

## Going beyond Disease to Address Disability

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One summer day about 10 years ago, a young woman flagged me down as I was rolling back to my hospital on my scooter wheelchair. An inpatient taking a sunshine break, she sat on a bench, intravenous pole in tow. She explained, tears brimming, that complications from diabetes made walking increasingly difficult. She was a single mother, and she could no longer get to the grocery store. She had asked her physician to prescribe a power wheelchair, but he had refused, insisting that she keep walking.

Unable to meet her family's basic needs, she had bought a cheap manual wheelchair, and her 10-year-old son, barely tall enough to see over her, pushed her to the store. "How can I get a scooter like yours?" she asked.

This story, among the first told by my "rolling focus group" — strangers who ask me about living with disability — started me thinking. Although the tales are as diverse as the tellers, they have two common themes: a desire to remain active and independent, and a quest for information about

options that permit educated choices for conducting daily activities and maximizing the quality of life. A lack of open, productive, informative dialogue with physicians can impede, delay, or derail these choices. This woman's doctor had a legitimate concern regarding physical activity, but she still needed groceries. Together, they might have devised solutions to meet both her health and practical needs; instead, she felt anxious and abandoned. What is the physician's role in going beyond treating disease to address dis-

### Selected Medical School Activities Related to Patients with Disabilities

#### Tufts University School of Medicine, Boston

*Standardized Patient Educator Curriculum, Family Medicine Clerkship.* In this required third- or fourth-year clerkship, persons with disabilities serve as standardized patients in simulated medical interviews, integrating a common primary care concern with disability-related issues; they then provide narrative feedback to students about their behavior, attitudes, and skills in the interview.

#### University of Medicine and Dentistry of New Jersey, New Jersey Medical School, Newark

*Standardized Patient Exercise, Pediatric Clerkship.* During their pediatric rotation, all third-year students spend one day at Matheny Medical and Education Center, which serves children and adults with developmental disabilities. After introductory sessions, each student performs a 20-minute interview with a standardized patient, an adult who is nonverbal because of cerebral palsy and has been trained to represent common medical conditions. After the interviews, standardized patients provide feedback using electronic communication devices or yes-or-no responses to questions.

#### University of South Florida College of Medicine, Tampa

*Caring for Adults with Disabilities.* This module is integrated into the 16-week primary-care clerkship for third-year students. It addresses older adolescents and adults with physical, sensory, and cognitive disabilities through two afternoon seminars with guests from the local community of persons with disabilities; home and community visits; service learning projects; and writing a reflection on the experience.

#### University of Illinois–Chicago College of Medicine, Chicago

*Annual Disability Plenary Session.* This half-day session is part of a required Essentials of Clinical Medicine course for second-year students. Presentations vary from year to year, including performances by artists with disabilities, films about living with disability, and presentations from faculty members with expertise in caring for persons with specific disabilities.

#### University of Pennsylvania School of Medicine, Philadelphia

*The "Wheelchair Experience."* This four-hour disability simulation is required of all first-year students as part of the Doctoring I Professionalism and Humanism curriculum. Students work in pairs, one using a wheelchair to perform specified day-to-day tasks while the other serves as caregiver; students then switch roles. Afterward, students write a two-page essay about the experience. In addition, a person with a disability or a family caregiver interacts with students in small groups, describing disability-related experiences and answering students' questions.

#### University of Massachusetts Medical School, Worcester

*Community Health Clerkship in Disability and Long-Term Care Policy.* This clerkship offers an elective, two-week curriculum for first-year students, in partnership with a community organization. It teaches students about living with a disability, community resources, and how physicians can enhance the ability of persons with disabilities to lead full lives in the community.

ability? And how should doctors be taught to fulfill this role?

Although physicians learn volumes about treating underlying causes, many receive little training in addressing resultant disability — difficulty performing daily activities and fulfilling social roles because of physical, sensory, emotional, or cognitive impairment, often compounded by environmental barriers. Approximately 54 million Americans currently live with some type of disability.<sup>1</sup> Medical interventions now allow many persons with clinically significant congenital conditions or impairments acquired in childhood or early adulthood to live long, productive lives. With baby boomers moving into their seventh decade, the number of persons with disabling conditions, such as impaired walking, hearing, vision, speech, or cognition, will soon skyrocket. Given the rising rates of childhood obesity,

asthma, diabetes, and arthritis, disabilities may develop at younger ages. Virtually all active clinicians can expect to see persons with disabilities in their practices.

Despite these demographics, efforts to train physicians to address disability confront substantial challenges. Chronic disability can thwart physicians' motivation to cure diseases. Some physicians see disability as outside their purview: "It's social-worker-type stuff," a general internist told me. Our society has historically marginalized persons with disabilities, and many physicians have internalized common views. "My upbringing was like everybody else's," another general internist observed. "Don't talk about it, don't stare, it's somehow hurtful." Patients may perceive this discomfort or wonder what their doctors can do anyway. Disability becomes the elephant in the room — present, but unmentioned.

Such attitudes carry consequences. In 2000, the Healthy People 2010 initiative identified Americans with disabilities as vulnerable to substandard care, asserting that erroneous assumptions about this population contribute to disparities in services.<sup>2</sup> In a "Call to Action" issued July 26, 2005, the 15th anniversary of the Americans with Disabilities Act (ADA), the U.S. Surgeon General urged health care providers to treat persons with disabilities with dignity, as whole persons.<sup>1</sup>

One place to begin physicians' training about disability is the realm of patient-physician communication. Communication is key to achieving patient-centered care, a touchstone for improving the quality of health care.<sup>3</sup> Care that respects patients' preferences, needs, and values has special resonance for persons with disabilities, who often find others defining and circumscribing their

#### Selected Educational and Informational Resources on Disability

##### U.S. Department of Justice, Washington, DC

*ADA Home Page: Information and Technical Assistance on the Americans with Disabilities Act* ([www.ada.gov/adahom1.htm](http://www.ada.gov/adahom1.htm)). Includes details about ADA mandates and regulations; links to other federal agencies with ADA responsibilities; updates about ADA enforcement, including ADA Mediation Program activities with health care providers; and settlement agreements and consent decrees with health care providers, detailing steps needed to meet ADA requirements.

##### North Carolina Office on Disability and Health, Chapel Hill

*Removing Barriers to Health Care: A Guide for Health Professionals; Removing Barriers: Tips and Strategies to Promote Accessible Communication; Partners in Health Care: People with Disabilities & Their Health Care Providers*; and other booklets produced in partnership by the North Carolina Division of Public Health and the Frank Porter Graham Child Development Institute, University of North Carolina, Chapel Hill ([www.fpg.unc.edu/~ncodh/pubs.htm](http://www.fpg.unc.edu/~ncodh/pubs.htm)).

##### World Institute on Disability, Oakland, CA

*Access to Medical Care: Adults with Physical Disabilities* ([www.wid.org/publications](http://www.wid.org/publications)). A 22-minute educational video about caring for persons with mobility, vision, hearing, and communication impairments in outpatient settings, along with a 30-page training curriculum for health care professionals.

##### Rehabilitation Institute of Chicago, Chicago

*Learning to Act in Partnership: Women with Disabilities Speak to Health Professionals*. A 38-minute educational video about health care experiences, needs, and preferences of women with disabilities ([kkirschner@ric.org](mailto:kkirschner@ric.org)).

##### Kaiser Permanente National Diversity Department, Oakland, CA

*A Provider's Handbook on Culturally Competent Care: Individuals with Disabilities*, Kaiser Foundation Health Plan, 2004. An 87-page handbook, covering topics including cultural perspectives, attitudes, and beliefs about disability; communication barriers; access to care; risk factors; and specific areas of clinical focus, such as pain, mental health, and reproduction, sexuality, and pregnancy. National Diversity Hotline, 510-271-6663.

lives and options. A patient-centered orientation requires open communication between patients and physicians, unhampered by false assumptions about patients' abilities and aspirations. Optimal care then demands collaboration between patients and physicians, each bringing their respective expertise to decision making: physicians possess critical technical knowledge, but patients are the experts on their own lives.

Communication between physicians and persons with disabilities can falter on many levels.<sup>4</sup> An initial barrier arises when physicians "medicalize" disability. Although diseases do produce disability, persons with long-term disabilities do not necessarily approach their conditions as illnesses. "I'm not sick," says a woman who has had multiple sclerosis for 30 years. "I just can't stand up!" Rather than seeking treatment for her disease, she wants advice about performing daily activities, perhaps with assistance, at home. "The medical community has a pathologic view of deaf people," said a deaf woman who communicates using sign language. "They don't see us as a linguistic minority. I don't identify myself as disabled." When she visited the emergency room with an injured ankle, the physician's first question was about why she was deaf.

The ADA and other laws require clinicians to communicate effectively with patients, but physicians don't always do so. For instance, they often write notes to deaf patients, not recognizing that some sign-language users may have low proficiency in English. Hospital policies required a woman to relinquish her hearing aids before surgery. "Afterward, they told me, 'You took a long time to come out of anesthesia. We kept talking to

you.' But I couldn't hear them!" An elderly man, hospitalized because of deep-vein thrombosis, was given written instructions along with injectable medications to self-administer at home. The nurse and pharmacist who counseled him on discharge failed to recognize that he was blind. Unable to read the instructions, he didn't take his medication.

Uninformed assumptions about persons with disabilities can erode respect and trust, the bedrock of open communication. For instance, physicians may underestimate the intelligence of persons with communication disorders, such as speech impairments related to cerebral palsy (see shaded box). "When doctors hear I have a psychiatric disability, they question my judgment on everything," said one woman. "I don't have a relationship of trust." Persons with disabilities sometimes fear that physicians may not treat acute conditions aggressively, believing that the patient's quality of life is poor anyway.

Some persons with disabilities note that their physicians do not make basic connections between functional impairments and daily

needs. "When my shoulders were hurting, my doctor told me, 'Don't use your arms so much,'" reported a woman who self-propels her wheelchair. "I'm paraplegic — all I have is my arms! How can I get around without them?" Physicians may not acknowledge that people with long-term disabilities often know more about their conditions than their doctors do. Several persons with spinal cord injury reported physicians' refusal to believe that they could feel pain below the level of their injuries. One physician biopsied a leg lesion without administering local anesthetic.

Finally, many persons with disabilities believe that physicians do not appreciate the richness of their lives, leaving them feeling disrespected or degraded. Some offenses, such as speaking to sign language interpreters rather than directly to deaf patients or grabbing the arms of blind persons when escorting them to examining rooms, probably reflect poor training. Others represent basic failures of physicians to imagine full and varied lives for persons with disabilities. "Come see us in our own environment," urged one

"One summer during college, I worked at a rehab engineering center, where we gave assistive technology to people who needed it, mostly communications technology.

"This woman in her 20s came in. She was in a wheelchair and couldn't speak. Her head was to one side, and she was drooling. We all spoke to her as if she were a little child. She wasn't responding, and I thought she didn't understand a word I said.

"We set her up with a computer with word-prediction software with various shortcuts. . . . We were trying to teach her how to use it, telling her to hit the F button. She kept missing the F button and hitting the bathroom button, and we'd say, 'That's okay. You're doing great!' Finally, someone had the good sense to say, 'Do you need to go to the bathroom?'

"Then we got her set up with the word-processing program. Within about two seconds, she typed, 'This is just like having a baby. You wait nine months and then go to the hospital.' The baby was her getting the computer after waiting for so long. This was not at all what I had imagined from looking at her! I remind myself about this again and again — not to make assumptions based on how disabilities look."

— Fourth-year medical student

wheelchair user. “Doctors anticipate a much lower quality of life than we actually have.”

Unfortunately, structural barriers within the health care system can impede complete communication and efforts to provide patient-centered care to persons with disabilities. Health insurance does not reimburse more for patients who require extra time or resources (e.g., to make communication or physical accommodations, to consider complex health care needs, or to complete disability-related paperwork). In many circumstances, physicians must enlist colleagues from other disciplines, such as rehabilitation professionals and technology ex-

perts, to address patients’ concerns fully — requiring even more time to communicate and coordinate care. In addition, health insurance may not cover the long-term rehabilitation and assistive technology that patients need.

Even without extra time, training, and resources, however, two basic precepts can help to build better communication between physicians and persons with disabilities — and perhaps better care. First, make no assumptions. Second, just ask persons with disabilities — about their needs, preferences, and lives.

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1. Department of Health and Human Services. The Surgeon General’s call to action to improve the health and wellness of persons with disabilities. Rockville, MD: Public Health Service, 2005. (Accessed August 17, 2006, at <http://www.surgeongeneral.gov/library/disabilities/calltoaction/calltoaction.pdf>.)

2. Department of Health and Human Services. Healthy People 2010: understanding and improving health; objectives for improving health. 2nd ed. Washington, DC: Government Printing Office, November 2000.

3. Institute of Medicine, Committee on Quality of Health Care in America. Crossing the quality chasm: a new health system for the 21st century. Washington, DC: National Academy Press, 2001.

4. Iezzoni LI, O’Day BL. More than ramps: a guide to improving health care quality and access for people with disabilities. New York: Oxford University Press, 2006.

## BECOMING A PHYSICIAN

### The Script

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“What happened?” the patient asked. She was coming out of anesthesia after six hours of surgery. A weary resident cleaned dried blood and iodine from the skin around the surgical wound on her abdomen. The anesthesiologist had just removed her breathing tube. The patient, to my surprise, was staring straight at me — the medical student. She asked again: “What happened?”

During the previous 6 months, a rapidly expanding abdominal mass had developed. Early in her surgery, a frozen section had been sent to the laboratory, and 20 minutes later a voice over the intercom had confirmed what the surgeons had surmised: she had ovarian cancer. The tumor had spread through the pelvis and abdomen, attacking the uterus and loops of bowel. The surgeon and residents meticulously resected all

visible disease, but the prognosis was grim and everyone in the operating room knew it — except the patient. But surely it was not my place to relay this news.

The surgeon bailed me out. “Your surgery’s over,” he said in a calm, soothing voice. He told her they would talk more when she had fully awakened. But what — and how, exactly — would he tell her?

In medical school, we’re taught to follow a script: “What brought you to the hospital today?” it begins. It’s a starting point based on the assumption that you haven’t already read a triage nurse’s notes, reviewed the results of laboratory tests ordered in the emergency department, or met the patient during a previous examination. We learn to take a detailed history of the present illness before proceeding to the medical histo-

ry, the social history, and a series of questions: Current medications? Allergies? Surgical history? Prior hospitalizations? “Ask the questions in the same order, and you’ll never forget anything,” I was advised during my medicine clerkship.

“But I’ve already answered these questions five times,” patients occasionally protest midway through the script. “I’m sorry, but it’s important that we don’t miss anything,” I respond, noting that the patient is alert and oriented. From the first weeks of medical school through the licensing exam, this initial encounter is the focus of medical education. Whether you’re examining an elderly woman with diabetes who has a foot ulcer, a young man having a panic attack, or a vomiting infant, instructors drill this script into your head. Taking his-