to hospice care.

In the hallway, Hickson found the doctor. She asked why. And she recorded their conversation.

The recording is hard to hear, the doctor's voice a bit distant. But he tells Hickson: "The decision is: Do we want to be extremely aggressive with his care or do we feel like this would be futile?"

And then he adds: "As of right now, his quality of life — he doesn't have much of one."

Hickson challenges the doctor. "What do you mean?" she asks. "Because he's paralyzed with a brain injury, he doesn't have quality of life?"

"Correct," the doctor replies.

After a while, the doctor gives a different explanation: If we have to intubate him — put him on a more powerful ventilator — in his weakened condition, he's not going to survive.

Hickson was driving his wife to work three years ago when he went into sudden cardiac arrest. It resulted in an anoxic brain injury, blindness and quadriplegia.

*Melissa Hickson*

That didn't make sense to Melissa Hickson. The hospital wasn't overwhelmed with COVID-19 patients. It didn't need to ration care. Her husband had dealt with pneumonia before, and other hospitals had successfully treated it.

"This decision was not made based on a disability in any way," says Dr. DeVry Anderson, the chief medical officer at St. David's. He adds that it was not an issue of the hospital being short on its ability to treat COVID-19 patients.

Anderson says Michael Hickson was much sicker than his wife may have realized: He had sepsis, pneumonia in both lungs and that his organs were shutting down.

Anderson says a medical team — of doctors, palliative care specialists, a chaplain — made the decision that Hickson could not survive further treatment. The team then got signoff from Michael Hickson's medical guardian.

A Texas probate court earlier this year had stepped in and appointed an elder care agency to make medical decisions for Michael Hickson. That happened after Melissa Hickson disagreed with a previous hospital. She says it wanted to discharge her husband to a nursing home. She insisted he needed more specialized care at a brain and spinal cord injury center.

It's not unusual for caregivers and medical staff to fight. It's unusual, though, that a probate court would step in.

Anderson says that tape recording Melissa Hickson made — of the doctor at the hospital saying her husband had no quality of life — was just a miscommunication. He says the doctor misused the term "quality of life" and that he wasn't saying the hospital was ending care because her husband was disabled.

Anderson says: "But rather he was trying to help Mrs. Hickson understand compassion based on understanding what quality of life is — how someone might

suffer more based on doing things that we consider treatments or interventions that are actually not helping them be better or feel better."

NPR listened to the five-minute recording Melissa Hickson made of her conversation with the unnamed doctor. The doctor speaks of Michael Hickson's quality of life, of wanting to make a "humane" decision. He says he's seen only three people with COVID-19 on ventilators in the ICU — all young and previously in good health — recover.

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Hospital Visitor Bans Under Scrutiny After Disability Groups Raise Concerns Over Care

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THE CORONAVIRUS CRISIS

People With Disabilities Fear Pandemic Will Worsen Medical Biases

The difference between them and her husband, he says: "They're walking and talking." Her husband, he says, has "a number of medical problems."

Melissa Hickson agrees that she doesn't want her husband intubated. She asks if he could get Remdesivir, a drug in short supply that, studies suggest, can reduce the hospital stay of someone seriously ill from COVID-19. She wants the hospital to try some treatment to save her husband. "It doesn't make any sense to me to not try," she tells the doctor.

The doctor, on the tape, never mentions the issues that Anderson says led to the decision to end treatment — the sepsis and organ failure.

Hospitals call in Devan Stahl on cases just like this. Stahl is an associate professor of ethics at Baylor University in Waco, Texas.

She wasn't consulted on this case. She doesn't know all the details of Michael Hickson's medical condition.

But she's listened to the tape.

"It was very troubling. Kind of a gut punch," she says.

"Because a treatment working or not working has nothing to do with a patient's quality of life, however it's deemed by this physician," she says. "And by all accounts — by his wife — that he had a quality of life."

Stahl says there's research that we — all of us, and especially doctors — see someone such as Michael Hickson with a significant disability and say, I wouldn't want to live like that. And we have a bias to underestimate that person's quality of life.

Stahl says doctors need to protect against doing that with disabled patients. "That doesn't mean they should be triaged out of medical treatment," she says.

Melissa Hickson says no one asked Michael Hickson if he wanted treatment. "He would say, 'I want to live. I love my family and my children and they're the most important things to me,' " she says. "He would probably say that's the reason for the past three years I have fought to survive."

On June 11, Hickson tried to make a FaceTime call to her husband. The hospital said that she needed permission from that guardianship agency. The guardian said she needed it from the hospital.

The next morning she got up early and tried again.

Hickson participates in physical therapy.

*Melissa Hickson*

Later that morning she got a phone call — this time from the hospice agency. The message said: Michael Hickson had died the night before. It took 12 hours before anyone called to tell Melissa Hickson.

"Michael Hickson's life mattered — to his wife, to his children, and to his community," says a statement released by the National Council on Independent Living. "It should have mattered to the medical professionals charged to care for him."

On Friday, the council, along with seven other disability groups, asked the Office for Civil Rights to investigate his death. The complaint named the hospital, its parent company and Family Eldercare, the guardianship agency. The council represents a national network of 400 centers run by disabled people to advise and advocate for other disabled people.

A spokeswoman for the Office for Civil Rights would not say if the office would open an investigation. But sources told NPR that the office has been interested in pursuing a complaint if it thought a decision to triage care was based improperly on a person's disability.

The Office for Civil Rights "can't discuss open or potential investigations," spokesperson Arina Grossu says. If it does open an investigation, and finds that the hospital violated civil rights laws, it could then work on an agreement with the hospital to put systems in place to prevent that kind of decision on treatment from happening again. Or if a hospital fails to address a problem, the office can seek to get back or end federal funds to the hospital.

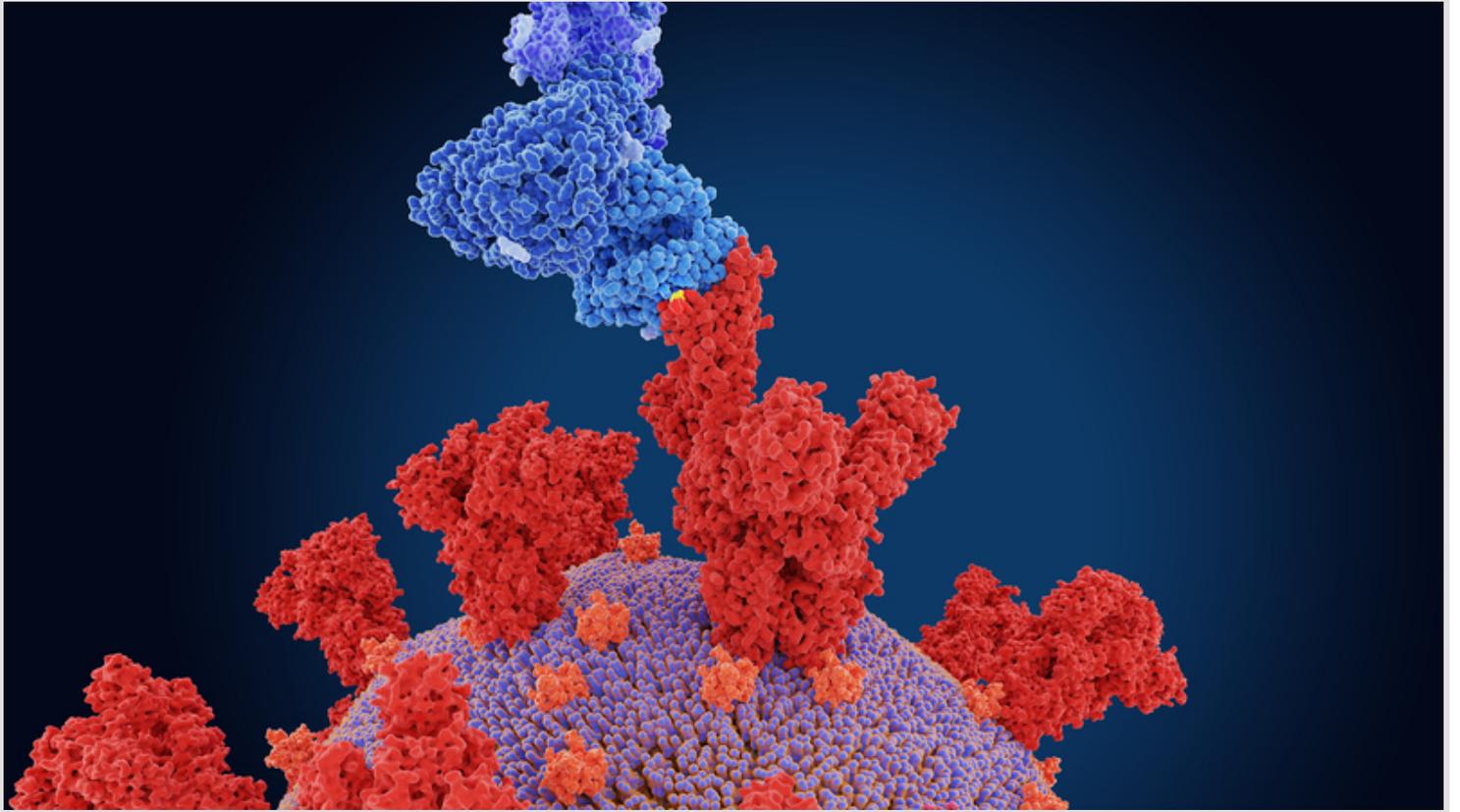
Disability groups have seen the Office for Civil Rights as an agency that will protect access to medical care during the pandemic. Groups in multiple states have filed complaints about state triage policies — often called "crisis standards of care plans" — that they feel allow medical providers to give lesser care to the elderly and people with disabilities.

One of the most recent complaints, filed July 22, comes from national and Texas disability groups, led by Disability Rights Texas. It asks the Office for Civil Rights to tell Texas to modify guidelines that allow hospitals to use a point scale to determine who is most likely to benefit from care when it is scarce. The point system, the complaint says, discriminates against people with disabilities because they lose points for their disabilities and underlying medical conditions.

The Office for Civil Rights has investigated complaints in other states and forced changes. Pennsylvania modified a system similar to the one now challenged in Texas; Alabama and Tennessee rewrote their rules to ensure that people with dementia, intellectual disabilities, traumatic brain injuries, advanced neuromuscular disease and other disabilities would not be denied ventilator and other care simply because of those conditions.

Now, the death of Michael Hickson, at that hospital in Austin, could be the next test of how doctors and hospitals, stressed by the coronavirus pandemic, provide medical care and whether they do it in a way that values the lives of people with disabilities.

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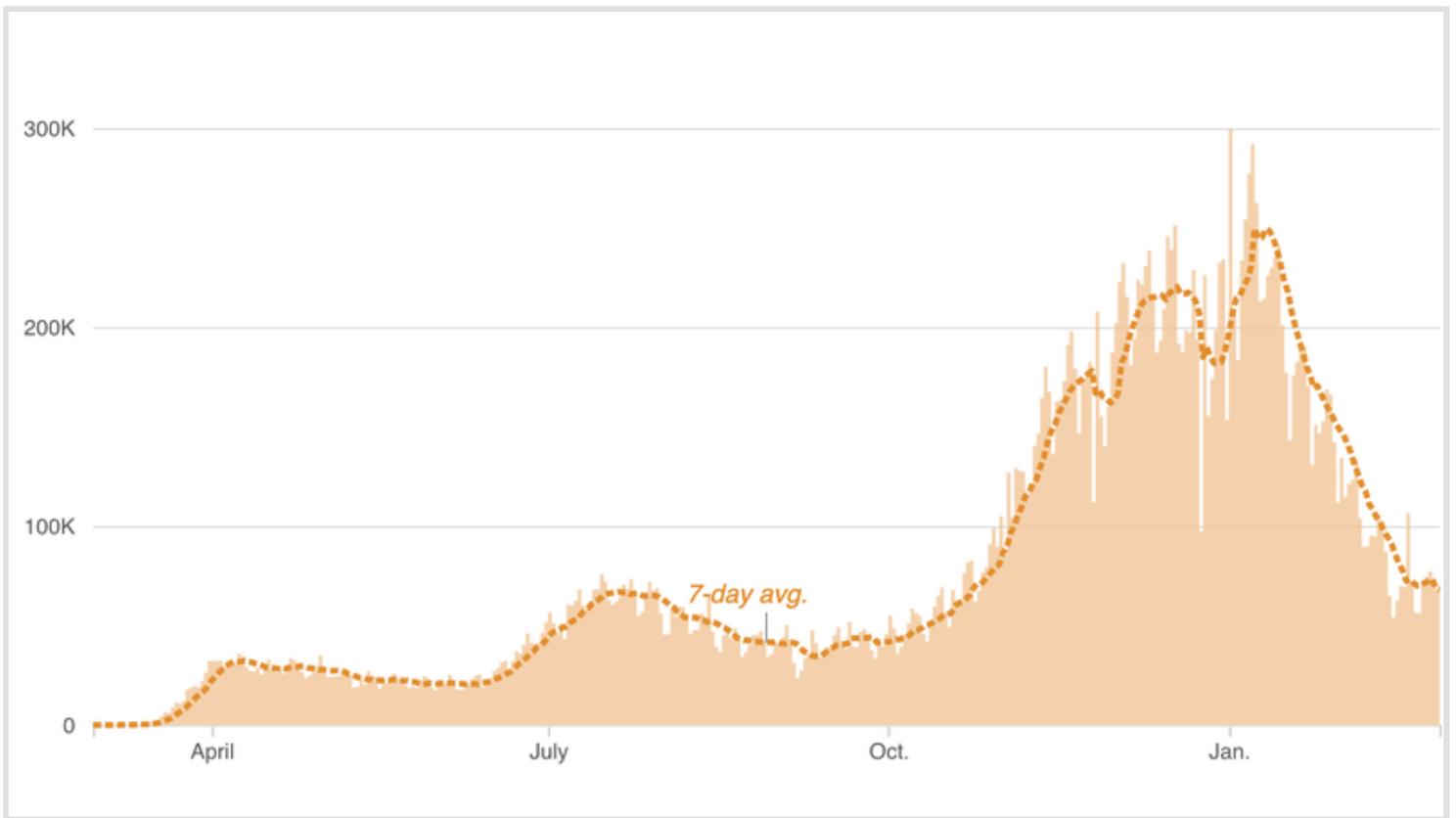
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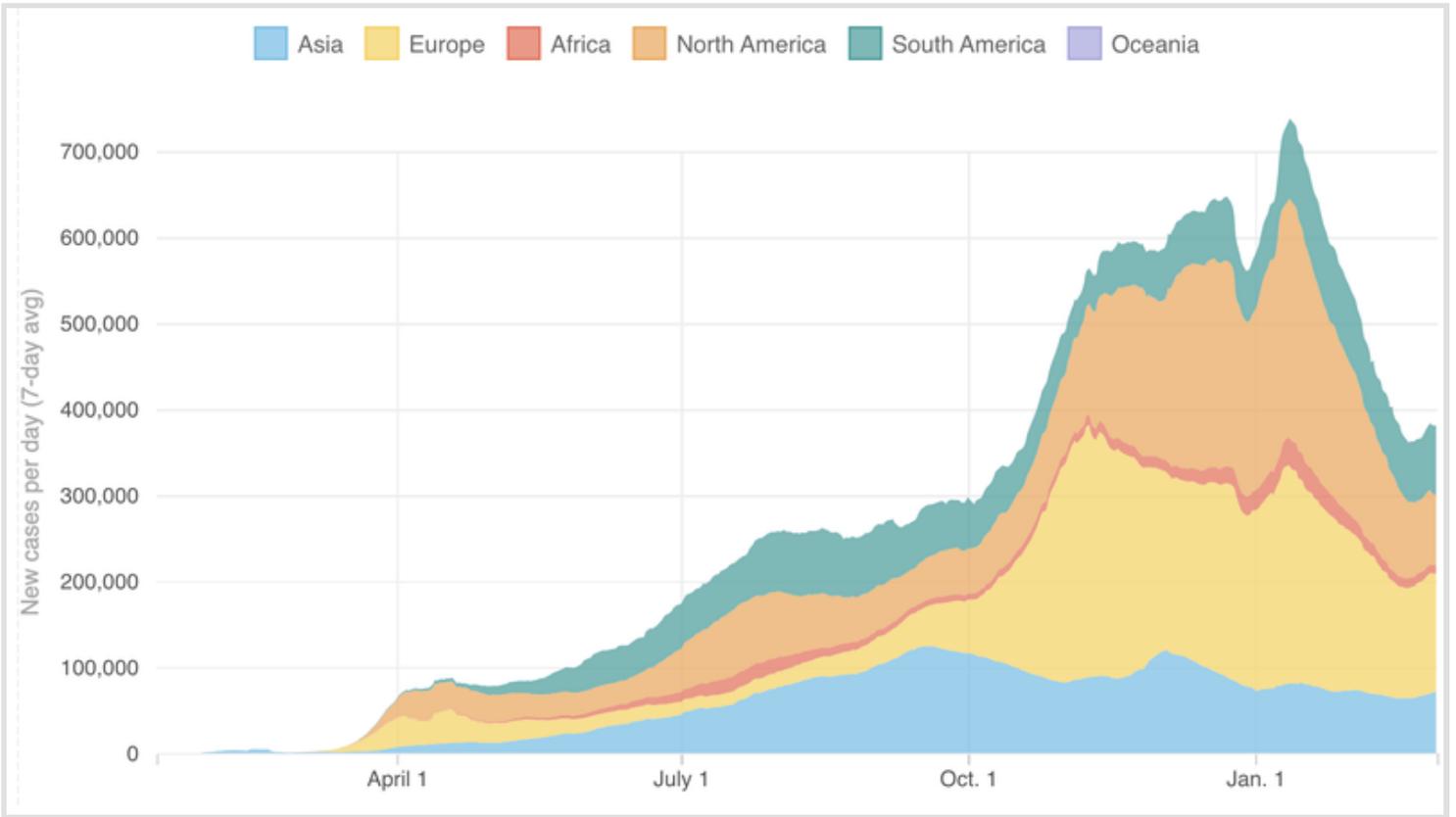


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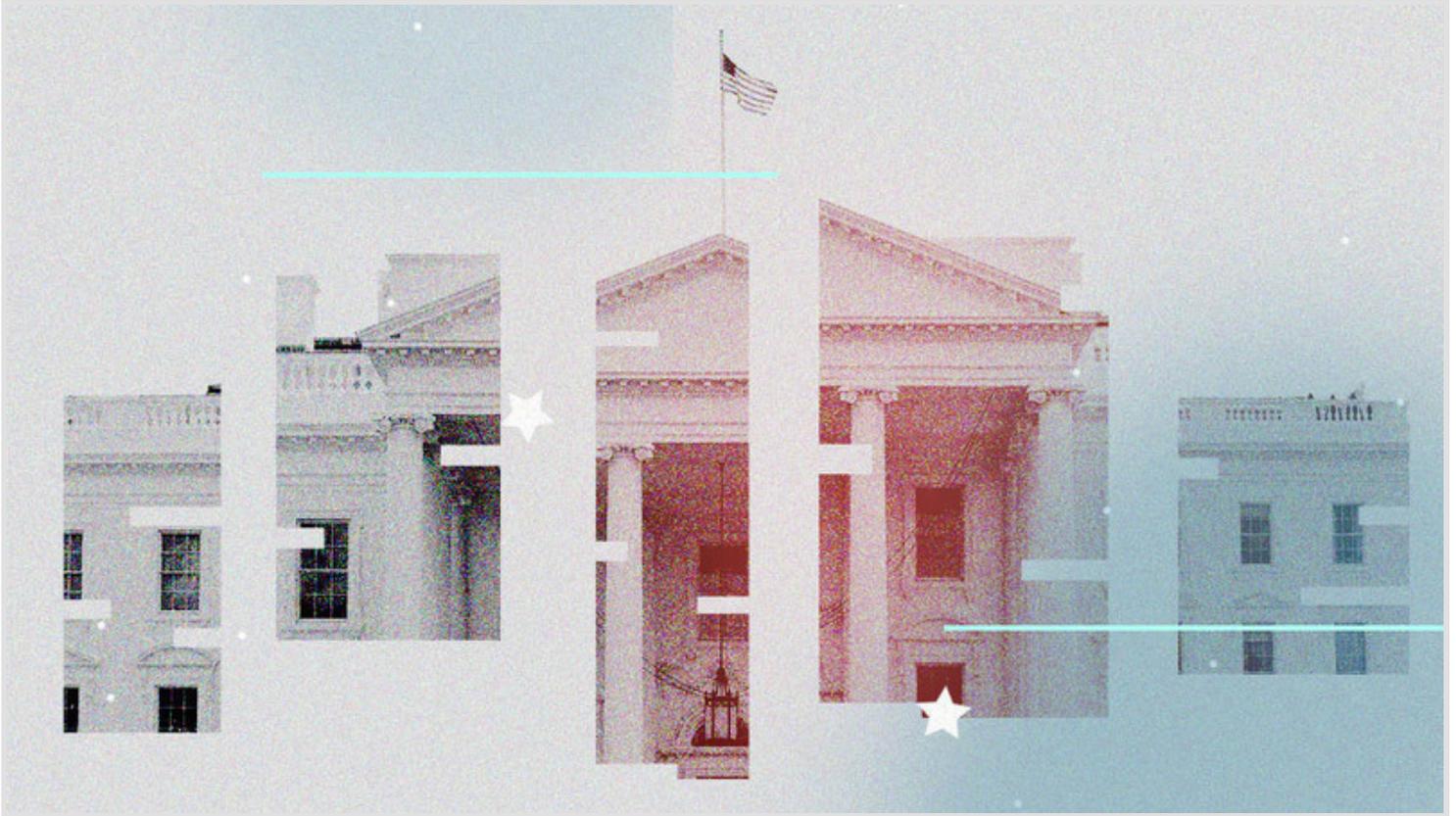
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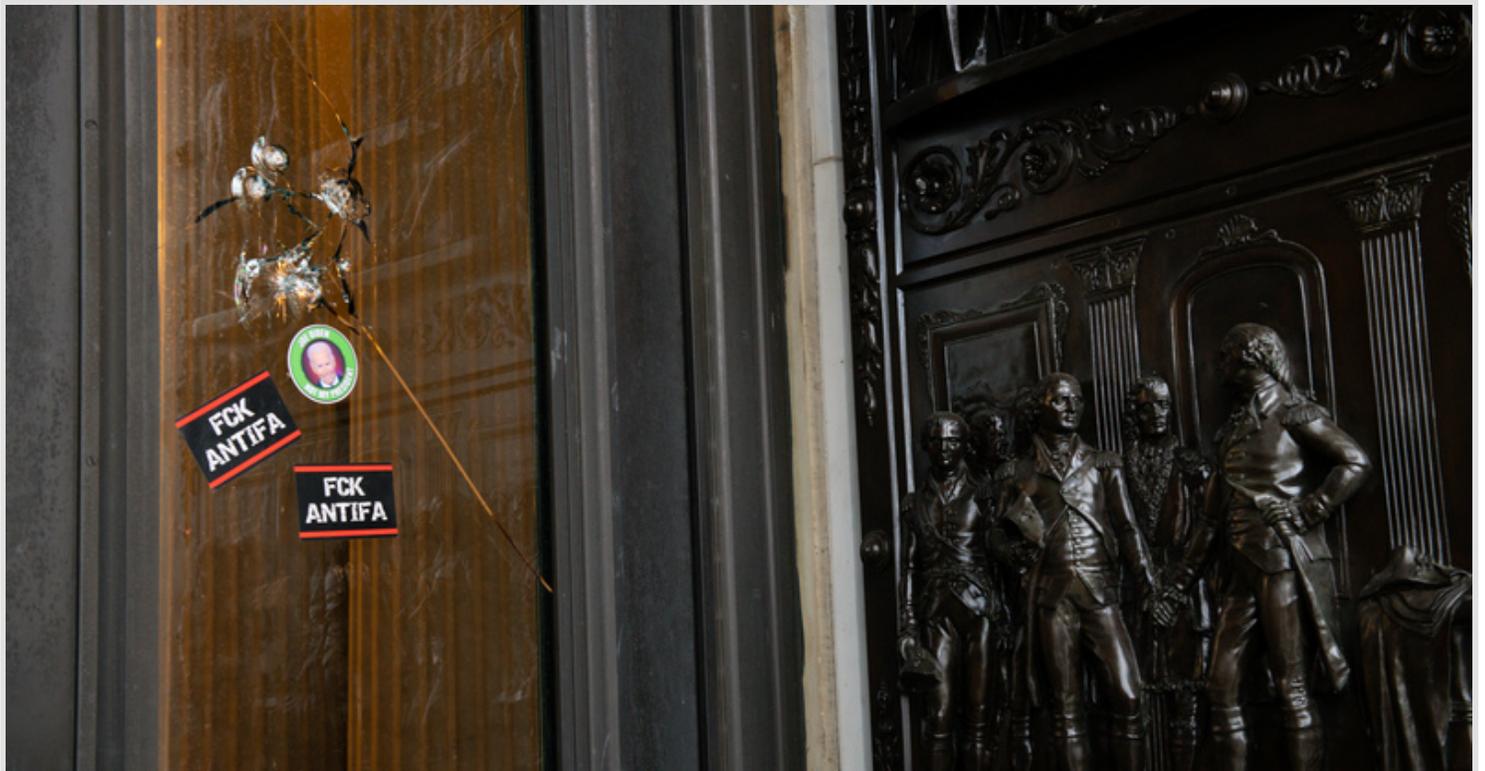
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