

# Blocked

*When examining tables and other medical equipment aren't accessible to patients in wheelchairs, there are insurmountable physical barriers to health care.*

BY LISA I. IEZZONI

**PREFACE:** *Hospitals are a world of their own. These three essays—all written by Narrative Matters veterans—explore the rich and complex challenges of life, death, and fairness in hospitals. Lisa Iezzoni, a professor of medicine at Harvard University, has written scholarly and narrative pieces (“Boundaries,” Health Affairs/Narrative Matters, November/December 1999) about barriers to care encountered by disabled patients. Here she provides a patient’s-eye view of hospital (and medical office) obstacles that she and others in wheelchairs endure. Ray Bingham, at the National Institutes of Health’s (NIH’s) National Institute of Nursing Research (“Leaving Nursing,” Health Affairs/Narrative Matters, January/February 2002), describes a skirmish between a nurse and a doctor over the care of a premature infant—a nuanced struggle that occurs more often on hospital wards than either profession would readily acknowledge. Victoria Sweet, a practicing physician and professor of medicine at the University of California, San Francisco (“Thy Will Be Done,” Health Affairs/Narrative Matters, May/June 2007), proposes that there needs to be middle ground between “Full Code” and “Do Not Resuscitate” for hospitalized patients who are capable of enjoying life but for whom efforts at resuscitation will offer nothing. A new medical order, Code Pearl, is her creative answer.*

**W**HEN WAVED BEFORE THE DEVICE positioned at wheelchair height, my plastic card had magically opened automatic doors in some of Harvard Medical School’s century-old quadrangle buildings. Six months ago, my card stopped working. This left me, on my occasional visits, to tug at massive doors from my scooter-type wheelchair until help arrived. With finally a few moments to replace the card, I went in search of the security office located in another early-twentieth-century building. But the security office wasn’t wheelchair accessible—the building’s lone elevator didn’t service that particular corridor. So I waited outside on the sidewalk at the base of blocky granite steps while an officer shuttled back and forth, verifying my identity, processing my request, and eventually producing the magical card. Fortunately, it was a beautiful late-spring day, and I had several pleasant conversations with passers-by who inquired if I needed assistance. I also enjoyed the obvious irony—another good wheelchair story, small but on point.

## Telling Fish Tales

**A**LTHOUGH MANY PEOPLE THINK that the 1990 Americans with Disabilities Act (ADA) paved the way for people with disabilities to move easily around communities, countless barriers still block our way. Sometimes

.....  
 Lisa Iezzoni (liezzoni@partners.org) is associate director of the Institute for Health Policy at Massachusetts General Hospital and a professor of medicine at Harvard Medical School in Boston, Massachusetts.

when we get together, wheelchair users play our own variant of telling fish tales: Can you top this instance of impediments to getting around? Most of us accumulate such tales, from the comical to the horrendous, often involving public transportation, streets, sidewalks, restaurants, hotels, airlines, and, inevitably, other humans. These days my fish-tale specialty is collecting stories about physical barriers to health care. If my Harvard Medical School tale holds any irony, it pales compared with the ironic reality of physical barriers crisscrossing health care settings.

Although economic, geographic, and sociocultural barriers to care appropriately cause considerable consternation, physical barriers to accessing care still attract only sporadic notice. The ADA's equal-access mandates have not ensured that all hospitals, clinics, private physician offices, and other health care settings are physically accessible. Automatic doors and ramps get people into buildings, but then what? Periodic lawsuits occasionally highlight this issue. For instance, on 26 July 2000—ten years to the day after President George H.W. Bush signed the ADA—three wheelchair users sued the gargantuan Kaiser Permanente of California for failing to provide accessible care. One plaintiff, a man with quadriplegia, had pleaded repeatedly with his clinicians to get him out of his wheelchair for full physical examinations, but the clinicians refused, arguing that they had neither the staff members nor equipment (for example, an adjustable examining table that automatically lowered to wheelchair height) to transfer him from his wheelchair.

---

**“Automatic doors and ramps get people into buildings, but then what?”**  
 .....

Meanwhile, a pressure ulcer developing on his buttock went undetected for perhaps a year. Kaiser Permanente immediately mobilized and settled the lawsuit, agreeing to widespread access improvements across its massive system.

Despite publicity surrounding this lawsuit, few other health care providers have made proactive and systematic efforts to ensure physical access throughout their facilities. Among wheelchair users and others with impaired mobility, stories about barriers to health care abound. Here are three such tales. I start with two small tales from my personal portfolio and then tell a big tale that happened to a colleague.

Before starting, let me note that I'm sometimes told that my stories sound too matter-of-fact—where's the emotion, anger, frustration? Many longtime wheelchair users—twenty years for me—learn early on that becoming agitated by barriers 24/7 is a recipe for exhaustion. Equally important, situational emoting rarely succeeds in gaining access—if the elevator's broken, it's broken. So we are often matter-of-fact, concentrating on the practical reality of figuring out what to do. Don't get me wrong. Some situations are so egregious that anger spills out. But when we wheelchair users get together and tell each other our tales, we spend much of our time rolling our eyes and shaking our heads: “Can you believe this? They just don't get it!”

## Two Small Fish Tales

WHEN SCHEDULING MY ANNUAL MAMMOGRAM, I told the appointment clerk about my wheelchair and asked if they could accommodate me. “Absolutely yes, no problem!” When I arrived, the receptionist eyed me knowingly, asked me to wait, and picked up the telephone. Two sturdy women emerged from a back room and escorted me to the mammography suite, where they indicated that they intended to lift me up and press me snug against the machine. Their equipment was not wheelchair accessible.

Now, this strategy has several flaws: It’s not safe for patients or for staff members who must lift and contort patients while preventing falls; it’s not respectful of patients, who must endure the unwanted intimacy of unfamiliar staff members hugging them close; such maneuvers might not assure high-quality images of delicate breast tissue; and, finally, it’s unnecessary, since accessible equipment does exist. Fortunately, my legs can hold me upright long enough to take each required view, so I raised up from and lowered down to a chair for twenty to thirty minutes getting the mammogram. This experience brought home one of many potential explanations for findings my colleagues and I had published in the *American Journal of Public Health* in 2000—that women with major difficulties walking were 30 percent less likely than other women to get mammograms, even after accounting for demographic characteristics, health insurance, and having a doctor. If women can’t access equipment, how can they get this critical test?

---

**“About to spend multiple millions, facility administrators simply hadn’t thought about how patients would get onto the new machines.”**

.....

My second small tale involves getting a spinal cord magnetic resonance image (MRI). People who need MRIs often have mobility problems (bad backs, bad knees, and so on), so I was surprised to confront a high fixed table that didn’t lower for easy transfers. Instead, I had to balance on a tiny stepstool, my elbows grasped firmly by two technicians who then rotated me onto the chilly flat surface for the test. With my tall frame swaying on unsteady legs, climbing this stool endangered both the technicians and me, and I concentrated hard, heart racing, to avoid falling. After the MRI, I fortuitously encountered an administrator in the hallway and described the inaccessible MRI machine. She was, she told me, preparing a request for proposals (RFP) detailing specifications for manufacturers that wanted to bid on supplying new radiology equipment; her draft RFP hadn’t included accessibility requirements. About to spend multiple millions, facility administrators simply hadn’t thought about how patients would get onto the new machines. After all, ADA physical access regulations relate to buildings, not to the equipment housed there.

## One Big Fish Tale

MARY LOU BRESLIN'S BREAST CANCER TREATMENT experiences exemplify a big fish story about barriers to health care. Mary Lou is quadriplegic from childhood polio and uses a power wheelchair. An influential disability rights leader for three decades, she continues her active advocacy in northern California. In 2004, as the following events unfolded, she and I, along with Judy Panko Reis and Kristi Kirschner from the Rehabilitation Institute of Chicago, were collaborating on a white paper titled *It Takes More than Ramps to Solve the Crisis of Healthcare for People with Disabilities*. In it, we argued that fundamental ADA principles can reshape health care delivery, including ensuring equitable and accessible patient-centered care. Mary Lou's virtually contemporaneous experiences offered a surreal example of life imitating art.

Mary Lou's story starts with a twist. When she was diagnosed with breast cancer, she had just changed health care providers. "Before then, I had a primary care doc," Mary Lou recalls when we talked recently, "but any exams she conducted were done in the wheelchair. We had many discussions about a height-adjustable examining table, and she would not purchase one." So, as her new provider, Mary Lou chose Kaiser Permanente, which had several years previously settled its ADA lawsuit. "I literally switched providers because I thought I would get better care from the disability perspective," she says.

---

**"Although the clinic had a Hoyer-type lift (simple, moveable equipment that raises people using slings), its sling was missing. This meant that Mary Lou remained in her wheelchair."**

Mary Lou acknowledges many challenges in treating her breast cancer. Most profound, she had virtually no scientific evidence to guide various treatment decisions: The small number of Americans living post-polio limits research possibilities. Unjustifiable, though, were physical barriers to her care. "Forget deciding what treatment you're going to have," Mary Lou says. "It's the disability part that was really a case study." During her breast cancer treatment at Kaiser facilities, every one of "twenty-plus outpatient encounters involved me being treated in

my [wheel]chair."

Mary Lou first underwent surgery. She thought her surgeon was "wonderful," but "every procedure she did on me post-surgically should have been done with me supine and wasn't." For instance, the surgeon inserted a portacath for easier intravenous access during her chemotherapy. "Right after it was installed, I was lightheaded and falling over in my chair while they were trying to access it. The surgeon said, 'You need to be lying down.'" But it didn't happen. Although the clinic had a Hoyer-type lift (simple, moveable equipment that raises people using slings), its sling was missing. This meant that Mary Lou remained in her wheel-

chair.

Although Mary Lou tells this big tale calmly, with minimal editorial comment, she readily admits that her chemotherapy experiences that came next riled her. Nowadays, virtually all breast cancer chemotherapy occurs in outpatient settings—safer and more comfortable for patients and less expensive than hospitalizations. Mary Lou met with the nurse who ran Kaiser’s outpatient chemotherapy clinic to plan ahead for her treatments. The clinic’s infusion chairs and beds were inaccessible, so Mary Lou would receive chemotherapy seated in her wheelchair. She wondered what would happen if she needed to lie down. “I’m looking around, and there are no height-adjustable exam tables. There’s certainly no lift. A cascade of activity ensued. Eventually the clinic came back and said, ‘We cannot treat you here because you’re not ambulatory. This is an ambulatory treatment facility. You’ll have to be admitted to the hospital.’ I just hit the roof over this.”

Working for a legal advocacy organization proved helpful: Attorneys for Mary Lou’s group contacted lawyers who had filed the 2000 ADA lawsuit. “They put us in touch with Kaiser’s ADA coordinator, who was really good,” Mary Lou says. “Everybody got in a room, and the ADA coordinator said to the chemo division, ‘Listen up. You guys have got the wrong model here. Ambulatory means outpatient. It doesn’t mean you have to be able to walk to be treated here.’” The clinic arranged for a lift in the chemotherapy unit and trained staff members to use it.

“The first day I had chemo, the ADA coordinator was there along with some hospital administrators,” Mary Lou reports. “They did not want anything to go wrong. The head nurse seemed upset, but everybody else was perfectly fine.” Mary Lou laughs at the memory. “It was a scene! I’ve got my own entourage of three people, and there are three people from administration watching everything. Everyone stayed there for all five hours.” She tolerated the chemotherapy well.

After this first wave of accommodation fervor, serious practical questions remained. “One problem is using the bathroom.” Mary Lou explains. “I’m an ‘old polio,’ and if there’s anything we do well, it’s not pee.” Copious fluids administered with chemotherapy, however, challenged even Mary Lou, who describes herself as “the iron-bladder of the Western universe. I needed to use the bathroom a couple of times in a five-hour period. My friends were perfectly willing and able to help me in the bathroom.” That worked for Mary Lou, but the outpatient staff had a policy that they wouldn’t provide bathroom assistance—if patients needed help and couldn’t supply it themselves, they were supposed to be hospitalized for chemotherapy. “The policy is probably about protecting staff from injury or some liability issue,” Mary Lou sur-

---

**“The outpatient staff had a policy that they wouldn’t provide bathroom assistance—if patients needed help and couldn’t supply it themselves, they were supposed to be hospitalized for chemotherapy.”**

---

mises. “But the impact is significant. How do people deal with this if they don’t have family or friends to help them?”

Mary Lou’s radiation therapy, the final phase of treatment, produced an instructive surprise about what’s possible. Kaiser offered Mary Lou a choice of two outside radiotherapy providers. She chose a small community hospital near her home and says that “they were fabulous!” After examining her, “the radiation oncologist said, ‘OK. We have to get you on the table every day. What’s the best way to do that? Do we need lifters? Would you prefer a mechanical lift?’ My jaw dropped. It was completely routine from her perspective.” Mary Lou worried about protecting her healing mastectomy wound, wanting to avoid “somebody wrapping their arms around my chest to drag me from my chair.” The oncologist called physical therapy (PT), and “PT came down with the Hoyer lift. Every single day I showed up for radiation, someone from PT was there. After we’d done it two or three times, the radiation staff and PT staff had it all figured it out. We could do it in about ten seconds. The whole thing was really fast, really efficient, and amazingly easy.”

Mary Lou’s breast cancer treatment ended three years ago, and—knock on wood—she is cured. She still uses Kaiser for routine care. “I need to start telephoning two days in advance to lay the groundwork for every visit,” Mary Lou says. “I must decide whether a particular exam has to be done on an examining table. Their default position is doing it in the [wheel]chair unless you’re aggressive about it. Sometimes even when I make arrangements in advance, the lift team isn’t there. I’ve had to leave, reschedule, and come back.”

Mary Lou’s doctors never make her accommodation arrangements; most departmental managers seem unsure how to proceed. “The OB/GYN manager took me aside and said, ‘I had no idea what to do. I don’t know what we would have done if you had just shown up.’” As Mary Lou observes—with what I consider great forbearance—“It’s hard turning around such a big ship when problems reside so deeply in every facet of professional training and service delivery.”

### Breaking Down Barriers—And Keeping Them Down

**P**HYSICAL ACCESS BARRIERS CARRY CLEAR CONSEQUENCES for people like Mary Lou and me and others with mobility difficulties, including safety risks, potentially inadequate care, psychological stress, and extensive time and effort planning ahead of time, all the while hoping against hope to avoid the many hazards. Mary Lou’s story demonstrates that removing barriers requires effort on multiple levels. Obviously, equipment must change, but so, too, must mindsets. Clinicians and other staff members should proactively recognize physical barriers within their environments and work collaboratively with patients to ensure safe and accessible care.

As the 2007 Institute of Medicine report *The Future of Disability in America* ob-

...serves, aging baby boomers will soon begin flooding health care settings with their various disabling conditions. Now is the time for providers to ensure that their facilities and equipment easily accommodate patients. Planning ahead for physical access is cheaper than retrofitting later. And along with helping patients, accessible equipment minimizes injury risks to staff members transferring patients. Nonetheless, few health care providers have undertaken systematic access assessments and improvements. Some, like Washington Hospital Center in Washington, D.C., must do so under watchful oversight from a 2005 U.S. Department of Justice settlement, which contains useful guidance for other health care providers about ADA compliance (<http://www.ada.gov/whc.htm>).

Although ADA regulations and guidelines address many access barriers (for example, buildings and communication), they don't include specifications for equipment and devices within medical settings. In 2007, Sen. Tom Harkin (D-IA) introduced legislation (S. 1050) that establishes accessibility standards for medical diagnostic equipment, as well as requiring accessible examination tables, mammogram machines, and weight scales when providers purchase or replace equipment. This bill contains no enforcement mechanism, but such efforts could eventually link to ADA requirements.

Ensuring patient-centered physical access will require a sea change in both attitudes and design in an area historically dominated by maximizing clinicians' convenience tempered by assumptions of beneficence: "Don't worry," they tell people in wheelchairs. "If it's necessary, we'll move you." The fish tales told here, however, show that benevolent intentions don't always stick. Even if they do, the ironic accompaniment is often creating risks to patients' safety and dignity, not to mention equity and quality of care.

Physical barriers unnecessarily compromise health care for people who already must navigate countless hurdles daily throughout their communities. Everyone should work toward a day when fish tales of physical barriers no longer occur in health care. Remember, someday that might be you sitting eye-to-eye with the examining table, blocked from easy access to the care you need.

.....  
*The author thanks Mary Lou Breslin for sharing her story and the National Cancer Institute for its funding (Grant no. R21 CA122130).*