

HEALTH

Doctors Are Failing Patients With Disabilities

Decades after the ADA passed, medical care still isn't accessible.

By Emma Yasinski



Ruben Bonilla Gonzalo / Getty

NOVEMBER 13, 2022

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This piece was originally published by [Undark Magazine](#).

Ben Salentine, the associate director of health-sciences managed care at the University of Illinois Hospital and Health Sciences System, hasn't been weighed in more than a decade. His doctors "just kind of guess" his weight, he says, because they don't have a wheelchair-accessible scale.

He's far from alone. Many people with disabilities describe challenges in finding physicians prepared to care for them. "You would assume that medical spaces would be the most accessible places there are, and they're not," says Angel Miles, a rehabilitation-program specialist at the Administration for Community Living, part of the Department of Health and Human Services.

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Not only do many clinics lack the necessary equipment—such as scales that can accommodate people who use wheelchairs—but at least some physicians actively avoid patients with disabilities, using excuses like "I'm not taking new patients" or "You need a specialist," according to a paper in the October 2022 issue of *Health Affairs*.

The work, which analyzed focus-group discussions with 22 physicians, adds context to a larger study published in February 2021 (also in *Health Affairs*) that showed that only 56 percent of doctors "strongly" welcome patients with disabilities into their practice. Less than half were "very confident" that they could provide the same quality of care to people with disabilities as they could to other patients. The studies add to a larger body of research suggesting that patients with conditions that doctors may deem difficult to treat often struggle to find quality care. The Americans With

Disabilities Act of 1990 (ADA) theoretically protects the one in four adults in the U.S. with a disability from discrimination in public and private medical practices—but enforcing it is a challenge.

map of percentage of the disabled

Laura VanPuymbrouck, an assistant professor in the Department of Occupational Therapy at Rush University, calls the 2021 survey “groundbreaking—it was the crack that broke the dam a little bit.” Now researchers are hoping that medical schools, payers, and the Joint Commission (a group that accredits hospitals) will push health-care providers for more equitable care.

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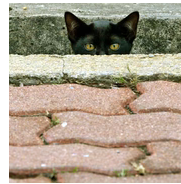
Due in part to scant data, information about health care for people with disabilities is limited, according to Tara Lagu, a co-author of both the 2021 and 2022 papers and the director of the Institute for Public Health and Medicine's Center for Health Services & Outcomes Research at Northwestern University Feinberg School of Medicine. The few studies that have been done suggest that people with disabilities get preventive care less frequently and have worse outcomes than their nondisabled counterparts.

Comparison by bar plot on outcome

About a decade ago, Lagu was discharging a patient who was partially paralyzed and used a wheelchair. The

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patient's discharge notes repeatedly recommended an appointment with a specialist, but it hadn't happened. Lagu asked why. Eventually, the patient's adult daughter told Lagu that she hadn't been able to find a specialist who would see a patient in a wheelchair. Incredulous, Lagu started making calls. "I could not find that kind of doctor within 100 miles of her house who would see her," she says, "unless she came in an ambulance and was transferred to an exam table by EMS—which would have cost her family more than \$1,000 out of pocket."



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In recent years, studies have shown that even when patients with disabilities can see physicians, their doctors' biases toward conditions such as obesity, intellectual disabilities, and substance-use disorders can have profound impacts on the care they receive. Physicians may assume that an individual's symptoms are caused by obesity and tell them to lose weight before considering tests.

For one patient, this meant a seriously delayed diagnosis of lung cancer. Patients with mobility or intellectual challenges are often assumed to be celibate, so their providers skip any discussion of sexual health. Those in wheelchairs may not get weighed even if they're pregnant—a time when tracking one's weight is especially important, because gaining too little or too much is associated with the baby being at risk for developmental delays or the mother being at risk for complications during delivery.

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These issues are well known to Lisa Iezzoni, a health-policy researcher at Massachusetts General Hospital and a professor of medicine at Harvard Medical School. Over the past 25 years, Iezzoni has interviewed about 300 people with disabilities for her research into their health-care experiences and outcomes, and she realized that “every single person with a disability tells me their doctors don’t respect them, has erroneous assumptions about them, or is clueless about how to provide care.” In 2016, she decided it was time to talk to doctors. Once the National Institutes of Health funded the work, she and Lagu recruited the 714 physicians that took the survey for the study published in 2021 in *Health Affairs*.

Not only did many doctors report feeling incapable of properly caring for people with disabilities, but a large majority held the false belief that those patients have a worse quality of life, which could prompt them to offer fewer treatment options.

During the 2021 study, Iezzoni’s team recorded three focus-group discussions with 22 anonymous physicians. Although the open-ended discussions weren’t included in the initial publication, Lagu says she was “completely shocked” by some of the comments. Some doctors in the focus groups welcomed the idea of additional education to help them better care for patients with disabilities, but others said that they were overburdened and that the 15 minutes typically allotted for office visits aren’t enough to provide these patients with proper care. Still others “started to describe that they felt these patients were a burden and that they would discharge patients with disability from their practice,” Lagu says. “We had to write it up.”

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The American Medical Association, the largest professional organization representing

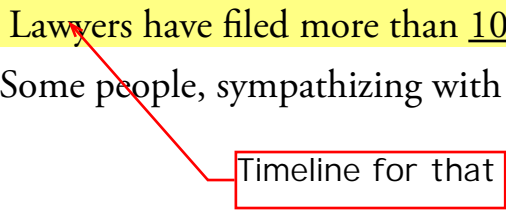
doctors, declined an interview request and would not comment on the most recent *Health Affairs* study. When asked about the organization's policies on caring for patients with disabilities, a representative pointed to the AMA's strategic plan, which includes a commitment to equity.

Patients with disabilities are supposed to be protected by law. Nearly 50 years ago, Congress passed Section 504 of the Rehabilitation Act of 1973, which prohibited any programs that receive federal funding, such as Medicare and Medicaid, from excluding or discriminating against individuals with disabilities. In 1990, the ADA mandated that public and private institutions also provide these protections.

The ADA offers some guidelines for accessible buildings, including requiring ramps, but it does not specify details about medical equipment, such as adjustable exam tables and wheelchair-accessible scales. Although these items are necessary to provide adequate care for many people with disabilities, many facilities lack them: In a recent California survey, for instance, only 19.1 percent of doctor's offices had adjustable exam tables, and only 10.9 percent had wheelchair-accessible scales.

Miles says she's noticed an improvement in care since the ADA went into effect, but she still frequently experiences challenges in health care as a Black woman who uses a wheelchair. "We need to keep in mind the ADA is not a building code. It's a civil-rights law," says Heidi Johnson-Wright, an ADA coordinator for Miami-Dade County in Florida, who was not speaking on behalf of the county. "If I don't have access to a wellness check at a doctor's office or treatment at a hospital, then you're basically denying me my civil rights."

The ADA isn't easy to enforce. There are no "ADA police," Johnson-Wright says, to check if doctor's offices and hospitals are accessible. In many cases, a private citizen or the Department of Justice has to sue a business or an institution believed to be in violation of the ADA. Lawyers have filed more than 10,000 ADA Title III lawsuits each year since 2018. Some people, sympathizing with businesses and doctors, accuse



Timeline for that

the plaintiffs of profiteering.

And it's not just about accessible equipment. In 2018, the Justice Department sued a skilled nursing facility for violating the ADA, after the facility refused to treat a patient with a substance-use disorder who needed medication to help maintain sobriety. Since then, the department settled with eight other skilled nursing facilities for similar discrimination. "It is a violation of the ADA" to deny someone care based on the medications they need, Sarah Wakeman, an addiction-medicine specialist at Massachusetts General Hospital, wrote in an email, "and yet continues to happen."

Indeed, in the focus groups led by Lagu and Iezzoni, some of the doctors revealed that they view the ADA and the people it protects with contempt. One called people with disabilities "an entitled population." Another said that the ADA works "against physicians."

The Department of Health and Human Services is aware of the issue. In a response to emailed questions, an HHS spokesperson wrote, "While we recognize the progress of the ADA, important work remains to uphold the rights of people with disabilities." The Office of Civil Rights, the spokesperson continued, "has taken a number of important actions to ensure that health care providers do not deny health care to individuals on the basis of disability and to guarantee that people with disabilities have full access to reasonable accommodations when receiving health care and human services, free of discriminatory barriers and bias."

Researchers and advocates told me that the key to improving health care for those with disabilities is addressing it directly in medical education and training. "People with disabilities are probably one of the larger populations" that physicians serve, Salentine said.

Ryan McGraw, a community organizer with Access Living, helps provide education about treating patients with disabilities to medical schools in the Chicago area. He regularly receives positive feedback from medical students but says the information

needs to be embedded in the medical-school curriculum, so it's not "one and done."

In one effort to address the issue, the Alliance for Disabilities in Health Care Education, a coalition of professionals and educators of which McGraw is a member, put together a list of 10 core competencies that should be included in a doctor's education, including considerations for accessibility, effective communication, and patient-centered decision making.

Read: What police officers don't know about the ADA

One of the simplest solutions might be hanging signs or providing accessible information in exam rooms on patients' rights. "It'd be there for patients, but it'd be also there as a reminder to the providers. I think that's a super easy thing to do," Laura VanPuymbrouck says. Miles says this could be a good start, but "it's not enough to just give people a little pamphlet that tells you about your rights as a patient." Although all doctors should be willing and able to care for patients with disabilities, she thinks a registry that shows which providers take certain types of insurance, such as Medicaid, and also have disability accommodations, such as wheelchair-accessible equipment, would go a long way.

Some advocates have called on the Joint Commission for more than 10 years to require disability accommodations for hospitals that want accreditation. The step could be effective, because accreditation "is extremely important" to hospitals, Lagu says.

On January 1, 2023, new Joint Commission guidelines will require that hospitals create plans to identify and reduce at least one health-care disparity among their patients. Improving outcomes for people with disabilities could be one such goal. However, Maureen Lyons, a spokesperson for the Joint Commission, adds, "if individuals circumvent the law, standards won't be any more effective."

Finally, Lagu says, "we have to pay more when you are providing accommodations that take time or cost money. There's got to be some accounting for that in the way we

pay physicians.”

One of the most basic things people with disabilities are asking for is respect. The biggest finding of the 2021 survey, Iezzoni says, is that doctors don’t realize that the proper way to determine what accommodations a facility needs for patients with disabilities is to just ask the patients.

“I can’t tell you how many times I go to a doctor’s office and I’m talking, but they’re not hearing anything,” Salentine says. “They’re ready to speak over me.”
