

# *These Doctors Admit They Don't Want Patients With Disabilities*

When granted anonymity in focus groups, physicians let their guards down and shared opinions consistent with experiences of many people with disabilities.



By Gina Kolata

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For a quarter of a century, Dr. Lisa Iezzoni, a professor of medicine at Harvard, has heard the same story during research with hundreds of people who have disabilities: Health care that was substandard. Medical offices that were not accessible. Doctors who did not treat them with respect.

“Everywhere I looked, there were disparities,” Dr. Iezzoni said. Yet, what patients told her was no surprise, given her own experiences with multiple sclerosis and using a wheelchair.

It was time for the next step.

“I thought I needed to start talking to doctors,” Dr. Iezzoni said. She proposed asking physicians what they really thought when a patient with a disability showed up in their offices.

The result was a study that gathered doctors, a mix of primary care physicians and specialists recruited from across the United States, into three focus groups on video conferences. Protected by anonymity — only first names or nicknames were used — the groups of eight to 10 doctors began to talk. At first, they were guarded, but as the sessions that Dr. Iezzoni moderated wore on, they began to speak more frankly. In their Zoom meetings, they could not see that Dr. Iezzoni was seated in a wheelchair.

The study’s findings, published earlier this month in the journal *Health Affairs*, stunned one of the study’s authors, Dr. Tara Lagu, professor of medicine and medical social science at Northwestern University.

“It was so shocking, I almost couldn’t believe it,” she said.

While disability takes many forms, the doctors had much to say about people who use wheelchairs. Some doctors said their office scales could not accommodate wheelchairs, so they had told patients to go to a supermarket, a grain elevator, a cattle processing plant or a zoo to be weighed, or they would tell a new patient the practice was closed.

One said he didn't think he could legally just refuse to see a patient who has a disability — he had to give the patient an appointment. But, he added, “You have to come up with a solution that this is a small facility, we are not doing justice to you, it is better you would be taken care of in a special facility.”

The doctors also explained why they could be so eager to get rid of these patients, focusing on the shrinking amount of time doctors are allotted to spend with individual patients.

“Seeing patients at a 15-minute clip is absolutely ridiculous,” one doctor said. “To have someone say, ‘Well we're still going to see those patients with mild to moderate disability in those time frames’ — it's just unreasonable and it's unacceptable to me.”

The focus group participants also raised communication difficulties — one doctor said he had hired a sign language interpreter for a deaf patient, a decision which cost so much that he lost \$30 each time the patient visited. A specialist in one focus group said disabled patients took too much time, adding that they were “a disruption to clinic flow.”

The researchers acknowledged limitations to the study, including that the focus group members were self-selected from verified users of a social network for physicians. The study's authors said they used research methods to include doctors from a variety of fields and parts of the United States.

Dr. Iezzoni said she decided on anonymity for the doctors because she thought it would be difficult to get physicians to openly admit that they treat patients with disabilities differently, and not only because of the legal repercussions of violating the Americans with Disabilities Act. They also “don't want to come across as horrible people,” she said.

August Rocha of Milwaukee said he hesitates to complain and he worries that the doctor might spread the word that he is a difficult patient. "You want the doctor to be on your side," he said. Kevin Miyazaki for The New York Times

People with disabilities who were interviewed for this article said the strategies doctors described to limit their care or get rid of them rang all too true.

Jason Miller, 46, who lives in Green Bay, Wis., has a rare bone disorder, osteogenesis imperfecta, and says he has suffered many indignities. For example, when he called a doctor for an appointment, all went well until he mentioned he used a wheelchair. Then, all of a sudden, he said, his appointment was canceled. The person he was speaking to at the doctor's office said there was a mistake — the doctor was on vacation. They would call back to reschedule. They never did.

August Rocha, 27, who lives in Milwaukee, and makes TikTok videos about being transgender and disabled, has Behçet's disease, a genetic disorder that causes chronic pain. He uses both a wheelchair and a walker. And he says he has heard it all.

"Some will find every excuse not to see you. They will say, 'Our machinery isn't good enough for you. Maybe you shouldn't come in.'" Or doctors will have trouble examining him because they cannot get him onto an exam table, so he said they will tell him directly, "I really don't know what to do with you. Maybe you should go elsewhere."

He hesitates to complain. “You want the doctor to be on your side,” he said. And he worries that the doctor might spread word that he is a difficult patient, making other doctors spurn him.

Dr. Lagu said there are no easy solutions. One change she would like to see, which the National Council on Disability proposed this year, is including disability in the data health care systems collect about their patients. Not doing so makes it impossible to track disparities in treatment and outcomes.

“We have data on racial disparities because health systems are forced to collect data on race,” Dr. Lagu said.

Doctors need to know ahead of time that they will be seeing a patient with a disability. All too often, Dr. Lagu said, a patient will call and explain their disability, but the doctor’s office does not convey the message to the provider. “At the end of the day, when they get there, the doctor still doesn’t know the patient is coming,” she said.

Dr. Iezzoni said accessibility is another high priority for patients. That includes equipment, like exam tables with adjustable heights and scales that can weigh everyone, as well as communication accommodations for those whose hearing, vision or speech is impaired. Many patients also want doctors to have some knowledge about their conditions while appreciating a patient’s extensive knowledge of how disability affects their daily lives.

But that is just the start.

When it comes to discriminatory thinking around disability, “I know for sure that we have to change the culture of medicine,” Dr. Lagu said.

Neelam Bohra contributed reporting.