

# Chicago

## MEDICINE

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## A Disabled Physician's Perspective on Patient Care

Advice on Breaking Down Biases and Other Barriers to Care for Disabled Patients



**Antitrust Fears Derail Cigna-Humana Mega Insurer Merger**

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# A Disabled Physician's Advice on Disabled Patients

How physicians can better serve their disabled patients

By Delia O'Hara

**OPPOSITE:** Allison Kessler, MD, seated in her wheelchair, talks with colleagues at Shirley Ryan AbilityLab in Chicago where she is section chief of the Renée Crown Center for Spinal Cord Innovation.

**I**N A 2021 SURVEY in *Health Affairs*, just 57% of 700 doctors said they would welcome patients with disabilities into their practices. Even fewer, only 41%, thought they could provide disabled patients with quality care.

Given that 25% of American adults have some type of disability, these were discouraging findings.

It was not news, however, to Allison Kessler, MD, section chief of the Renée Crown Center for Spinal Cord Innovation at Shirley Ryan AbilityLab in Chicago. Dr. Kessler herself sustained a spinal cord injury as a teenager in a skiing accident and now uses a wheelchair. She is married and the mother of two young children, and an advocate for the rights of disabled people to live full lives and enjoy equal access to health care.

Dr. Kessler is passionate about changing the attitudes and practices that keep disabled people from getting the care they need. She spoke to *Chicago*

*Medicine* about what she thinks doctors can and should do to serve their disabled patients. This interview has been edited for length and clarity.

**Chicago Medicine:** How do you define disability?

**Allison Kessler, MD:** I like the World Health Organization's (WHO) definition. There's an impairment—my impairment is that I have paraplegia, my legs are weak—and so I have an activity limitation. I can't climb stairs — that's a participation restriction. If a doctor's office is accessible only by stairs, then I can't go to that doctor's office. The disability is not just the physical impairment, it's the interplay of the body component, the activity limitation and the participation restrictions. That's from WHO's International Classification of Functioning, Disability and Health.

**Chicago Medicine:** What does *The Americans with*





A female nurse in dark blue scrubs stands on the left. She has her hair in a bun and is wearing a blue lanyard with 'RN' printed on it. She is holding a yellow pencil and looking towards the male doctor.

A male doctor in a white lab coat stands in the center. He is wearing a green lanyard with 'DR' printed on it. His lab coat has a name tag that reads 'Dr. Kevin Ozment, Resident Physician'. He is holding a stack of papers and looking down at them.

A female doctor in a white lab coat is seated in a wheelchair on the right. She is wearing a green lanyard and a name tag. She is looking up at the male doctor and holding a pen and a piece of paper.



*Disabilities Act* guarantee disabled patients?

**Dr. Kessler:** They should have the same access to health care as non-disabled people. That is the law, and it's not happening.

**More than 80% of physicians believe that people with a significant disability have worse quality of life than non-disabled people, according to a 2021 nationwide survey of doctors published in the health policy journal *Health Affairs*.**

**Chicago Medicine:** What does it mean for disabled patients that so many doctors aren't comfortable caring for them?

**Dr. Kessler:** People with disabilities have known this for a long time. I have had many patients tell me that they can't find a primary care doctor they feel wants to take care of them. This survey gives validation to what they're saying. It's disheartening and upsetting, but it's shining a light and saying, "This is real." We as a society, and as physicians, need to do something about it.

**Chicago Medicine:** How should the healthcare system address this situation?

**Dr. Kessler:** The first thing is that we physicians need to recognize that we all have internal biases, and that we need to work to counteract them. Second, many physicians feel that they didn't get adequate training in how to care for a person with a disability. There are structural issues, too, like how care is reimbursed, so there are financial pressures, and literacy issues and physical barriers. It isn't just one thing.

**Chicago Medicine:** What biases do physicians hold about disabled people that interfere with their care?

**Dr. Kessler:** I think the most insidious is the "quality of life" one, because it informs our decisions as physicians and how we counsel people. If you don't think a person has a good quality of life, then you're going to be less aggressive about counseling them and what you're offering them. We have been looking at quality of life data for years. There was a term coined back in the '90s, "the disability paradox," which refers to the fact that people with disabilities rate their quality of life about as well as non-disabled age- and sex-matched individuals do. It's the outside observer, without a disability, who rates their quality of life negatively. This is ubiquitous in our society. This is how we portray people in media, in social media, even in Oscar-winning movies like "Million Dollar Baby," where the end of the story is, Oh, shoot the person with the disability to put her out of her misery, because who would want to live like that, right? That is what our society's vision is of what it means to be disabled—except those movies are written by non-disabled people.

So, for example, people with disabilities are often not counseled about birth control or safe sex practices because there is this thought that this person isn't having sex, when in reality, they are, so we see high rates of unintended pregnancy. And while disabled people smoke cigarettes at a much higher rate than non-disabled people, physicians may not counsel them to quit, perhaps because the doctor thinks that person's life is sad, and doesn't want to take away something the person loves. But we know that smoking is terrible for you, health-wise. That physician is making a judgment on quality of life on behalf of that person, solely on the basis of their disability.

Even the old sign for disability access is a symbol of somebody sitting upright in a wheelchair, with no motion and no autonomy. But our patients with disabilities are still people. They're going to have all the same needs that other people have.

We have to acknowledge that the



system is stacked against them and work to fix it, rather than just say, “I don’t want to take care of them because it’s too hard.”

**Chicago Medicine:** What are some of the difficulties doctors perceive in taking care of disabled patients?

**Dr. Kessler:** Reimbursements for physicians are going down, and healthcare complexity is going up. Often, physicians will be allocated 15 minutes to see a patient in clinic, right? Well, if you have a person with a disability that has, let’s say, a communication deficit where you need some sort of assisted communication, that visit is going to take longer than 15 minutes. In one example [from a 2022 *Health Affairs* study that explored physicians’ frustrations with the requirements of the ADA], a physician said that they lost money on an appointment because they had to pay for a sign language interpreter, that the interpreter cost more than what Medicare reimbursed for the entire visit.

**Chicago Medicine:** What would you tell doctors who have disabled patients in their practices, who have experienced not being able to do the same exam with a disabled person that they would do with a patient who is not disabled?

**Dr. Kessler:** Not every room needs to be accessible, but you do need to think about universal design for at least one of your exam rooms. The ADA has a great website that explains different scenarios. If you notice a problem during a visit, go

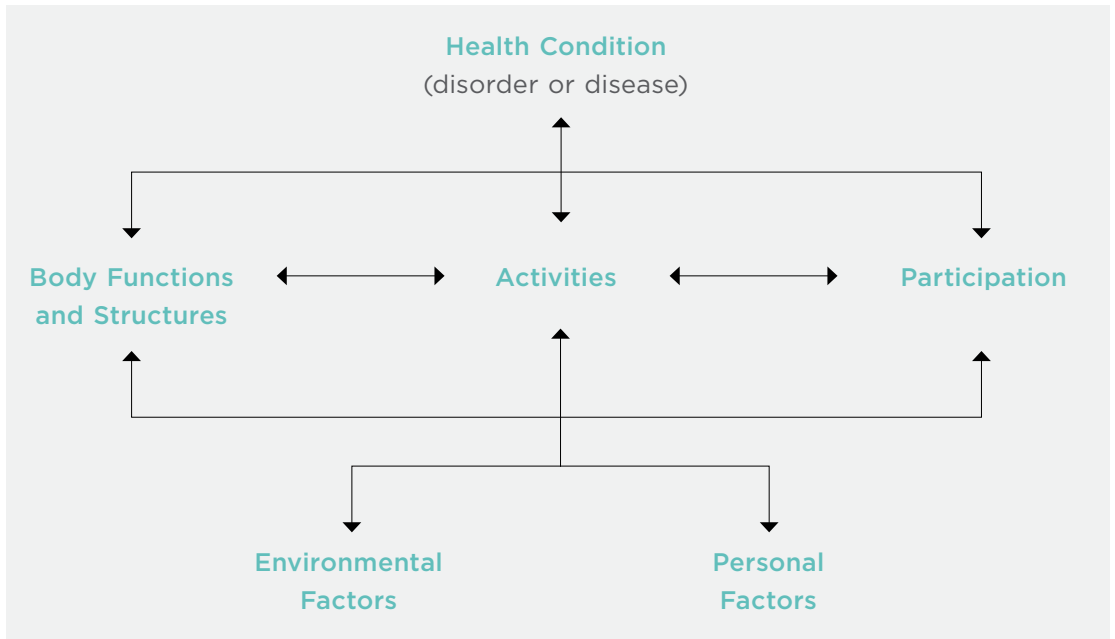
to your leadership and say something. Everybody has a responsibility to improve the system.

If you are in leadership, do a root-cause analysis, just as you would with any other problem. It’s usually not just one thing. If a patient needs some accommodation, and you didn’t know that beforehand, it can derail the whole purpose of the visit, and frustrate the patient, the physician, the clinic staff.

But if you’ve trained your front-desk staff to ask, while setting up the appointment, if a person needs anything special—an adjustable-height table, or a lift, or a wheelchair-accessible scale, or a sign-language interpreter—you can make sure everything’s set up and ready to go before they come in. And if you aren’t able to do everything you need to do, bring the person back another day.

**Chicago Medicine:** There are many different kinds of disabilities. How can physicians anticipate all

**The interactive model of disability depicts a dynamic between a person’s disorder or health condition, that person’s personal characteristics, and the environmental factors that affect the person’s ability to take part in activities.**



**LEFT:** The old accessibility symbol, which shows an individual bolt upright in a wheelchair, is “a static picture,” says Dr. Kessler. “There’s no motion, no autonomy.”  
**RIGHT:** This new accessibility symbol has been designed to focus less on the wheelchair and more on the body moving through space. “It evokes a very different emotion,” Dr. Kessler says.

**OPPOSITE: Allison Kessler, MD, talks with a patient at Shirley Ryan AbilityLab in Chicago.**

the various needs of their disabled patients?

**Dr. Kessler:** Talk to the patient. Start when the appointment is scheduled. Ask the question, “What can we do to make this appointment more effective?” And remember that not all patients can always tell you what they need. Many patients don’t even know that there are accommodations they can ask for. Sometimes they don’t even understand what that word “accommodation” means. Use simple language and give examples.

**Chicago Medicine:** What about enhancing training for doctors about disability?

**Dr. Kessler:** Physicians need to be trained for real world care, which means that when a person with a disability comes to your cardiology clinic or your pulmonary clinic, you need to be able to care for them. Only about half of medical schools have any curriculum around disability, and when they do, it’s often taught as an afterthought, not reflective of the fact that one in four adults has a disability. We need to integrate disability into the curriculum.

Then, the traditional view of disability is the medical model, which says that this person has a defect, so let’s try to fix it. But disability is so much more than that. An alternative view of disability is the social model, which talks about the interplay between a person’s physical impairment and surroundings, which causes the disability. Some schools have started teaching about social determinants of health, but they don’t include disability as one of them, and they should.

**Chicago Medicine:** Is telehealth a better way to deliver care to disabled patients?

**Dr. Kessler:** In some ways, and for some people with disabilities, telehealth visits are great, because they can access their physicians without leaving home. But other people have a very difficult time



communicating in a telehealth setting. You have to have reliable Internet service, or a cell phone. Those things are expensive, and adults with disabilities are more than twice as likely to be of lower socioeconomic status than those without

## How to Advocate for Your Patients with Disabilities

**FACE THE PATIENT** and speak directly to them. Do not speak to the patient’s caregiver, family member or interpreter. Even if the patient cannot speak to you, they should be the primary focus of the conversation.

Use person-first language, which places the person before the disability, as your default. Examples include “a person who is blind” or “people with spinal cord injuries.” However, identity-first language—“disabled person” or “autistic person”—may be acceptable or even preferable to some people. You can ask your patient which they prefer.

Avoid ableist language both in person and in your medical record, such as “suffers from,” “wheelchair-bound,” “bedridden,” or “handicapped” and common hurtful or judgmental words and expressions like “dumb,” “crazy,” or “Unfortunately, this person....”

Train front-line staff to ask about accommodations that will be needed for an appointment, such as a lift, adjustable-height table, or communication devices. If no system exists for identifying accommodation needs in your office or clinic, work to create one.

If you don’t have the appropriate equipment to provide equitable care,

identify the patient’s needs and bring the patient back when you have secured the equipment. Don’t assume they will be able to access this care elsewhere or identify the care they need on their own.

Don’t make assumptions about a patient’s lifestyle, experiences or needs based on their disability. Ask the appropriate history questions.

Don’t touch assistive devices without asking first. Consider them part of the patient’s personal space.

Don’t be afraid to ask questions.

—Allison Kessler, MD






disabilities. And some people's disabilities can interfere with communicating via telehealth, such as issues with eyesight or hearing.

**Chicago Medicine:** What about the big picture?

**Dr. Kessler:** Hospitals need to be welcoming, too. They need to have somebody thinking about serving patients with disabilities, and looking at that from an organizational standpoint to say, why are our outcomes not as good? Okay, well, what

can we do to address that? Some institutions are owning this and working to address it but there are plenty that aren't.

We need people to lobby, too, and to advocate on a larger scale. We need to look at our policies, our reimbursement structures, our social offerings, and we need to include disability in this discussion.

And we need to see past the disability to all the other things that make that person who they are. 

## Resources on Disability for Providers

**The World Health Organization's page on disability**

[www.who.int/health-topics/disability](http://www.who.int/health-topics/disability)

**Americans with Disabilities Act website / ADA.gov**

[www.ada.gov/resources/medical-care-mobility](http://www.ada.gov/resources/medical-care-mobility)

**The Center for Disease Control and Prevention / Disability and Health Overview**

[www.cdc.gov/ncbddd/disabilityandhealth/disability.html](http://www.cdc.gov/ncbddd/disabilityandhealth/disability.html)

**An Introduction to Disability Theory / University of Illinois Libraries**

<https://guides.library.illinois.edu>