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The Coronavirus Crisis

People With Disabilities Fear Pandemic Will Worsen Medical Biases

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Heard on Morning Edition



JOSEPH SHAPIRO

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When Lex Frieden broke his hip, a Texas hospital decided against an operation. Frieden, a quadriplegic since 1967, would never walk, so the surgery wasn't necessary, the doctors reasoned, a decision that left him with lasting pain.

Mack Taylor / Houston METRO

It's a moment that people with disabilities have long feared: there's a shortage of life-saving equipment, like ventilators, and doctors say they may be forced to decide who lives and who dies.

People with disabilities worry those judgments will reflect a prejudice that their lives hold less value.

State health officials have drafted rationing plans that exclude some people with significant disabilities from ventilators and other treatment.

Mostly, though, the belief among people with disabilities that they will get lesser treatment is based on something even more concrete — their own harsh experiences in the medical system before the pandemic.

Almost every person with a disability, or their family, can tell a story of a time when they were treated dismissively or even denied the care they needed.



THE CORONAVIRUS CRISIS

HHS Warns States Not To Put People With Disabilities At The Back Of The Line For Care



THE CORONAVIRUS CRISIS

People With Disabilities Say Rationing Care Policies Violate Civil Rights

That includes people like Lex Frieden. He's a research scientist and a professor at the University of Texas Health Science Center at Houston now and was the staff director of the federal agency that wrote the first version of the Americans with Disabilities Act, which prohibits discrimination against people with disabilities.

But none of that helped Frieden when he went to the emergency room.

"A car ran a red light and hit us on the side of the vehicle," he recalls. "The impact literally threw me from the wheelchair onto the floor of the vehicle."

Frieden is a quadriplegic — the result of another car accident, years before — so couldn't tell if he'd been injured.

But at the emergency room, the doctor told him his hip had been crushed.

"The doctor who was attending me said: 'You've got a badly broken injured hip. We've also observed that you're not walking.'" Frieden says. "And I said, 'No sir, I broke my neck in 1967 and I haven't walked since then.' And he said, 'Well, we're not going to repair the hip then.'"

The doctor's decision — that it didn't make sense to fix the broken hip of a man who would never walk anyway — led to years of pain for Frieden.

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He still needs to sit up in his wheelchair, but now can't put weight on his broken hip. All the weight on his good hip causes pain, limiting how many hours he can sit in his wheelchair. And that limits how much he can get around.

Months after the accident, in 2006, Frieden went back to the hospital and argued he got the wrong care.

The hospital changed its policy.

"People who go to that emergency room with disabilities are looked at in a different framework," says Frieden. "And I'm happy about that."

Three laws protect the civil rights of people with disabilities in medical settings: The ADA, Section 504 of the Rehabilitation Act, and the Affordable Care Act.

In April and March, disability groups cited those laws when they filed complaints against the "crisis of care" guidelines in several states. Kansas and Tennessee, according to lawyers who filed the complaint, would cut care to some people who rely upon home ventilators to breathe, although many use them to lead active lives. New York's plan says that a person who shows up at a hospital with their personal home ventilator could have it taken from them and given to someone else. And Washington State would factor in old age and disability. Similar complaints have been filed from Pennsylvania, Utah and other states.

On March 28, the Office for Civil Rights at the Department of Health and Human Services announced it had opened or would open investigations based on these complaints and warned states that any guidelines for triage of care could not put disabled people and the elderly "at the end of the line" for care.

On April 8, the civil rights office announced its first case resolution in one of these investigations. Alabama said a policy no longer applied that would have allowed doctors to deny ventilators to some adults and children with intellectual disabilities or people with "moderate to severe dementia."

"Particularly, we're concerned that crisis standards of care may start relying on value judgments as to the relative worth of one human being versus another, based on the presence or absence of disability," Roger Severino, director of the HHS civil rights office, told NPR. "We're concerned that stereotypes about what life is like living with a disability can be improperly used to exclude people from needed care."



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THE CORONAVIRUS CRISIS

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People with significant disabilities, including quadriplegics like Frieden and even those who use home ventilators, say their lives are full. They work, go to school and are part of families. They are not — as some rationing plans suggest — people close to death. Some are, however, because of their underlying health conditions, at a higher risk if they contract COVID-19.

But the public, and many in the medical community, can underestimate the lives of people with disabilities.

Dr. Lisa Iezzoni, a physician and researcher at Harvard Medical School recently conducted a nationwide survey that aimed to assess doctors' attitudes about disability. A "vast majority" rated the quality of life of people with significant disabilities as a little to a lot worse than that of others.

"I was horrified," Iezzoni says.

People with significant disabilities tell Iezzoni they rate their lives as the same or better than others. Iezzoni is one of them. She has multiple sclerosis and has used a wheelchair since 1988.



Dr. Lisa Iezzoni and her friend, Michael Ogg, crossing the George Washington Bridge, over New York's Hudson River, in their motorized wheelchairs, after Ogg survived a cancer diagnosis. Iezzoni has written about another doctor who declined to do a physical exam of Ogg. Merely lifting his shirt would have revealed evidence of cancer, she says.

Lisa Iezzoni

"There's a lot of us roaming around with significant disabilities and who feel we have a pretty good quality of life," she says.

Those misconceptions have come up in other moments when the health care system has faced decisions to ration care. In the days after Hurricane Katrina in 2005, doctors and staff at Memorial Medical Center — where generators, lights and sewage went out — first rescued patients who could walk. One doctor said he left when colleagues spoke of euthanizing other patients. A state homicide investigation later found 20 had died with elevated levels of morphine in their system, even though only a few of them had been prescribed it for pain. A grand jury later declined to bring charges.

People with disabilities often have complex relationships with their medical providers. They distrust the system, but they work hard to find understanding doctors who provide care that keeps them healthy and independent.

"Any doctor we know we can trust is practically a secular saint in the community," says Riva Lehrer, a Chicago writer and artist who was born with spina bifida. At the start of the pandemic, her personal care physician called her at home and "read me the riot act." Stay at home, her doctor told her, and if you go outside and someone approaches, make sure you turn your body away from them.

Growing up in California, Rebecca Cokley's parents took her to conventions of little people where doctors who specialized in dwarfism would come and give free medical care.

At these conventions, little people formed friendships - including Cokley as she grew up - with the sympathetic doctors. "I've sat at the bar and had scotch and cigars with my neurosurgeon," Cokley says. "I've sung karaoke with geneticists. These are people I have known pretty much my entire life and I would trust 100 percent with my care."

So she was caught off guard in 2013 when, lying on the operating table after she'd just given birth to her second child, she overheard the anesthesiologist talking to the obstetrician.

"He made a comment to her and said: 'While you're down there, why don't you go ahead and just tie her tubes,'" she recalled.

Cokley and her husband objected: "I said what are you talking about? And he said, 'Now that you've had two, you don't need to have more kids.'"

"It was really mind-blowing to me," she says, "in that position of ultimate vulnerability — literally, being opened up on an operating room table — that I would have to sit there and actively advocate for my rights at that moment."

A few years ago, Cokley, who runs the Disability Justice Initiative at the Center for American Progress, went back to that same hospital in Washington — with no problems — for the birth of her third child.

It's easy for doctors and health care providers, she says, to pick up the biases of a system that views people with disabilities as "the problem."

Doctors, for example, Cokley says, "are trained to prevent birth defects. They are trained to provide a level of care so that people don't acquire underlying conditions."

When Alisha Hauber's son, Lane, was born with life-threatening disabilities, and rushed to the neonatal intensive care unit of a Fort Worth hospital, she and her husband noticed paperwork on the baby's crib with some unfamiliar letters: DNR.

When her husband asked a nurse what it meant, she was silent. Later, the Haubers were summoned to a room with doctors and hospital administrators. DNR, they were told, stands for Do Not Resuscitate. Without asking the parents, the doctors decided they would not do anything to rescue the boy if he went into distress. And the doctors declined to perform the surgery they said was needed to repair the baby's heart.

The Haubers were given no choice in the matter. "I just didn't know any better how to fight for him at the hospital at the time," Alisha Hauber says. "When you have big people at a huge hospital, you know, looking at you, telling you: You don't have a choice. So I trusted what they were telling me."

Their doctors sent the Haubers home with their son and told them to be ready for him to die.

But the doctors were wrong.

Lane is 11 now.

"He is full of personality," Hauber says with a laugh. "He is the sweetest boy."

Lane doesn't walk or use words but communicates with sounds and can shake his head yes or no. He laughs at jokes. He smiles when his mother reads books to him and he turns the pages. Hauber says he is more at risk because doctors declined to give him that early heart surgery.

"He's a huge part of our family. All of his siblings love him. We love him. He makes us laugh all the time," Hauber says.

Many people with disabilities fight, not just for life-saving care, but even to get access to care at all. Research shows disabled people get lesser routine medical care. Sometimes it's simply because an examination table is too high to get up on, or a doctor declines to give a full exam to someone who can't easily get out of a wheelchair.

That happened to a close friend of Iezzoni, Michael Ogg. Iezzoni has written in medical journals about how Ogg's doctor said he could not lift him out of his wheelchair to give him a physical exam. It was an assertion that "lacked merit," Iezzoni wrote in the *New England Journal of Medicine*. "Merely lifting his shirt would have revealed his protuberant abdomen," a sign of the untreated cancer.

Studies have found that disabled women are less likely to get mammograms and Pap tests. Another study found that those who get breast cancer are less likely to receive standard treatments and, as a result, are more likely to die.

Angel Miles has a PhD, and is the health policy analyst at Access Living, a Chicago disability center, but she still fights to be treated seriously when she visits doctors.

Even with her expertise, when she seeks treatment, she says she's dismissed as a black woman in a wheelchair. She reels off a list of frustrations: The doctor's office that insists she bring someone with her to help her get onto their inaccessible examination table; the people in medical offices who don't even talk to her directly.

"I'm often ignored," she says. "I'm often spoken at, and not to. Sometimes, the person next to me is addressed instead of me. And I don't even know them half the time."



Angel Miles says her PhD and her job as a health policy analyst aren't enough to win her respect when she goes to the doctor's office. She recently sued a hospital for what she says was poor care.

Morgan Clawson Photography

In February, Miles sued a hospital that, twice, gave her hospital rooms that she says were inaccessible for her with her wheelchair.

She sued, in part, because — with her education and her job — she feels she can make change. And that's especially important in a pandemic.

"Right now...we cannot afford to have these barriers. We can't afford to have these biases. Because they literally are life and death," she says.

Alice Wong worries about those biases, too. Now 46, she was born with a progressive neuromuscular disease.

Wong's portable ventilator is on the back of her wheelchair. She speaks through a plastic mask and the tube to the ventilator.

She says people, including medical providers, see her and underestimate the quality of her life.

"It's not easy," she says, "but my life is so rich."

She's an on-line organizer, a founder of the Disability Visibility Project. A book she edited about disability will be published this spring.

"It's ironic," Wong says from her home in San Francisco, "but at a time when I'm really the most disabled I've ever been in my entire life, I've been the most active in the things I want to do in my life and in choices I'm making."



Alice Wong says she's more disabled than she's ever been, but that her life is richer than ever, too. She's an organizer and she's edited a new book, "Disability Visibility." She worries whether she'd get treatment if she gets sick.

Eddie Hernandez

Technology and the medical system — especially some devoted doctors — allow her to live that active life.

But she's still afraid of a system that's overwhelmed, by the pandemic. "I really don't think I could survive if I was affected," she says. "I think about that a lot. I think about

how much of a priority will I be given? Will I even get tested? Will I even have access to treatment?"

Late last year, the little known National Council on Disability released a series of reports looking at discrimination in health care against people with disabilities. It highlighted problems like insurance companies that use "quality of life" scores to deny medications and treatment; and organ transplants refused to people with autism, intellectual disabilities, mental illnesses or with HIV, even though scientific studies show their results with transplants are as good or better than the population at large.

The studies, from those months before the spread of the coronavirus, did not consider discrimination in medical care during a pandemic.

"But for people with disabilities, almost every day is a pandemic," says Neil Romano, chair of agency that issued the reports. "Because quite often they have to worry about what kind of care they're going to get, the quality of care, or if someone's even going to give them care."

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