Disabilities: Looking Back and Looking Ahead

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Neither numbers nor definitions come easily when considering disabilities. Although 35 to 49 million Americans are formally classified as disabled,1 many more disabilities may be unreported or undiagnosed. Disabilities differ in kind and degree of functional impairment and in the role they play in shaping a person’s identity.

In this issue we explore how the Americans With Disabilities Act (ADA) has affected medical education and medical practice, since the ADA’s major provisions were implemented 5 years ago.2 Additionally, we were curious to learn about the experiences of individuals living with a disability. In our authors’ candid accounts we saw their focus on adaptation and success rather than failure, and their development of insights and compensations that may bring a special compassion to the profession.

The medical profession has historically played an important part in the formation of attitudes toward people with disabilities.3 Physicians who themselves have disabilities have recently been at the forefront of legislative and organizational activism, especially since the Association of Academic Physiatrists began in the 1990s to advocate for improved matriculation rates of disabled students and retention of disabled physicians in medical practice.4

Nonetheless, misunderstanding and outright hostility continue to confront people with disabilities. As numerous court cases against health professions schools and other institutions of higher learning have attested in the past few years, these issues will probably not be settled quickly, definitively, or free of legal contention.5

To begin, we consider the basic nature of functional limitation and functional competence. Can competence be evaluated by the presence of specific abilities rather than the absence of all disabilities? Michael Reichgott proposes that new assessment models may offer greater equality of opportunity without compromising educational quality.

Such a proposal involves high stakes. Systems of evaluation defining the boundaries of medical education and practice have serious ramifications for those who find adaptation to traditional standards or systems of placement difficult or impossible. Mehri Brown and Kevin Takakuwa vividly describe the spectrum of disabilities from severe impairment to subtle differences in brain function. Cesar Aristeiguieta makes the point that the ADA may both heighten awareness of the prevalence of disabilities and encourage efforts in acceptance and retention of disabled medical students and professionals.

Finally, we examine the effects the ADA might have on those without disabilities. Alicia Conill, a medical educator, and Rochelle Haas, a medical student, describe connections between people with disabilities and people who do not think of themselves as disabled. In the wake of the ADA, medical education is irrevocably changing. We leave our readers to consider their part in its reshaping. What is fair? What is not? How do we find our way from one to the other?

References
The Disabled Student as Undifferentiated Graduate: A Medical School Challenge

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More than 20 years have passed since implementation of the Rehabilitation Act of 1973, and it has been almost a decade since those protections were expanded by the Americans With Disabilities Act (ADA) of 1990. These statutes prohibit discrimination against a disabled but “otherwise qualified” person seeking admission to an institution of higher learning. Yet, physically disabled individuals continue to be denied admission to medical schools.

Students with disabilities account for 0.2% of medical school graduates. Considering that 8.8% of college freshmen have some disability, these reports suggest that a very low percentage of the physically disabled enter medical school.

This resistance arises from the premise that the ideal graduate should be prepared “to enter without handicap any one of the fields of medical practice.” Thus, every student is expected to acquire the knowledge and skills needed to enter any residency. Prospective students unable to become “undifferentiated graduates” may be excluded from medical school admission.

Under the ADA, reconsideration of the “undifferentiated graduate” concept has posed a serious challenge. ADA regulations obligate a faculty to review the school’s curriculum, develop standards for admission, and apply those standards uniformly to all applicants. Simply stated, the ADA requires the following:

• Schools must judge applicants on their expected ability to complete the educational program, without regard to disability.
• An applicant must be able to perform the “essential functions” of the curriculum.
• A school must provide “reasonable accommodation,” so an “otherwise qualified” but disabled person is not prevented from completing the curriculum.
• Reasonable accommodation does not require “fundamental alteration” of a program, or actions that impose “undue burden.”
• A school may not solicit information concerning disability.
• A student requesting accommodation must present documentation including exact diagnosis; nature of impairment; specific recommendations for accommodations.

In 1979, a special advisory panel of the Association of American Medical Colleges (AAMC) responded to the 1979 Rehabilitation Act. The AAMC wrote that acceptable candidates required skills including observation, communication, motor function, conceptual, integrative and quantitative thinking, and appropriate behavioral and social attributes. The panel also concluded that a medical student should perform independently. Technologic compensation for handicaps was acceptable but assistants were not, since an intermediary might interpose “someone else’s power of selection and observation” on a student’s judgment.

These standards have inhibited acceptance of disabled students. A blind student, for example, required assistance to perform an “essential function,” the acquisition of visual information. Use of an intermediary was considered a “fundamental alteration” of the program.

The ADA provides an opportunity to rethink certain applications of these standards. For instance, decreased upper extremity motor function may require the use of assistants. Under earlier AAMC standards, such a student would not be acceptable. But under the ADA, the curriculum’s “essential functions” may be more specifically defined. Is direct palpation by the physician necessary to conceptualize disease? Does use of an intermediary impair clinical judgment?

Indeed, in modern medical practice, support staff frequently collect data for the physician’s interpretation, making the ability to work with intermediaries an asset.

Medical schools must determine how any qualified applicant, regardless of physical ability, can be effectively accommodated and counseled in achieving the most appropriate medical career. In this era of technologic diagnostics and professional assistants, the “essential functions” of medical education might be restated as acquiring fundamental knowledge; developing communication skills; interpreting data; integrating knowledge to establish clinical judgment; and developing appropriate professional attitudes and behaviors.

If carefully selected and supported, a significantly disabled student can succeed in a rigorous medical school program. An intermediary need not intrude on analysis and decision-making, and independent motor performance may no longer be an essential requirement.

Any student achieving these restated essentials could be an “undifferentiated graduate.” If we succeed in effecting this conceptual change, all graduates will be prepared for residency and practice “without handicap.”

References
1. 29 USC §794.
2. 42 USC §12101 et seq.
8. Association of American Medical Colleges. Functions and Structure of a Medical School: Standards for Accreditation of Medical Education Programs Leading to the MD Degree. Washington, DC: Association of American Medical Colleges, Liaison Committee on Medical Education; 1997.
In 1973 the American Medical Association’s Council on Mental Health defined impairment as “the inability to practice medicine with reasonable skill and safety to patients by reasons of physical or mental illness, including alcoholism or drug dependence.” Today, medical student and physician impairment is still a major cause of concern, with alcohol and drug addictions representing 80% to 94% of all cases investigated by state physician impairment programs. Because the classification of addiction as a disease is still not widely accepted, impaired students and physicians tend to be seen as weak in character, rather than ill. The Americans With Disabilities Act (ADA) of 1990 offers an opportunity to assist and protect students with disabilities due to substance abuse or mental illness.

The prevalence of mental illness among medical students, including substance abuse, may differ from the general population in a few notable respects. For example, American medical students use alcohol, benzodiazepines, and prescription opiates at a higher rate than similar age-matched cohorts. As for other forms of mental illness, an 8-year study at the University of Louisville revealed that approximately 20% of their medical students sought psychiatric consultation and treatment, for reasons such as adjustment, mood, anxiety, compulsive and dependent personality disorders, and marital problems. It remains unclear whether medical students are more likely to develop mental health problems. Entrance requirements for medical school may select students with obsessive and narcissistic traits or an irrational fear of failure. Subsequent crisis and increased stress may elicit maladaptive behaviors, possibly leading to depression.

The ADA, first implemented in 1992, guarantees that individuals with disabilities receive equal opportunities in employment, public accommodations, state and local government services, transportation, and telecommunications. However, considerable debate exists over the degree of protection that the ADA may provide to impaired medical students.

For a student to be considered disabled under the ADA, he or she must have a physical or mental impairment that substantially limits 1 or more major life activities. A mental impairment is defined as any recognized mental or psychological disorder, including specific learning disabilities. Included as disabilities are recovery from alcoholism and addiction, as well as active alcoholism that does not adversely affect performance. Excluded are minor or temporary impairments; sex addictions; compulsive gambling; kleptomania; pyromania; and current, illegal use of prescription or illicit drugs.

To qualify for ADA protection, the student must demonstrate that he or she has met all requirements for admission, can fulfill the fundamental requirements of medical education, with or without reasonable accommodations, and poses no direct risk of substantial harm to the health and safety of others. The student is responsible for obtaining a medical evaluation to determine if an impairment exists. The ADA then requires that schools make reasonable accommodations to help otherwise qualified disabled students overcome unnecessary barriers that may prevent or restrict educational opportunities. The ADA does not require lower performance standards, disruptive or cost-prohibitive accommodations, or a stress-free environment.

For students already enrolled, medical schools may initiate a medical inquiry only after evidence of academic difficulty, actions not specifically covered by the ADA, or new evidence of a direct risk to the health and safety of others. Medical schools may dismiss disabled students who pose a distinct risk of substantial harm to the health and safety of others. They may also dismiss otherwise qualified disabled students when reasonable accommodations have been provided and the student cannot satisfy the fundamental academic requirements, or when no reasonable accommodation is possible.

Evidence shows that treated physicians are no more of a risk to the public than other physicians. A renewed effort is needed to encourage the acceptance of those disabled by substance abuse and mental illness and to focus on prevention, early detection, and treatment. Although seemingly cumbersome, implementation of the ADA should encourage the greater acceptance and assistance of medical students with disabilities.

References

Coping With a Learning Disability in Medical School

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The first time I ever thought about learning disabilities (LDs) was when a fellow student described her experiences in a postbaccalaureate psychology class. I had never before considered how learning styles could differ and what some people might do to compensate for those differences. Never did I imagine that just a few years later I myself would be diagnosed with an LD and be faced with academic difficulties in my own career.

The diagnosis of an LD is based on standardized test data, when the performance expected from a person based on age, education, and intelligence level differs substantially from the person’s actual performance. My LD is called an auditory and visual information processing deficit, which means that my brain processes information in a manner different from other people. My LD affects my reading—I comfortably read below the first percentile in standardized reading tests—and it affects my ability to memorize information.

This description is not satisfactory to some people. It seems everyone has heard of dyslexia and can easily associate it with reversing letters, a simple concept demonstrating how reading is affected by an LD. In fact, the spectrum of LDs includes many other disabilities. In addition, LDs do not always fall into neatly comprehensible categories, although the false preciseness of the Diagnostic and Statistical Manual of Mental Disorders might convince one otherwise.1 That few have heard of my LD is likely due to the complexity of establishing clinical categories for the very subtle manifestations of a slightly different brain chemistry.

I was not diagnosed with an LD until the year before I started medical school, after an abysmal experience with the Medical College Admissions Test. My situation is not unusual. Many bright individuals with LDs learn to compensate for their weaknesses.2 Often it is not until they reach higher levels of education that their compensatory abilities are overwhelmed, thereby exposing a previously unrecognized LD.

The accommodations I receive for my LD are double time on my exams and a semiprivate testing room where I can read aloud. As for studying the large amounts of material required in medical school, I knew I had to consider how to maximize my learning, which involves conceptualizing, organizing, visualizing, and discussing material. Reading and attending lectures are inefficient because they provide only one modality of processing information, either visual or auditory. Therefore, I chose an option offered at my school to extend the first 2 preclinical years to 3.

Besides requiring that I take more time to learn, my LD seems to affect me mostly in testing situations—specifically in standardized and multiple-choice formats. I have spent much time trying to understand this phenomenon. Often I wonder whether I simply do not know the material as well as other students. However, in essay format tests, which accounted for the vast majority of my exams as an undergraduate and were occasionally offered in medical school, I perform without any difficulties. The unfortunate consequence of this testing bias is that I spent much of my second and third years practicing exam formats, leaving less time for class material.

As my past performance could have predicted, I obtained strong evaluations in my clinical rotations but poor scores on the required National Board shelf exams. In my second required clinical rotation, I did not pass a shelf exam and was placed on academic probation, despite obtaining honors in 5 of 8 categories of my clinical evaluation and an 85% mark on my oral examination. Obviously, it is distressing to feel competent and perform well clinically but be in academic jeopardy.

I often wonder how my experiences as a person with a LD differ from those of other medical students. I also occasionally wonder to what greater degree, if any, I am impacted since many of my struggles are shared by students without LDs. Since I have always functioned in this way, successfully for the most part, I cannot comprehend how it might be to learn in a modality other than my own. I have struggled with feelings of frustration in a way that seems common to many medical students, although in my case to a much greater degree.

Some might argue that because of my LD I am less fit to be a doctor and that my disability might cause me to miss some critical piece of information. I reply that I have successfully compensated for my learning differences and am affected in ways that have not been related to patient care. Indeed, in my patients’ and preceptors’ eyes, I am like any other student. My LD, like many LDs, is invisible, and few suspect that a medical student like myself could have an LD.

I believe that because I have struggled with these issues in medical school, I will ultimately relate better to the daily struggles of my patients. I hope for others like myself that the medical education system will devise better means for educating, evaluating, and assisting students with LDs.

References

I obtained my medical degree over a year ago. Because I have a disability, I twice failed to place in a pediatrics residency. I am now collecting unemployment checks. I have cerebral palsy.

Becoming a doctor is not a dream that a child with a disability usually has. Although I attended regular school, my parents never really thought I would go to college. Becoming a doctor never seemed like an option for me, who could barely cut up food or tie shoelaces. But I gradually began to think, why not? I liked science and I enjoyed working with people—aren’t those the two most common and simple reasons for wanting to be a doctor?

In premedical classes, I heard professors object to my intent to pursue a medical career. My first-year medical school classmates initially had similar reservations. Even after the second month, students expressed concern because I could not perform a clean anatomical dissection.

Speaking to classmates at an informal lunch was one of the best things I did to alleviate the other students’ anxiety. I presented myself as a person with a disability and explained what cerebral palsy was and how it affected me. I answered some very basic questions and explained that my reasons for being in medical school were those of any other student. I realized that medical students have the same misconceptions of disabled people that most people do: that a disability is the worst thing a young person can have; that physical disability implies some mental or emotional instability; and that being a good doctor requires perfect abilities in all areas of functioning.

I completed medical school with a few scheduling adjustments and a determination to accept and adapt to the procedural limitations I have. As I had anticipated, I enjoyed my pediatrics rotation the most. Just as I had asked myself in applying to medical school, I once again asked myself, why not?

I have always contended that cerebral palsy is simply one attribute of my identity, just like being a single woman in her late 20s is another. Having cerebral palsy does not mean my goals and interests are any different.

However, I failed to match with pediatric programs twice. I believe the match, competitive as it is, presents particular problems for candidates who require special strategy development. In lieu of pediatrics, I completed a transitional year in internal medicine. I now have a Rhode Island medical license but feel unprepared to practice without further training.

So I am collecting unemployment checks while I apply to several other specialties.

For now, I miss seeing and influencing patients, and I miss thinking and practicing medicine. I am determined, however, to continue my medical career, and to continue educating others about my abilities as well as my disabilities.

Experiences With d/Deaf Culture

No one in my family is deaf (unable to hear) or Deaf (part of Deaf culture). I did not know anyone who was d/Deaf until, as a college senior, I taught at a summer camp where I had learned some basic sign language several years earlier. I had always remembered the signs and wanted to communicate in this way. Unfortunately, American Sign Language (ASL) was not offered at my college, and by the time I entered medical school, I realized that I was going to have to seek out a means of learning ASL.

I spent the summer after my second year of medical school at Gallaudet University in Washington, DC. At the time, Gallaudet represented a quick opportunity to learn ASL. I had little idea what being at Gallaudet would come to mean to me.

Gallaudet University is the only liberal arts college for the d/Deaf in the world. In my 4 weeks there, I learned a new set of customs, rules, and etiquette. Most significantly, I learned that our health care system continues to be a source of difficulty for the d/Deaf community because of a lack of understanding of d/Deaf culture.

Previously, I had learned about many different “minority” cultures, but “deaf culture” was never mentioned. Many people are surprised to learn that ASL is the third most common language in the United States. But sign language is only one part of being Deaf. More important is an understanding of Deaf culture. For example, many deaf individuals do not consider an inability to hear pathological. Deaf people feel threatened when seen as patients to be “cured.”

My only regret is that I waited so long to learn about Deaf culture. After my experience at Gallaudet, I designed an elective offered at my medical school to provide other students with information about Deaf culture, the basics of medical sign language, and exposure to the d/Deaf community.

My experience at Gallaudet was only a beginning. I did not and could not come to a complete understanding of the language or culture. However, I have an awareness that I did not have before, and I urge other medical students to make the effort to learn about d/Deaf culture so that we can begin to build a better relationship between it and our own.
Living With Disability: A Proposal for Medical Education

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The time has come for physicians in training to learn about living with a disability. This is not a novel idea. Many schools of nursing, physical therapy, and some schools of medicine have attempted these “sensitivity trainings,” as they are commonly called. Yet these experiences are usually brief, lasting 3 to 4 hours at the most, in a controlled environment, and the impairments that are reproduced are limited, with no specific focus on the care provider’s role in relation to the patient. Current training programs do not usually include extensive educational components disseminated in didactic, interactive, and experiential modes.

We decided to broaden and deepen the experience so that it would be a valuable learning tool for medical students. We approached the University of Pennsylvania with a 48-hour pilot program for first- and second-year students on the topic “living with a disability.” Thus our course began.

We convened 14 students over dinner, gave them the ground rules, and taught them the basics about using devices such as walkers, canes, wheelchairs, braces, and crutches. We taught them how to initiate a transfer from bed to chair and how to assist in a transfer without injuring themselves. Then, pair by pair, the students assumed their assigned roles of patient and caregiver. Each pair received a set of information and devices including the medical diagnosis of the patient, an explanation of the relationship between patient and caregiver, devices to be used for the patient, a list of suggested observations to make and record over the next 24 hours, and a detailed itinerary for a field trip around the campus the next morning. They were to stay in role all night.

That next morning, the students looked haggard. None had slept more than 4 hours because “everything takes so much longer.” They felt tired, sad, angry, and frustrated. Emotions expressed by caregivers and patients were similar, a phenomenon that is a real occurrence in medical practice. After discussion of some of these issues, the students resumed their roles and set off on their assigned field trips for the rest of the morning.

When they returned, the students were eager to talk about their day. They noted that bathroom accessibility is not always what it is meant to be, that they were often overlooked or stared at, and that curbs and sidewalks were unfriendly to the wheel of a wheelchair or the tip of a crutch. The caregivers were tired of waiting, worrying, helping too much or not enough, and feeling guilty for wanting space and time alone.

We spent the remainder of the afternoon acknowledging the students’ courage and recognizing the grace and good fortune of a healthy body. The students also learned some basic information that every health care provider needs to know: What is a disability? What is a handicap? What is “reasonable accommodation?” What else does the Americans with Disabilities Act say? What are the issues that arise in employment, finances, family dynamics, and a patient’s own sense of self? What are the stages of coming to terms with a chronic illness? Why is depression a common, treatable, coexisting process? How can physical therapy, occupational therapy, counseling, and rehabilitation medicine help? How can students and doctors help?

Chronic illness can be unpredictable, lasts a long, often unforeseeable amount of time, and resists most efforts at “cure.” Patients with chronic illnesses do not expect a cure. What they ask for is much less well defined and, therefore, much harder to teach young physicians in training. These patients want someone who seeks to understand not only their disease, but their experience of illness—the composite of the patient’s views, feelings, and responses to disease, and its effects on the patient’s life and the lives of those with whom they relate.

It was not until I myself became a patient facing the diagnosis of a chronic, unpredictable disease, multiple sclerosis, that I finally understood. It was through repeated experiences in the role of a patient, struggling to accept a body that seems to betray you, relinquishing control and having to ask for assistance with tasks that even a child can perform, having to redefine my role in a profession that I cherished, that I truly understood.

The path before us as medical educators is different now than it was several years ago. We must begin to focus on collaborative, integrated care for the chronically ill, including aspects such as communication and technological skills, ethics, diversity, pain control, nutrition, complementary therapies, spirituality, and most importantly, improved educational models. The time has come for medical educators to recognize these changing needs in educating our future physicians.

What I have seen is that my 14 students lingered past closing time, asking questions, sharing insights, and suggesting how to spread the word to their peers. Their evaluations were overwhelmingly positive. As they left, looking exhausted, I was energized. It was just a start, but for me it was enough to restore my faith that we can teach these skills and to inspire me to continue to press for similar programs in medical school curricula throughout the country.