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# AMA Journal of Ethics®

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#### FROM THE EDITOR

# Health Professionals with Disabilities: Motivating Inclusiveness and Representation

Medical schools seeking to increase representation of minorities in the profession have sought to improve matriculation and graduation rates of racial and ethnic minorities [1]. But one minority group whose needs remain neglected in the medical field is persons with disabilities.

Although 18.7 percent of the US population [2, 3] and up to 8.9 percent of US residents aged 18 to 24 self-identify as having at least one disability [4], less than 1 percent of medical students have disabilities known to school administrators. A study published in 2012 found that since 2001, only 0.56 percent of matriculating and 0.42 percent of graduating medical students have physical or sensory disabilities [5]. These data suggest that persons with physical, cognitive, or sensory disabilities face significant hurdles in entering, continuing, and completing training in health professional fields. Furthermore, physicians who develop disabilities after completing their training can have difficulty obtaining accommodations from their employers and consequently leave clinical practice for administrative, teaching, or corporate positions that do not require direct patient care, preventing patients with disabilities from benefiting from the experiences of physicians intimately familiar with the process of adapting their activities of daily living.

The goal of this issue of the *AMA Journal of Ethics*® is to discuss the importance of increasing representation of people with disabilities in the medical field and to outline some of the obstacles that health professionals and trainees encounter in pursuing or continuing medical practice.

Health professionals with disabilities have a wealth of knowledge about and experience in achieving goals through accommodations that could benefit patients with disabilities and diversify the health professions. Lisa I. lezzoni considers the positive impact that greater numbers of physicians with disabilities might have on <a href="health-outcomes for patients">health outcomes for patients with disabilities</a>.

One barrier to entering the medical profession that people with disabilities face is narrow interpretations of medical school technical standards—the description of motor, sensory, and cognitive capacities that medical school applicants and students are required to have in order to matriculate, advance, and graduate. Michael McKee, Ben Case, Maureen Fausone, Philip Zazove, Alicia Ouellette, and Michael D. Fetters propose

ways of refining and <u>updating technical standards</u> that focus on abilities rather than on limitations of medical students with disabilities.

Another barrier to entry into the medical profession is related to accommodations. Although the Americans with Disabilities Act of 1990 requires programs receiving federal financial assistance to provide "reasonable accommodations" unless doing so would pose an "undue hardship" [6], medical students with disabilities are often denied accommodations that they need in order to complete their medical education [4]. Samuel R. Bagenstos discusses this problem and examines the disability rights legislation that prohibits discrimination against qualified medical students with disabilities who request reasonable accommodations. However, medical school or residency program directors might be unfamiliar with how to handle requests for accommodations from trainees who either enter the program with pre-existing disabilities or who develop disabilities after their training begins. To guide the process of setting standards for applicants with disabilities and to assist faculty administrators and advisers, Joel A. DeLisa and Jacob Jay Lindenthal propose future research for improving our understanding of the needs of medical students and physicians with disabilities. Relatedly, Patricia M. Davidson, Cynda Hylton Rushton, Jennifer Dotzenrod, Christina A. Godack, Deborah Baker, and Marie N. Nolan discuss strategies for accommodating nurses, <u>nursing</u> students, and other health care professionals with disabilities in order to promote an inclusive and diverse health care workforce.

In addition to barriers posed by technical standards and obtaining accommodations, the courts' interpretation of disability under the Americans with Disabilities Act (ADA) of 1990 can affect whether a person with disabilities is covered under the ADA. A narrow reading of the ADA could mean that some people, including health professionals and trainees, are denied what they're entitled to under the law. Leslie Francis and Anita Silvers explore the evolution of the <u>definition of "disability"</u> in a policy context and discuss the benefits and ethical implications of flexible interpretations and applications of the concept of disability in the policy arena.

This issue also addresses challenges unique to medical students and professionals with specific disabilities. Michael Argenyi highlights the hurdles faced by premedical and medical students who are <u>deaf and hard of hearing</u> (DHoH) and considers some of the ethical implications of refining technical standards to allow for greater inclusiveness of DHoH individuals in health professions. Frederick Romberg, Bennett Shaywitz, and Sally Shaywitz examine dilemmas faced by medical <u>students with dyslexia</u> and propose ways to increase physician and faculty education about dyslexia. And in the podcast, Louise Andrew addresses some of the challenges encountered by <u>physicians with depression</u> and other disabling mental illnesses.

At the same time, this issue addresses the challenges posed by inevitable, age-related changes. The impact of aging on physicians' cognitive or physical abilities has led to concerns about ensuring safe and effective patient care without discriminating against physicians due to age. Krista L. Kaups considers this dilemma and discusses the ethical and practical implications of hospital policies that affect aging physicians. Peter Angelos addresses concerns specific to the surgical field in his discussion of a case of an aging surgeon who has experienced a decline in his ability to operate safely.

A significant proportion of the American population will develop a disability over the course of their lives, and health professionals are no exception. From a patient standpoint, increasing the representation of people with disabilities within the medical field has the potential to improve outcomes and clinical experiences. From the perspective of the medical profession, the obstacles encountered by trainees and physicians with disabilities not only limit diversity within the field but also unjustly limit clinicians with disabilities from practicing patient care. This issue of the *AMA Journal of Ethics* aims to illuminate these hurdles and contribute to the discussion of how health professionals and students with disabilities can be better integrated into health care service provision.

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#### **ETHICS CASE**

#### How Should Medical Schools Respond to Students with Dyslexia?

Commentary by Frederick Romberg, MD, Bennett A. Shaywitz, MD, and Sally E. Shaywitz, MD

#### **Abstract**

We examine the dilemmas faced by a medical student with dyslexia who wonders whether he should "out" himself to faculty to receive the accommodations entitled by federal law. We first discuss scientific evidence on dyslexia's prevalence, unexpected nature, and neurobiology. We then examine the experiences of medical students who have revealed their dyslexia to illustrate the point that, far too often, attending physicians who know little about dyslexia can misperceive the motives or behavior of students with dyslexia. Because ignorance and misperception of dyslexia can result in bias against students with dyslexia, we strongly recommend a mandatory course for faculty that provides a basic scientific and clinical overview of dyslexia to facilitate greater understanding of dyslexia and support for students with dyslexia.

#### Case

Dr. Miller is a senior physician and an influential administrator at a medical school. She is meeting with James, an incoming first-year medical student. James has dyslexia and requested to meet with Dr. Miller when he heard of her past efforts to try to help students with disabilities. James informs Dr. Miller that he was diagnosed with dyslexia after his fourth grade teacher noted his difficulty with reading and his parents arranged for him to be assessed by an educational psychologist. In grade school, he attended special reading programs to improve his reading and spelling skills. He studied twice as hard as his peers, received accommodations for extra testing time from grade school through college, and performed well in school exams.

By his junior year of college, James had maintained a GPA of 3.8 and excelled in clinical research in the Department of Radiology at his school's affiliated medical school, fueling his ambition to become a radiologist. He took the Medical College Admissions Test (MCAT) with accommodations and was accepted to his college's affiliated medical school, where he enrolled. Now a first-year medical student, James is struggling with the fear that his dyslexia will negatively impact his education, performance, and reputation among faculty and fellow students. He explains to Dr. Miller that he is worried that requesting accommodations could lead faculty and classmates to perceive him as less

capable of becoming a qualified physician. However, he knows that he would struggle to perform well in medical school without accommodations.

Dr. Miller realizes that James will likely suffer either way that she advises him. That is, either James must "out" himself to faculty and administrators if he is to use accommodations and thus risk being stigmatized, or he must remain silent about his disability and take his exams without accommodations to which he is legally entitled and risk performing poorly in his medical school coursework. Dr. Miller feels dismayed about this dilemma and wonders how her medical school's policies and culture can be reformed to advocate for students like James. Specifically, she has wanted to make her medical school's environment more accepting of students with disabilities for a few years now, but she's also aware that this might upset some influential faculty who are not supportive of this goal. Dr. Miller wonders what to do next.

#### **Commentary**

In our experience, James's history and current dilemma are quite common. Dyslexia was first reported in 1896 in the British Medical Journal by a physician, W. Pringle Morgan [1], and, since that initial report, major medical journals including JAMA, the New England Journal of Medicine, and the Journal of Pediatrics have continued to publish research furthering the scientific understanding of dyslexia [2-4]. Given the scientific progress in understanding the epidemiology, cognitive basis, and neurobiology of dyslexia, it is surprising that ignorance of the condition persists [5]; such ignorance continues to result in faculty misperceptions of dyslexia. For example, the very common and physiologically based symptom of slow reading in dyslexia can be misinterpreted as slow thinking; a resulting need for additional time on tests can then be misperceived as trying to game the system. Over time, accumulating misperceptions create a negative, though false, image that can marginalize and bring harm to the medical student with dyslexia, the medical school, and the medical school's faculty. We suggest that knowledge of dyslexia's scientific basis and resulting symptoms would improve the medical climate for students with dyslexia as well as the faculty and should be widely disseminated within and across the medical school community.

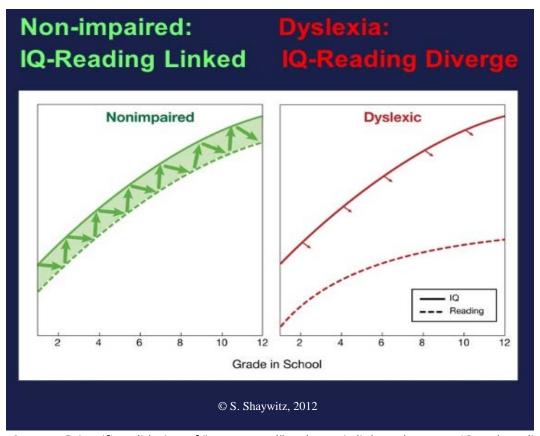
#### **Understanding Dyslexia**

To begin with, it is important to understand the critical difference between dyslexia and <u>learning disabilities</u>. In contrast to dyslexia, which is a highly specific condition, learning disabilities represent a more general, nonspecific category. To illustrate, the difference between learning disability and dyslexia parallels the difference between diagnosing a sore throat as an "infectious disease" which is nonspecific, or as "strep throat," which is highly specific and amenable to a targeted, evidence-based treatment, penicillin.

*Prevalence*. Dyslexia affects 20 percent of the US population [2, 6, 7]. It occurs crossculturally and knows no boundaries of language, geography, socioeconomic status, race,

ethnicity, or gender. To illustrate its cross-cultural nature, *Overcoming Dyslexia*, written by one of us (SES), has been translated into multiple languages, including not only alphabetic scripts but also logographic scripts such as Japanese, Korean, and Mandarin [8].

Definition. Although first described in the late nineteenth century, increasing scientific understanding of and interest in dyslexia has led to a twenty-first century definition of the condition, emphasizing that dyslexia is "an unexpected difficulty in reading for an individual who has the intelligence to be a much better reader" (italics added) [9]. Empirical evidence supports this definition. Ferrer et al.'s 2010 study [6] reports that, in typical readers, intelligence and reading are dynamically linked; over time, reading and IQ mutually influence one another. In other words, if someone is very bright, he or she can be expected to be a very good reader and, conversely, if someone is a very good reader, he or she is most often quite bright, (see figure 1, left panel). In contrast, in people who have dyslexia, IQ and reading are not linked and do not mutually influence one another (see right panel in figure 1). In other words, a person with dyslexia can be quite intelligent and yet not read quickly.



**Figure 1.** Scientific validation of "unexpected"—dynamic linkage between IQ and reading in typical readers and their divergence in dyslexia [6]. © 2012 by S. Shaywitz.

Awareness by faculty and students alike that in dyslexia there is a disparity between a person's often high intelligence (for example, as measured by the Wechsler Adult Intelligence Scale) and the same person's slow, effortful reading should be a powerful antidote to the mistaken belief that those who have dyslexia are not intelligent. Testifying before the US Senate Health, Education, Labor and Pensions Committee hearing on dyslexia on May 10, 2016, attorney David Boies, who is open about his dyslexia [10], commented on the disconnect between a person with dyslexia's ability to reason and analyze and that person's reading speed: "Success in life is not a function of how fast a person can read" [11].

Deficit in decoding. The first step in learning to read is mastering decoding, or breaking a word into its letter sounds. Decoding words is so hard for people with dyslexia because, at its core, dyslexia is a difficulty in phonology, i.e., appreciating the elemental sound structure of spoken language. In brief, the phonologic theory recognizes that speech is natural and inherent, but that reading is acquired and must be taught. To read, the beginning reader must connect the letters and letter strings (i.e., the orthography) to something that already has inherent meaning—the sounds of spoken language. In the process, a child has to develop the insight that spoken words can be pulled apart into the elemental particles of speech (i.e., phonemes) and that the letters in a written word represent these sounds; such awareness is largely deficient in children and adults with dyslexia [8]. As readers gain experience and continue to practice reading they develop reading fluency, the ability to read accurately, rapidly, and with good prosody. Reading fluency is of critical importance because it allows for the automatic, attention-free recognition of words.

Research has demonstrated that early interventions designed to improve the child's ability to decode words are helpful and will allow the child with dyslexia to become an accurate, but not a fluent, reader [12]. A person with dyslexia can be intelligent, even highly intelligent, and learn to read accurately and with good comprehension but, for physiological reasons, must read slowly and with some effort—that is, not automatically or efficiently. As a consequence, readers with dyslexia must focus their attention and concentrate very hard on the page in front of them. Assuming that medical school faculty members are aware that a student has dyslexia, understanding its impact should allow acceptance of the student's need for a separate, quiet room and extra time for test taking [8].

It is also well established that, when speaking, the person with dyslexia has difficulties in word retrieval—that is, the problem is not in conceptualizing what he or she wants to say but in the act of retrieving the specific words he or she intends to say [13]. The result is that a person with dyslexia may not be able to respond quickly to a question—even when he or she knows the answer. If attending physicians understood the symptoms and underlying neurobiological basis of dyslexia, they might be more supportive when

trainees who might have dyslexia are slow to retrieve the answer to a question. Unfortunately, in our experience, many physicians are not aware of scientific progress in dyslexia and know little about the condition. This, despite the fact that many extraordinarily accomplished physicians have—and are open about having—dyslexia [8, 14], including Delos "Toby" Cosgrove, cardiac surgeon and CEO of the Cleveland Clinic [15]; Beryl Benacerraf, professor of radiology at Harvard Medical School and international authority on prenatal ultrasonography [16]; Karen Santucci, professor of pediatrics at Yale Medical School and chief of the pediatric emergency department [17]; and Stuart C. Yudofsky, Distinguished Service Professor and chairman, Menninger Department of Psychiatry & Behavioral Sciences and the Drs. Beth K. and Stuart C. Yudofsky Presidential Chair in Neuropsychiatry at Baylor College of Medicine [18].

#### Misunderstanding Dyslexia

As James's situation demonstrates, the medical student with dyslexia is frequently faced with what seem to be two very poor choices: if the student self-identifies as having dyslexia and asks for what he physiologically requires—the accommodation of extra time—his instructors and other students might think he is not very smart or is trying to game the system. However, if the student does not self-identify, he will not receive accommodations to which he is entitled by law and will not be able to demonstrate his knowledge. In what follows, we draw anecdotally upon quotations from trainees we've met over the years at various medical schools. Below we quote one trainee's reflections on what an attending physician in internal medicine wrote on his evaluation after he told the attending physician he had dyslexia, "Bob (a pseudonym) should really think before telling people he's dyslexic. He shouldn't expect to be treated any different from anybody else."

My attending was thinking that I was trying to get around something, that if I knew the material I shouldn't have to say I was dyslexic. She missed the point and was not understanding that sure, I could learn but had a different style of learning, for example, requiring more time to read the materials. Clearly, my attending did not understand anything about dyslexia.

Requests for accommodations often bring out such comments. Another student with dyslexia shared the following:

"Wait a minute, why is he getting extra time? Why is he getting to take the test in a separate room?" With the accommodations, there was a definite palpable and often voiced perception that I was trying to gain an advantage. In the first two years, I wished the professors understood more about dyslexia. For all the hard work just to be on a level playing

field and then to be kind of critiqued for that, that was a little bit frustrating.

Revealing one has dyslexia also affects one's relations with other students. As another physician with dyslexia recalled, "My medical school had student-based learning so once I revealed my dyslexia, the other students would shy away or try to—they didn't want it to be perceived that they were associating with me. They acted like somehow I was holding them back, not wanting the 'slow' learner to hold them back."

Basic knowledge of dyslexia such as its negative impact on word retrieval would have made a major difference for another medical student with dyslexia who was traumatized by an attending physician who knew about her dyslexia. Here is how she described her experience to one of us (BAS):

One of the low points was being grilled by a surgeon who just did not give me any time to answer. If I didn't answer quickly enough, he assumed that I didn't know. I remember this surgeon asking me a question and before I could respond, he smiled in a kind of smirky way and said, "You just don't know that, do you?" A lot of the evaluation in this rotation is done on the fly. People who were more glib were thought of as knowing the content even if their knowledge was more superficial.

For a physician with dyslexia, in our experience, internship and residency can be better than medical school. As one physician with dyslexia recalled, "Residency is less an evaluative process and more doing the job. In residency you just focus on the patient—your evaluation depends on how well you took care of the patient and not how quickly you answered a question."

In a perfect world, a student who has dyslexia should not have any conflict or concern about sharing that he or she has dyslexia and, with it, requires certain accommodations. This perfect world depends on the medical school culture, specifically whether those faculty physicians with whom the student will be interacting understand dyslexia, its neurobiological basis, and its impact on the student. In such an ideal world, the medical school environment would be accepting and supportive of dyslexia. However, as we have seen with the cases discussed here, each of the students told their attending faculty physician that he or she had dyslexia, and suffered negative consequences. Disappointingly, in each case, which involved the most common symptoms of dyslexia (i.e., slow reading, word retrieval difficulties), the attending faculty physicians reacted negatively, either indicating that the student was using dyslexia as an excuse to receive special treatment, showing resentment towards the student, or chastising the student for not responding quickly enough to questions. In addition, in this case and in the cases of the students quoted above, it was not only attending faculty physicians but also other students who misinterpreted the student with dyslexia's slow reading as reflecting low

intelligence. All of these reactions are expressions of a disappointing lack of awareness about dyslexia, the scientific progress made in understanding dyslexia, and the impact of the condition on the person with dyslexia—reactions all the more disappointing because they occurred in a medical school environment where science is highly valued and science and research are a major focus. Each of these students worked extremely hard and, even with the difficulties described, were unanimous in sharing that if they could do it all over again, without question, they would still not hesitate to disclose their having dyslexia.

The quoted medical students, who had all previously taken high stakes standardized tests with accommodations, were aware of their absolute requirement for accommodations, as, no doubt, is James. The students noted, too, the great positive difference made by the occasional attending faculty physician who had a deep understanding of dyslexia or who had dyslexia him- or herself. And although at times medical school was quite stressful, each of the quoted students did graduate. Two of the students are now in residency programs, while two others successfully completed their residencies, passed their specialty boards (with accommodations), and are engaged in successful medical practices.

Simply put, there is really no choice for a medical student with dyslexia but to disclose. Without accommodations, especially extra time for tests, the tests would be a reflection of the student's disability rather than his or her knowledge of the subject matter. Given this situation—the lack of understanding within a medical environment of what is, after all, a medical condition—there are possible solutions, discussed below.

#### **Changing Medical Culture**

What should be done to change medical schools' policies and culture to be more accepting of students with dyslexia? Medical students with dyslexia we have known have suggested a mandatory, required short course for faculty that would provide a basic scientific and clinical overview of dyslexia, which could better enable faculty physicians who take the course to be supportive of students with dyslexia. A key emphasis of this course would be understanding that dyslexia is not slow learning and that a request by a student with dyslexia for extra time to complete a test is not an attempt to gain an advantage over other students but, instead, to ensure that the results of the examination reflect the student's ability rather than his or her disability. Students with dyslexia are legally entitled to, for example, the accommodation of extra time, which levels the playing field so that these students are able to demonstrate their knowledge.

Physicians with dyslexia, such as Karen Santucci who heads the pediatric emergency department at Yale School of Medicine, will tell you that, while she reads slowly, she thinks quickly and is able to provide immediate excellent care to a full range of her patients in her emergency medicine practice [17].

When one of us (SES) was applying to medical school, a dreaded question (addressed only to women) during an interview was, "What are you going to do about having a family?" Fortunately, for many years now, medical schools have been forbidden by law to ask this and other discriminatory questions. Specifically, for purposes of admission, medical schools cannot inquire whether an applicant has a disability, including dyslexia, and cannot ask whether he or she received testing accommodations for a disability, including dyslexia, during college or medical school [19]. Once an applicant has been admitted, then medical schools may inquire whether admitted students require any modifications to policies, practices, or procedures to accommodate a disability [20-22]. "Flagging policies that impede individuals with disabilities from fairly competing for and pursuing educational and employment opportunities are prohibited by the ADA" [23]. The revised final regulations for implementing Titles II and III of the ADA recognize explicitly that flagging test scores to indicate that an exam was taken with a testing accommodation is prohibited by the ADA and can lead to bias and unjust discrimination against applicants, who may choose to forgo the accommodations to which they are entitled by law out of fear of these negative consequences [23]. It should be up to an individual applicant or student to decide whether to disclose such information. According to the law, medical schools and residency programs cannot refuse to offer accommodations to students with dyslexia [24]. If a person has been diagnosed with dyslexia, he or she is entitled to accommodations. A student can be successful—he or she does not have to fail—to be eligible for and receive accommodations, a point emphasized by Congress in passing the ADA Amendments Act in 2008 [24, 25].

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#### **ETHICS CASE**

How Should Colleagues Respond to Diminishing Capacities of an Aging Surgeon? Commentary by Peter Angelos, MD, PhD

#### **Abstract**

When an esteemed elderly colleague needs assistance completing procedures safely, fellow health professionals have the responsibility to respond in order to mitigate risk to patients. There is a strong ethical basis for bringing the surgeon's declining capacity to his or her attention as well as to the attention of others. Ongoing capacity assessments could be one method for tracking diminished capacities among surgeons so that they can stop practicing surgery before putting patients at risk.

#### Case

Dr. Roberts is a revered 70-year-old general surgeon at a major university-affiliated hospital, where he has been practicing surgery for almost four decades. He has mentored many generations of surgeons, including his junior colleague Dr. Patel, a 39-year-old surgeon who completed his residency four years ago. Because Dr. Roberts trained and advised him throughout medical school and residency, Dr. Patel holds his long-term mentor in high esteem.

In the last few months, Dr. Patel has realized that more of Dr. Roberts's patients have been experiencing postsurgical complications than in the past and that his laparoscopic surgeries have resulted in patients bleeding more than usual, which has in turn led to those patients' need for transfusions. Furthermore, Dr. Roberts has been losing dexterity and endurance during long procedures and has relied increasingly on Dr. Patel and other junior colleagues to step in to finish operations. Recently, Dr. Roberts even started falling asleep near the end of a long procedure, and Dr. Patel and a resident had to quickly step in to keep the patient safe. Numerous colleagues of Dr. Roberts have also noticed decline in his performance, but they are reluctant to discuss their concerns due to their regard for their long-term mentor.

While Dr. Patel feels that he is obligated to address his and his colleagues' concerns, he is not sure whom to approach or what to do.

#### **Commentary**

An aging academic surgeon who has been a pillar of his department is getting older and his abilities are diminishing. His colleagues have had to step in to ensure his patients'

safety. In my experience, the scenario described is unfortunately all too familiar in American surgery. Evidence suggests that <u>surgical performance declines with age</u>. For example, older surgeons' patients have higher mortality rates than younger surgeons' patients for carotid endarterectomy [1, 2], pancreatectomy, and coronary artery bypass grafts [2], although the effect is small and contributed by older surgeons with low procedure volumes [2]. Moreover, there are a large number of aging surgeons: approximately one-third of all practicing surgeons are over age 55 [3].

It is sad to see a master surgeon like Dr. Roberts decline in skill and endurance, but it is an inevitable consequence for all aging professionals. Indeed, one study found that though surgeons performed better than the general population on tests of psychomotor function, they exhibited expected age-related declines [4]. And there is some evidence that declines in psychomotor function are greatest for those aged 70 and older, like Dr. Roberts, as another study found that only 38 percent of practicing surgeons 70 and older performed within the range of younger surgeons on psychomotor tasks compared with 78 percent of those aged 60 to 64 [5]. If Dr. Roberts cannot do surgery safely, he should not be operating, but he might still have much to offer in teaching and mentorship. For example, as acknowledged in the American College of Surgeons's "Statement on the Aging Surgeon," "Surgeons relinquishing clinical roles can contribute significantly to teaching, surgical assisting, research, or administration. If their abilities permit, and if they are willing, they should be given opportunities to contribute to these areas" [3].

Nearly every surgeon can identify specific teachers who have played major roles in their education and surgical practice development. Positive mentors and role models, while important in all aspects of medical education, are perhaps more important in surgery than in any other field in influencing career choice [6, 7]. Moreover, surgical education relies heavily on the apprenticeship model, in which trainees observe a limited number of faculty performing a great many surgeries [8]. In my experience, if I ask almost any surgeon why he or she performs an operation in a particular fashion, almost inevitably some part of the answer will include that "I trained this way" or that "Dr. so-and-so did it this way." Often how surgeons do things in the operating room is not grounded on any particular evidence-based benefit. This is not to suggest that there is no evidence to support operative techniques, but rather that the small individual differences in technique might not be evidence-based. Instead, surgeons rely on their own experience with a technique and the outcomes that they have seen follow from using a technique repeatedly over time. Indeed, evidence suggests that practicing surgeons tend to rely more on their own judgment and journal summaries of the latest research than on clinical practice guidelines [9], although efforts are being made to incorporate evidencebased medicine into surgical education [10].

Because of the nature and scope of the influence of the apprenticeship model, it can be difficult for surgeons to be critical of their teachers, mentors, and role models, even

when patients are sometimes put at risk, as this case illustrates. Nevertheless, as professionals, surgeons must exercise the same level of <u>self-regulation</u> that all physicians in other specialties in medicine are expected to uphold. By agreeing to care for patients, all health care professionals are obliged to try to maximize benefits to them and minimize their risks of being harmed. From this ethics perspective, if a surgeon sees another surgeon putting patients unnecessarily at risk due to his or her diminished physical capacities, he or she has clear ethical responsibilities. The surgeon (whether attending, fellow, or resident) must immediately act to protect the patient [11], in this case, by attempting to bring the operation to a safe conclusion. However, the scope of responsibility does not end there. The surgeon who intervenes (in this case, Dr. Patel) also must communicate with the impaired surgeon about what has happened and why it was necessary to step in. Allegiance to an esteemed colleague should never stand in the way of patient safety. Finally, physicians have an obligation "to report a physician who seems to be impaired to an appropriate authority" [12], so Dr. Patel has an obligation to report Dr. Roberts to the chief of staff or chair of surgery.

# When and How Should Colleagues Intervene, and Which Ethical Values Can Help Colleagues Deliberate?

There is no doubt that telling a highly regarded senior colleague that he or she is putting patients in jeopardy is a challenging task. However, we should assume that any ethical surgeon would want to know if he or she was putting patients at increased risk due to diminished skills—physical and cognitive—or endurance. Since physicians have been shown to have a limited ability for accurate self-assessment [13], aging surgeons might not realize that their capacities have declined to the point where patients are being put at risk—as appears to be the case with Dr. Roberts, who "started falling asleep near the end of a long procedure." Yet there is evidence of a relationship between surgeons' selfperceived cognitive decline and retirement status [4], which suggests that those who are aware that they are no longer able to meet the level of safe, high-quality care that patients need take steps to ensure that patients are not put at risk. If surgeons can be supplied with objective evidence of their declining capacities—such as higher complication rates or worse outcomes—they might be more willing to respond positively. For example, Dr. Roberts could limit his practice to shorter, less technically demanding surgical procedures and refer patients for more challenging procedures to his associates in the department.

What should be done when a surgeon is not willing to step back from the operating room, even after being presented with evidence that patients are being put at risk? In these circumstances, his or her colleagues—and particularly if the risk is not imminent, the chair of surgery or chief of the section—have a professional responsibility to intervene. This responsibility is part of the implicit <u>social contract</u>; it is required of surgeons in return for the profession's autonomy and ability to self-regulate [14]. Much as the American Board of Surgery or any other surgical specialty board certifies that a

surgeon has the requisite skill and judgment to practice surgery, each surgical department chair has a similar duty to ensure that surgeons who practice in his or her group are able to care for patients in a safe fashion and to act if notified of incompetence [15].

How should a surgical department chair intervene with an aging surgeon whose capacities have declined? Perhaps the most important aspect of the interaction would be to emphasize that declining skill, dexterity, and endurance—while they could be putting patients at risk—are not evidence that a surgeon can no longer contribute to a department or group in other capacities. Dr. Roberts clearly should not be doing all of the operations he has been doing, but he likely has much that he still can offer a department of surgery. The accumulated experience of a senior surgeon can be invaluable in helping to educate and mentor younger surgeons and students, long after the surgeon has given up operating [3]. Some surgeons may measure their self-worth in terms of their ability to operate. Yet the cognitive aspects of surgical practice—including planning, decision—making, and error-detection—are difficult to teach. Such training promotes surgeons' efficient learning and accurate execution of skills [16]. This is one area where an experienced senior surgeon may be able to make significant contributions even after he or she stops operating.

As an academic surgeon (and one who is clearly aging), I can anticipate the rebuttal to some of the statements above. For example, someone might ask, "What about the master surgeon who started at a level of skill and experience far above his or her peers? Even with a decline in capacity, he or she may still be able to practice surgery at very high levels." Certainly this is true of some surgeons. And, in some cases, a declining experienced surgeon could be safer than, say, a young inexperienced surgeon. However, the level of surgical care can never fall below the minimal threshold for safety. Unfortunately, it can be difficult to know when an aging surgeon is approaching this minimum threshold. Open questions remain: When does "decline" become "impairment"? And when does "impairment" compromise safety?

Additionally, how should minimum thresholds be defined and established, and by whom? Might patients define this differently than surgeons? Perhaps a key ethical indicator is the value of *transparency*. That is, if you were a patient, would you want to know that this surgeon is, in the eyes of his colleagues, declining in capacity and ability? When the answer is "yes," this can change the ethical significance of surgeon's colleagues' responses to knowing about an unsafe or potentially unsafe situation. Because surgeons peak at different levels of skill and dexterity, age alone is not a good measure of decline. We all know that physical and mental capacities decline at different rates in different people as they age [17]. Ideally, however, intervention should happen long before a surgeon falls below the minimum threshold of safety to avoid putting patients at risk.

#### **Monitoring Surgeons as They Age**

Could surgeons' declining capacities be monitored to protect patients from harm without removing capable surgeons from clinical activities? One way to accomplish this goal is a formal evaluation of physical and cognitive skills, such as that offered by the Aging Surgeon Program [18]. Yet there is evidence that surgeons do not change their practice in response to objective assessments [4]. Another way to answer this important question would be to gather data on young surgeons' manual dexterity, physical endurance, and clinical judgment using objective instruments; follow each surgeon over time to document individualized trajectories of surgical capacity and endurance over time; and then make that evidence available to the surgeons whose data was collected. Although the question of when to intervene would still remain, if data for all surgeons had been gathered, for a given surgeon, objective evidence, over time, that a decline in surgery-related skills was taking place might be enough to prompt more introspection and self-awareness. If the evidence does not prompt an individual surgeon to take proactive steps when declining capabilities become evident, this data would also be a valuable source of objective evidence if surgical leaders in the department or section needed to intervene. Of course, reliable assessment tools would first need to be created and validated for this purpose.

It might seem naïve to believe that surgeons would voluntarily limit their practices if they knew that their capacities had significantly declined. However, much as we depend on the professionalism of surgeons to maintain their continuing education so that their patient care improves with our data, we also need to depend on surgeons to take seriously their ethical responsibility to ensure that they can safely care for every patient who seeks their care.

Although it may be difficult for Dr. Patel to discuss his concerns with his mentor, Dr. Roberts, the responsibility that all physicians have to protect patients requires him to do so. In addition, the prior relationship between Dr. Patel and Dr. Roberts should further enable Dr. Patel to intervene to preserve Dr. Roberts's reputation as an excellent surgeon. If Dr. Roberts is unwilling to voluntarily alter his practice to avoid putting patients at risk, Dr. Patel's duty to future patients requires him to notify departmental leadership to compel the limitation of Dr. Roberts's surgical practice. Undoubtedly, such a circumstance would be a tragic end to a surgical career, but one that is necessary to protect patients as well as the integrity of the surgical profession.

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#### **MEDICAL EDUCATION**

Medical Schools' Willingness to Accommodate Medical Students with Sensory and Physical Disabilities: Ethical Foundations of a Functional Challenge to "Organic" Technical Standards

Michael McKee, MD, MPH, Ben Case, Maureen Fausone, Philip Zazove, MD, MM, Alicia Ouellette, JD, and Michael D. Fetters, MD, MPH, MA

#### Abstract

Students with sensory and physical disabilities are underrepresented in medical schools despite the availability of assistive technologies and accommodations. Unfortunately, many medical schools have adopted restrictive "organic" technical standards based on deficits rather than on the ability to do the work. Compelling ethical considerations of justice and beneficence should prompt change in this arena. Medical schools should instead embrace "functional" technical standards that permit accommodations for disabilities and update their admissions policies to promote applications from qualified students with disabilities. Medical schools thus should focus on what students with disabilities can do, rather than what they cannot do, because these students further diversify the health care profession and improve our ability to care for an expanding population of patients with disabilities.

#### Introduction

Enacted over 25 years ago, the Americans with Disabilities Act (ADA) promotes social justice by protecting people with disabilities (PWDs) from discrimination and prejudice; giving them fair access to goods, services, and education; and promoting equal opportunity [1]. The ADA was intended to ensure fairness and equality of opportunity for PWDs, including those with sensory and physical disabilities. Among other things, the ADA prohibits institutions of higher education from discriminating against a qualified person on the basis of disability in admission or recruitment and requires entities that must comply with the law to make reasonable accommodations in order to afford an otherwise qualified applicant an equal opportunity to participate in the institution's programs [2]. "Reasonable accommodations" include modifications that do not fundamentally alter an academic program, such as changes in the length of time to complete a degree or in the way a course is conducted [3]. But "academic requirements that . . . are essential to the instruction being pursued by such [otherwise qualified]

student or to any directly related licensing requirement will not be regarded as discriminatory" [3].

Unfortunately, equal opportunity for medical students with sensory and physical disabilities (SWDs) has not been realized. Roughly 19 percent of America's noninstitutionalized population has a disability [4, 5] compared to less than 1 percent of medical students [6] and 2-10 percent of practicing physicians [7]. Yet accommodations—both technical (e.g., amplified stethoscope) and nontechnical (e.g., sign language interpreter)—are now widely available, effective, and used [8]. How can this discrepancy be explained?

Research suggests that a critical barrier to matriculation of SWDs in medical schools is the schools' posted technical standards (TS) [6]. These are used to assess the qualifications of SWDs for the study of medicine [9]. However, many medical schools' TS—which emphasize sensorimotor functions over cognitive abilities—effectively preclude SWDs from being admitted to medical school [10], despite many compelling examples of successful physicians with disabilities [11-15]. The schools' TS pose a barrier because they "do not support provision of reasonable accommodations for students with disabilities as intended by the ADA" [16]. This, in turn, has resulted in legal interventions by SWDs to require schools to comply with the ADA and provide reasonable accommodations. For example, a federal court recently ordered Pacific Northwest University of Health Sciences to re-enroll a deaf student, finding that the reasonable and necessary accommodations of a sign language interpreter and captioning services would not alter the nature of the program and cause an undue burden on the school, and that the school's concerns of patient safety were unfounded [17, 18]. These restrictive practices have affected persons with hearing [19, 20], mobility [14], and visual [21, 22] disabilities.

With the aim of promoting greater inclusiveness, the objective of this paper is to provide information about TS, challenge assumptions underlying "organic" TS, propose the use of "functional" TS [13, 23, 24] as an alternative to organic TS, and offer ethical justification for a policy of inclusivity for SWDs.

#### **Organic and Functional Technical Standards**

The Association of American Medical Colleges (AAMC) provided TS guidelines in 1979 and 1993 [25] to aid medical schools' ability to assess SWDs' qualifications for the field of medicine. However, the specific TS language is left up to each school's admission committee to determine. Consequently, schools vary widely in how TS are incorporated, implemented, and made available. Many TS are vague and not clearly presented in the school admission materials or on schools' websites [6].

We propose that one way to evaluate medical schools' TS is to categorize them as either

organic or functional. Organic TS highlight students' limitations or deficits rather than their abilities. Thus, organic TS require students to demonstrate certain physical, cognitive, behavioral, and sensory abilities without assistance (e.g., for hearing, TS may require the student to be able to hear at a certain decibel without assistance). Functional TS, on the other hand, focus on the students' abilities with or without the use of accommodations or assistive technologies. For example, for hearing, the student must be able to acquire the necessary information by hearing or other means. The <u>functional TS approach</u> allows SWDs to use rapidly developing, cutting-edge assistive technologies and accommodations to successfully perform essential tasks. Currently, the majority of US medical schools use organic TS [6].

#### Functional Challenge to the Justification for Organic Technical Standards

Organic TS are likely based on at least three assumptions: potential risks to patient safety posed by accommodations, accommodation costs, and ensuring performance standards such that graduates can pass licensure exams without accommodations [26, 27]. All three arguments, however, lack empirical support.

Patient Safety. Patient safety concerns are based on fear that patients could be endangered due to a physician's disability, such as an inability to respond appropriately to emergencies in a timely or standard fashion [28]. However, SWDs are typically keenly aware of their limitations and develop communication and accommodation strategies that are practical in different environments and satisfy different needs [11, 12, 14, 15]. Furthermore, emergencies in clinical settings are rarely addressed by a single health professional, but more commonly by a team whose members each fulfill a different role. Hence a person with a mobility disability would not need to be able to intubate a cardiac arrest patient, for example. Many schools also have clinical simulations in which students can conduct "real-life" emergency scenarios that allow them to identify and refine any accommodations needed for actual emergencies. Despite concerns about patient safety, not a single legal case known to the authors has been filed in which patient harm resulted from an accommodation provided to an SWD.

Cost. Accommodations vary in type and cost. The ADA does not permit cost to justify discrimination practices against SWDs [6, 25]. Medical schools are ultimately responsible for paying for reasonable accommodations (though many do not acknowledge this, and some wrongly place this burden on the SWDs in their TS) [6]. Although costs vary tremendously, it should not be assumed that all accommodations are prohibitively costly [1]. Accommodations and assistive technologies rapidly change, and SWDs and PWDs can work with schools and disability offices to identify appropriate, cost-effective accommodations, which are listed and periodically updated on websites that focus on this issue [29-31].

Passing licensure examinations. A prevailing misconception is that incorporation of accommodations into licensure exam environments lessens licensure exams' efficacy in ensuring that performance standards are met [6, 28]. The assumption that graduates with disabilities *should* be able to pass licensure exams without accommodations despite the fact that they are entitled to them by law—is problematic. Licensure exams (e.g., United States Medical Licensing Examination®), objective structured clinical exams, and continuing medical education exams are required to comply with the ADA, including providing appropriate accommodations [28, 32] such as sign language interpreters, extended test times, and enlarged print sizes. Providing required accommodations thus complies with the law. From a practical perspective, such accommodations help maximize the independence of SWDs and have been implemented by a number of successful physicians with disabilities in their practice. Hence, the incorporation of accommodations into licensure exam environments is similar to the use of accommodations during the SWDs' medical school training and beyond. These accommodations do not "advantage" SWDs but rather provide a tool to maximize their functional capacity that they may not have otherwise [33]. Furthermore, since SWDs use accommodations during their training and medical practice, the licensure exams assess the SWDs' medical performances more accurately when SWDs are allowed to have their accommodations. From an ethical perspective, proscribing accommodations during licensure exams violates the ethical principle of social justice, as it systematically disadvantages a population of students who have the intellectual capacity to perform but need assistive devices to maximize their functional capacity. Hence, legal, practical, and ethical perspectives all support permitting accommodations during testing.

Organic TS thus cannot be justified on the basis of patient safety, accommodation costs, or licensure exam procedures as indicators of performance standards. Moreover, organic TS do not reflect the advancement of assistive technology and available accommodations that permit SWDs to be able to complete essential tasks in the field of medicine. Accordingly, we propose the use of functional TS instead of organic TS to ensure equity and justice.

Transitioning to a functional TS approach will require several steps. Deans should charge their admissions committee to take a functional approach by collaborating closely with the campus office for students with disabilities to articulate available and feasible accommodations for various applicants, rewrite their TSs accordingly, and update school websites to be supportive of SWDs. Medical schools should be familiar with disability-based student or health care provider organizations [34-37]. These organizations are a great source of information on best approaches for overcoming certain limitations, avenues for advocacy and mentorship, access to a network for individuals with disabilities, and at times they serve as a resource (e.g., by helping to find sign language interpreters). The Association of American Medical Colleges (AAMC) also should reiterate the expectation voiced by the organization's previous president, Jordan Cohen, that the

medical student population should more closely resemble the makeup of the patient population [38]. Finally, but not least, having a dedicated champion for SWDs at each medical school (probably from the diversity office) would provide a resource for both students and the school and ensure that appropriate attention is given to this issue.

#### Ethical Justifications for a Policy of Inclusion

Social justice considerations, as introduced above, provide a compelling ethical justification for schools to accommodate SWDs [39]. First, the acceptance and graduation of SWDs helps ensure fair access for patients with disabilities to physicians like themselves, since data show that minorities, including people with disabilities, are more likely to serve those of similar backgrounds [40-42]. Second, PWDs represent an underserved health population due to poor communication, lack of physical access, and reduced health knowledge, for example [39, 43]. Increasing the numbers of medical students and physicians with disabilities—who are more likely to serve PWDs—improves access to care for this population. Third, accommodating qualified SWDs promotes equal opportunity in matriculating and eventually practicing medicine. SWDs will benefit from personal and professional satisfaction, status, and job security in pursuing the profession of medicine. The former president of the AAMC, Jordan Cohen, emphasized that it is a "simple matter of social justice and equity" that our health care professional community mirror society also in the inclusion of physicians with disabilities [38].

Beneficence, the ethical imperative to do good for others, provides ethical justification for schools to accommodate SWDs. SWDs and physicians, due to their life experiences with disabilities, can effectively serve patients with disabilities who face medical issues [39, 41]. Students and physicians with disabilities better understand and empathize with PWDs than physicians without disabilities [39, 41]. A diverse population of physicians and students—including those with disabilities—benefits health care training and work environments by introducing new strategies for engaging with, and caring for, both general patients and PWDs [42]. While previous research has demonstrated the importance of diversity and inclusion of clinicians with disabilities in the health care workforce [39, 41], our personal experience and that of other faculty is that disability awareness and disability health training remains a weakness in most schools' curricula [44-46]. Actively increasing the number of SWDs—by not discriminating against them in the admissions process and after they matriculate—will likely result in students and physicians with disabilities who not only provide patients with clinicians who have a deep understanding of disability health but also contribute to educating fellow clinicians and students on disability-related health issues.

#### **Conclusion**

In short, the use of organic TS raises ethical problems from social justice to beneficence considerations. Schools should transition to functional TS and accommodation policies

that encourage applications from SWDs. Organic TS are outmoded in today's world of extensive technical and nontechnical accommodations, while functional TS use technical solutions and accommodations to help SWDs safely deliver patient care. Focusing on what SWDs can do, rather than on what they cannot do, results in two outcomes. First, it helps dispel current myths that SWDs are unable to meet the demands of medical school and medical practice, thus realizing the legal and ethical imperative for social justice embodied in the ADA. Second, it benefits society by providing patients with physicians who are like them, thus improving patient outcomes.

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#### STATE OF THE ART AND SCIENCE

**Learning from Physicians with Disabilities and Their Patients**Joel A. DeLisa, MD, MS, and Jacob Jay Lindenthal, PhD, DrPH

#### **Abstract**

Although progress has been made in diversifying medical school admissions and faculty, this has not extended to physicians with physical disabilities. To improve our understanding of medical students and physicians with physical and sensory disabilities, the authors propose systematically gathering information on the needs and experiences of four groups: physicians who had disabilities before beginning practice, physicians whose disabilities were incurred during their medical careers, physicians drawn from those two groups, and patients of physicians with disabilities. It is hoped these data would be used by counselors, administrators, and admissions committees in advising medical school applicants with disabilities and in revising institutional policies with a view to increasing matriculation and graduation rates of medical students with disabilities.

#### Introduction

Research has long supported the inclusion of persons with disabilities in the medical profession. Three decades ago, Stanley F. Wainapel reported the results of a survey among physicians with disabilities, whose physical condition was sufficiently severe to have affected their professional life [1]. Selection bias has suggested that those with more severe disabilities, e.g., visible functional deficits, were included among the respondents. With three of four respondents employed, Wainapel argued that medical schools and vocational counselors should bear in mind that disabilities are not necessarily incompatible with a medical career [1]. Two decades later, Joel A. DeLisa and Peter Thomas [2] advanced the case for inclusion of people with disabilities in the medical profession, arguing that the social matrix of medical practice coupled with the increased curricular emphasis on cognitive skills rather than motor skills and on the capacity for clinical judgment, strongly suggested "a need to reevaluate the goals and expectations of medical education and residency training" that pose barriers to applicants with disabilities [3]. Consistent with this recommendation, a survey of medical students, residents, and attending physicians found that the majority of respondents placed a higher value on communication skills than on motor skills [4].

While medical societies and society at large do support physicians with disabilities already in practice who wish to continue practicing medicine, the rates of matriculation and graduation of medical students with physical and sensory disabilities remain low [5]. Although about 20 percent of the US population has a disability [2, 6], only 0.56 percent of medical students who were enrolled between 2001 and 2010 had a physical or sensory disability at matriculation [5]. The cost of accommodations and medical schools' technical standards, which tend to emphasize motor over cognitive skills, are the most common reasons that applicants with disabilities cite for not attending medical school [6]. The immediate future thus does not portend well for students with disabilities, despite the opening of new medical schools [7] and the increase in medical school class size [8].

There remain two obstacles for these students to enter medical practice: (1) getting into medical school and (2) becoming a resident. In the first case, the largely unspoken standard of the "undifferentiated physician"—that is, the requirement that all medical school students be able to practice any medical specialty upon graduation—imposes standards that any student might have difficulty meeting. Despite the legal requirement for educational institutions receiving federal financial assistance to provide "auxiliary aids and services" to ensure effective communication [9] and for common carriers and the federal government to provide communications services for the DHoH [10], as set forth in the Americans with Disabilities Act, many medical schools' technical standards do not explicitly support accommodating disabilities [11]. Such technical standards continue to focus on incapacity rather than on preserved capacity [12]. Furthermore, these standards are not in keeping with current technological achievements to accommodate students with disabilities [11]. Another potential obstacle to matriculation faced by applicants who had taken the Medical College Admissions Test® (MCAT) with accommodation for a disability was that, until late March of 2015, their MCAT scores were marked with an asterisk [13, 14]; this indicated to anyone reading those applicants' American Medical College Application Service dossiers, including medical school admissions committee members, that a particular applicant probably has a disability. With regard to residency positions, Medicare funding has been capped at 1996 levels [15], making it even more difficult for students with disabilities, who remain a low priority for filling resident slots.

To address these two obstacles, DeLisa and Thomas argued for a "well controlled, formal epidemiologic survey... to accurately ascertain the prevalence of all degrees and types of physical disabilities among practicing physicians and medical students, as well as the effects of such disabilities on medical practice" [3; citing 16]. More recently, Sarah Eickmeyer and colleagues called for "a longitudinal study of matriculating students with disabilities ... to better understand the reasons underlying ... lower apparent graduation rates and to improve our understanding of the supports and accommodations needed to facilitate the success of students with PSDs [physical and sensory disabilities]" [17].

# Proposal for Collecting Data on Physicians with Disabilities

We recommend that information be gathered systematically over the life cycle of four groups: (1) physicians who had disabilities before beginning practice; (2) physicians whose disabilities occurred during the course of their medical practice careers; (3) physicians drawn from among those two groups; and (4) patients of physicians with disabilities. Physicians in the second category constitute the majority of physicians with disabilities and could serve as rich sources of information about the challenges they encounter [18]. Specifically, we recommend that information be gathered on physicians with disabilities' physical space and technology use and needs, self-reflections on accomplishments and regrets, willingness to adapt to the demands of practice, and their patients' views on care they provide; the goal of gathering this information is to learn how to better support physicians with disabilities and increase their representation in the profession.

Technologies. Modified means of transportation such as buses with lifts and cars fitted with modified driving controls, automated doors, and specialized computer controls among many other assistive devices can help maximize the potential of persons with disabilities [12]. Rapid advances in technology, such as adjustable patient examination tables, reachers, and robotic devices can also expand the capability of physicians with disabilities to deliver care. Rory Cooper and colleagues have described several emerging areas of development relevant to persons with disabilities, including assistive and coaching technologies, robotic-assisted therapy, and personal mobility and manipulation technologies [19]. We should, in the interim, learn from physicians with disabilities what their strongest needs are and how we can best use current and potential technology to assist them.

Self-reflections on accomplishments and regrets. Because performance and quality of care are linked, self-assessment can be valid [20]. Here we discuss two types of self-reported data that might be collected. Philosophical reflections of physicians with disabilities should be of more than passing interest. Stephen Hawking urged others with disabilities to "concentrate on things your disability doesn't prevent you doing well, and don't regret the things it interferes with" [21]. We should continually seek to determine how the practice of medicine both provides a sense of meaning and accomplishment in the lives of persons with disabilities and helps them extinguish perceived limitations. For example, we should learn how a disability can serve as an asset in the management of patients with disabilities—and of all patients. We should also learn more about any regrets a physician with disabilities might have about having become a physician. Would he or she have chosen the same profession or perhaps another specialty? Why? Reflections of physicians with disabilities on their accomplishments, regrets, and how they overcame barriers on their career paths can benefit younger colleagues with disabilities, particularly students considering careers in medicine.

Willingness to adapt. Meeting the demands of the medical system is a challenge for all physicians. Those with disabilities might be asked to demonstrate the ability to provide medical care equal to that provided by physicians with no disabilities. Professional organizations seeking to determine the readiness of clinicians with disabilities to adapt to the requirements of practice should collect information on the following: clinicians' willingness to adopt a modified role dictated by the specific nature of their disability, such as performing fewer surgeries owing to reduced stamina or, if hearing impaired, demonstrating their ability to communicate, during surgery, with assistants wearing surgical masks if they must rely on reading lips; their agreement to restrict the volume of their practices, if necessary; their willingness and ability to maintain up-to-date medical knowledge; and their ability to meet professional obligations to patients and colleagues to practice safely. Securing information about the psychological stressors faced by physicians with disabilities would be very helpful in this evaluative process. By working with physicians with disabilities, professional organizations can more intelligently advocate and strategize to help clinicians manage specific disabilities and capitalize on personal strengths.

Patients' views. Given the often limited ability of physicians to self-assess [22], information should also be collected from patients of physicians with disabilities on their experience of care, consistent with the Patient Protection and Affordable Care Act of 2010, which factors patient satisfaction scores in Medicare reimbursement [23]. Richard Grol cautions, however, that those who pursue this line of inquiry should be sensitive to "unrealistic patient autonomy and increased consumerism and the expectation that this may foster laissez-faire attitudes and loss of morale among professionals" [24]. Data from an initial series of in-depth interviews conducted by qualified clinicians with a limited number of physicians with disabilities and their patients could serve as the foundation for a larger survey. Enhancing our understanding of physicians with disabilities—their technological needs, perceived accomplishments and regrets, and willingness to adapt to the requirements of practice—can guide those contemplating careers in medicine as well as academic medical faculty members, counselors, administrators, and admissions committees seeking to refine criteria and standards for students with disabilities. Our understanding can be enhanced by inviting physicians with disabilities to medical schools to serve as counselors who can help sensitize medical students to the needs of their future patients and encouraging rotating observerships in the offices of physicians with disabilities.

## Conclusion

Mindful of the time and cost posed by the endeavors described above, we suggest that operationalizing data collection will require close cooperation from the American Medical Association and the Association of American Medical Colleges. Following up on the strategy we suggest would be in keeping with the spirit of the Americans with

Disabilities Act and the Affordable Care Act, while failure to do so would constitute a serious abrogation of professional responsibility.

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### **HEALTH LAW**

Technical Standards and Lawsuits Involving Accommodations for Health Professions Students

Samuel R. Bagenstos, JD

## **Abstract**

This article will discuss the legal obligations of medical schools to accommodate applicants and students with disabilities. The article begins by describing the problem of denial of medical education to such students, a problem that results from both discrimination in admissions and denial of accommodations to incumbent students with disabilities. The article then discusses the disability rights legislation that prohibits discrimination against—and requires reasonable accommodation of—qualified medical students with disabilities. It concludes by reviewing a number of lawsuits involving requests for accommodation and how disability rights law was applied in those cases.

### Introduction

Measuring the number of people with disabilities is notoriously slippery because of the variety of ways of defining the category [1]. But a recent CDC survey found that 53.3 million adults, or just over 22 percent of the adult population, reported having disabilities [2]. The rate among graduate students, who are generally younger than the average adult, is 7.6 percent [3]. Several studies have found that less than one percent of medical students have disabilities [4, 5].

This disparity cannot be attributed simply to the inherent effects of disability. Indeed, many successful physicians have disabilities [6]. Rather, I will argue, the underrepresentation of medical students with disabilities is largely attributable to medical school policies and practices that pose barriers to the admission and graduation of such students. At the admissions stage, students with disabilities are often barred by the requirement to meet inflexible technical standards that emphasize particular physical capacities over the ability to perform tasks that arise in medical practice. And students with disabilities who matriculate might find that their school fails to provide appropriate accommodations for their disabilities despite the passage of the Americans with Disabilities Act in 1990 [7]. A wave of recent judicial decisions demonstrates that schools that do not offer adequate accommodations to students with disabilities face serious risks of liability under antidiscrimination law [8-14].

Medical schools should be concerned about not only the legal liability they face by not offering accommodations to which students with disabilities are legally entitled, but also the harm to students who are unfairly excluded and the harm to effective medical practice. Underrepresentation of students with disabilities in American medical schools reduces the diversity of the medical profession, a result that is inconsistent with the values articulated by professional organizations [15]. But the harm is not merely abstract. An accumulating body of evidence suggests that the lack of exposure to persons with disabilities as peers inhibits the ability of physicians to provide effective medical care to patients with disabilities [16–18]. A lack of appropriate accommodations thus impairs the quality of the education that medical schools provide. Because the population of Americans with disabilities is large and growing as our population ages, this problem is especially acute.

The rest of this article will discuss the legal obligations of medical schools to accommodate applicants and students with disabilities. I will first review disability rights legislation that prohibits discrimination against—and requires reasonable accommodation of—qualified medical students with disabilities. I will then discuss a number of lawsuits involving requests for accommodations and how the courts applied disability rights law in those cases.

### The Rehabilitation Act and the Americans with Disabilities Act

All American medical schools must comply with Section 504 of the Rehabilitation Act of 1973 [19] as well as either Title II (for public medical schools and hospitals) [20] or Title III (for private medical schools and hospitals) of the Americans with Disabilities Act [21]. People who believe they have been discriminated against may file charges with the federal government or proceed directly to court; a school that has violated these laws might be required to pay money damages or provide accommodations to the person who complained and possibly make broader policy changes.

Although there are some differences of detail, the basic requirements of Section 504 and Titles II and III are the same: to refrain from discriminating against "qualified" persons with disabilities and to make "reasonable modifications" of policies and practices when necessary to avoid such discrimination—insofar as the modifications would not "fundamentally alter" the nature of an entity's enterprise [22]. An excessive cost is one of the factors that might make a modification unreasonable or transform it into a fundamental alteration, but the mere fact that an accommodation imposes cost does not excuse a medical school from providing it. A "qualified" person with a disability is one who can meet the "essential" requirements of a program, even if doing so requires reasonable modifications of policies, practices, and services [22]. Among the modifications required is the provision of an "auxiliary aid or service necessary to ensure effective communication" such as interpreters and video remote interpreting systems

when necessary to ensure that persons with disabilities can communicate as effectively as those without disabilities [23].

There is a more fundamental need for reasonable accommodations. The Supreme Court has explained that federal disability rights laws seek "to diminish or to eliminate the stereotypical thought processes, the thoughtless actions, and the hostile reactions that far too often bar those with disabilities from participating fully in the Nation's life" [24]. The requirement of reasonable modification rests on the view that people often design institutions, and set the criteria for access to those institutions, with "normal" participants in mind [25]. Those criteria will thus exclude people whose bodies and cognitive functions do not fit that taken-for-granted norm, when reflection might show that the exclusionary criteria are not essential to the institutions' mission and therefore might be modified to accommodate people with disabilities. As I discuss in the next section, some of the practices that have posed barriers to people with disabilities in American medical schools appear to constitute just this sort of unreflective exclusion.

# **Technical Standards and Lawsuits Involving Accommodations**

Pursuant to guidance from the Association of American Medical Colleges, US medical schools have established "technical standards" as criteria for admission [26]. Technical standards often require students to demonstrate motor functions, intellectual abilities, and the capacities for observation and communication. Inflexible application of these standards rests on the premise that all medical school graduates should have the basic skills and abilities to enter any field of medicine—that is, that they should be "undifferentiated graduates." In today's world of medical specialization, however, that ideal is unrealistic and unclear. And even if there is some pedagogical value to giving all students who have these basic skills and abilities preparation to receive specialized training in any practice area, it's not clear why or according to whom that outcome is worth the risk of entirely excluding some applicants with disabilities who could successfully practice in many specialties. Although some schools use "functional" technical standards that look to whether "medical students possess the skills necessary to be effective doctors, without dictating the precise means that they must use to do so," many others use "organic" technical standards that "focus on how students will perform tasks" without accommodations [27]. Bioethicist Alicia Ouellette has described organic technical standards as "ableist" because they specifically exclude persons with various disabilities (such as those who cannot see, hear, or use their hands) from attending medical school as they do not meet program requirements the school deems "essential" [28]. But why, for example, should the inability to use one's hands prevent a person from studying to become a psychiatrist? That is just the sort of question that disability discrimination law, with its focus on "reasonable" accommodations and "fundamental" alterations, requires schools to ask.

The lowa Supreme Court asked a version of this question in *Palmer College of Chiropractic v Davenport Civil Rights Commission* (2014) [8]. Palmer College had rejected a blind applicant because he could not meet its technical standard for "sufficient use of vision" to perform "the review of radiographs" [8]. The court held that the school was required to modify that technical standard, relying on evidence that many chiropractors are not called upon to visually interpret radiographic images in their practices and that other medical schools had successfully accommodated blind students.

Other cases have shown more deference to the inflexible application of ableist technical standards. In *McCulley v University of Kansas School of Medicine* (2014) [9], for example, the federal Tenth Circuit Court of Appeals held that a medical school could refuse to admit an applicant with spinal muscular atrophy that prevented her from lifting and positioning patients, stabilizing elderly patients, and providing basic life support. Even though the applicant did not intend to pursue a physically demanding specialty, the court deferred to the school's decision to adopt "a broad, undifferentiated medical curriculum that prepares students to serve as physicians in a wide range of practice areas" [9].

Although *McCulley* shows that medical schools can ultimately prevail in litigation if they insist on inflexible ableist technical standards, *Palmer College* demonstrates the significant risk that they could lose—a risk that will grow as more and more medical schools accommodate students with disabilities and concomitantly relax the undifferentiated-graduate ideal. And the court's conclusion in *Palmer College* is more consistent with the basic premises of disability discrimination law—and the ethical obligation to diversify health professions—than is the court's conclusion in *McCulley*. Medical schools would thus do well to learn from the *Palmer College* precedent.

### **Successful Lawsuits for Accommodations**

After applicants with disabilities gain admission to medical school, they can confront difficulties in obtaining needed accommodations from their schools. One common example is the denial of communication aids to deaf students. Although a pre-ADA case upheld a nursing school's refusal to allow a student to use a sign-language interpreter [10], more recent decisions have concluded that medical schools may not refuse to provide interpretive services. In *Argenyi v Creighton University* (2013) [11], a jury found that the defendant medical school violated the law by denying real-time transcription services to a deaf student. And in *Featherstone v Pacific Northwest University of Health Sciences* (2014) [12], the court granted a preliminary injunction that required the school to provide interpreters for a deaf student; the parties later settled. These decisions make clear that the provision of an "auxiliary aid or service necessary to ensure effective communication" [23] can be a required accommodation under the law, even if providing that accommodation imposes a meaningful cost on the school.

Another example of an accommodation that is commonly denied involves requests for extra time to study for tests or extra opportunities to take classes and tests. In Dean v University at Buffalo School of Medical & Biomedical Sciences (2015) [13], a student who was being treated for depression sought additional leave beyond that provided by school policies to study for Step 1 of the US Medical Licensing Exam. He argued that he needed the time to permit his medication regime to stabilize before he could study. The school rejected his request; he sued; and the federal Second Circuit Court of Appeals held that his case should proceed to trial. The court explained that the school had not shown that it had "diligently assessed whether the alteration would allow Dean the opportunity to continue in the MD program without imposing undue financial and administrative burdens on UBMED [University at Buffalo School of Medical & Biomedical Sciences] or requiring a fundamental alteration to the academic caliber of its offerings" [13]. But there are limits to the accommodations that a school must provide. In Powell v National Board of Medical Examiners [14], the same court held that a medical school did not violate the law when it insisted that a student with a disability, like all other students, pass the Step 1 exam by the third try. In that case, the court found the school's pedagogical arguments sufficient to make the requested modification of a fourth attempt unreasonable.

### **Conclusion**

Both the law and the ethical imperative to diversify the medical profession demand that medical schools reconsider inflexible practices that thoughtlessly exclude disabled students. Although many schools retain ableist technical standards for admission, the inflexible application of these standards is vulnerable to litigation under disability discrimination laws. Where technical standards and curricular requirements for enrolled students pose barriers to students with disabilities, the law will force schools to defend their refusal to modify those rules by showing that strict adherence to them is essential to their educational programs. The requirement to modify exclusionary policies is not limitless, but it is one that schools must take seriously if they are to prepare their graduates to serve the more than 50 million Americans with disabilities [29].

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## **POLICY FORUM**

Competence not Age Determines Ability to Practice: Ethical Considerations about Sensorimotor Agility, Dexterity, and Cognitive Capacity Krista L. Kaups, MD, MSc

### **Abstract**

Consideration of the effects of aging on physicians' practice is crucial to addressing aging clinicians' competence, that is, their ability to practice with reasonable skill and safety. Given physician workforce shortages even in resource abundant countries, the establishment of a compulsory retirement age in the US is impractical and unlikely. Several US hospitals and institutions have sought to address concerns about competence by establishing mandatory age-linked testing and evaluation for physicians. However, these procedures have raised questions regarding age discrimination and test validity.

### Introduction

As the US population ages, the physician population is also aging. Recent data show that more than one-quarter of physicians in the United States are age 60 or older [1], and more than 20 percent are over the age of 65 [2]. Although 65 is considered by many to be the traditional retirement age, it's clear from these data that a substantial proportion of physicians continue to practice beyond this point. The challenges of ensuring the competence of aging physicians can better be appreciated by examining the effects of aging on physicians, mandatory retirement ages, and regulatory efforts to ensure that physician ability is maintained and validated.

# Aging-Associated Changes in Sensorimotor and Cognitive Skills

For physicians, *competence* is the ability to practice with reasonable skill and safety, which involves both cognitive and physical considerations. Although clinicians' responsibility and commitment to practice competently does not change throughout their professional careers, age-related changes can influence their ability to do so. Beginning at age 40–50, vision and hearing begin to diminish [3]. Visual-spatial ability, inductive reasoning, verbal memory, and other cognitive functions also begin to deteriorate with age, with the steepest declines occurring after age 65 [4, 5]. However, the rate and extent of these changes vary significantly from person to person [6–8], as do declines in stamina, cognition, and fine-motor skills [9]. Sustained attention and ability to perform among distractions and in the presence of multiple visual, auditory, or other stimuli can also deteriorate with age [10].

Overall, these effects of aging can negatively influence physicians' performance. A systematic review of 62 studies found that physician performance (measured by adherence to clinical guidelines) generally decreased with years in practice, contravening the hypothesis that experience is associated with high-quality care [11]. Further complicating normal age-related decline is increasing incidence of dementia with age, estimated to be 5–10 percent in people age 65 or older [12]. Although higher educational levels are thought to be somewhat protective against dementia [13, 14], based on the foregoing estimate, approximately 8,000 physicians in the US were suffering from dementia in 2006 [12].

However, not all abilities decline with age and older physicians have some advantages. According to one source, although "fluid intelligence" (reasoning and cognitive flexibility) tends to decline with age, "crystallized knowledge" (accumulated knowledge) is generally maintained [15]. This source also suggests that though older clinicians might be more influenced by information acquired early in a patient's case, they also tend to demonstrate better ability to come to an early diagnosis, possibly by virtue of their accumulated knowledge. Moreover, several studies have demonstrated that older physicians experience less psychological distress and burnout than younger physicians [16].

The ability to assess the effect of age-related changes on physicians' performance is complicated by the fact that—as discussed above—these changes can vary widely, with some practitioners showing little alteration in function even at advanced ages [17]. Factors such as heredity and personal health status clearly contribute to job-related performance but are difficult to quantify. Physical fitness, for example, has been shown to be associated with maintenance of both cognitive and physical well-being [18]. Moreover, individual practitioners might be unable to accurately assess their own functioning. In a study of surgeons, for instance, self-perceived cognitive changes were not related to objective measures of cognitive deterioration in formal neuropsychological testing [6]. And it appears that people with mild cognitive impairment demonstrate a lack of insight about their impairments [19]. Adding further complexity to the discussion are varying physical and intellectual demands among and even within specialties and practice settings. The demands placed on a physician with a primarily office-based practice differ from those of a physician doing surgery, for example, with the latter experiencing prolonged work hours and physical demands and the need for rapid assessment and judgment. Although age-related changes are inevitable, variability among these changes makes establishing age-specific criteria for retirement challenging at best.

# Mandatory Retirement and Workforce Shortages

The Age Discrimination in Employment Act (ADEA) of 1967 protects people who are 40 years or older from age discrimination in employment, including mandatory retirement ages. However, the courts have generally concluded that, for certain occupations, particularly those in which public safety is involved, age is a bona fide occupational qualification (i.e., employment qualifications that employers are allowed to consider while making decisions about hiring and retention of employees, e.g., fitness requirements) [20]. Some of these professions include commercial airline pilots (mandatory retirement at age 65), FBI agents (age 57), and air-traffic controllers (generally age 56) [20].

Some countries, however, have policies and have implemented policy changes about age-based restrictions on physicians' practices, some of which have been modified in response to workforce needs. In the United Kingdom, health professionals can switch to part-time work while preserving their pension entitlements [21]. In other countries, compulsory retirement ages for physicians have been abolished in response to significant physician workforce shortages [22]. Physicians in Spain, for example, have a retirement age of 70 compared to age 65 for other professionals [23]. And in Germany, the retirement age of 68 for general practitioners and primary care specialists was lifted in 2009 [24].

The US faces workforce challenges, too. By 2025, the US will have a shortfall of 61,700–94,700 physicians [25], attributable to both a growing population and a rising proportion of elderly people within that population who are anticipated to have increasingly complex health care needs [25]. Since 20 percent of physicians are currently over the age of 65 [2], and since an increase in that proportion is expected, instituting a mandatory retirement age would further exacerbate physician shortages.

## Licensing, Certification, and Credentialing

Although imposing a mandatory retirement age for physicians in the US seems both impractical and unlikely, questions about aging physicians' competence still persist. In my experience, in most states, periodic relicensing for physicians—most often at two-year intervals—requires only an attestation of participation in continuing medical education and fee payment, and relicensing procedures tend to include no evidence of competency such as might be provided by a formal clinical evaluation, for example. However, because of the importance of evaluating and demonstrating physician competence, board-certification and credentialing by health care organizations also include requirements for regular clinical assessments.

*Certification.* The American Board of Medical Specialties and its 24 member boards have adopted a maintenance of certification requirement whereby, in order to maintain <u>board certification</u>, a physician must provide evidence of participation in <u>continuing professional development</u>. The requirements vary between boards but generally include

ongoing education and, for some, regular formal written examinations as well to test whether physicians' knowledge base for practicing the specialty is up-to-date [26]. These requirements have been met with active backlash by some specialty professional organizations and individual practitioners, mainly due to considerable fees, time demands to meet the requirements, and a lack of evidence demonstrating that maintenance of certification requirements protect patients or improve care [27].

Credentialing. Age-based testing can have legal benefits, particularly when appraised from a patient safety standpoint. In recognition of the need to ensure public safety, commercial airline pilots, beginning at age 40, undergo routine physical examinations at six-month intervals as well as flight simulator-based evaluations [28]. These assessment opportunities are conditions of employment. Public safety concerns are recognized; in many states, specific age-related stipulations are included for obtaining a driver's license (e.g., yearly testing after age 85) [29].

At present, only an estimated 5 percent of US medical centers have developed agerelated screening policies [30]. Among these few institutions, the University of Virginia and the Stanford Health system are well-known examples. In 2011, the University of Virginia Health System implemented a system of mandatory physical and cognitive examinations every two years for physicians and some other members of the clinical staff, beginning at age 70 [31]. And in 2012, Stanford Hospital and Clinics instituted a late-career practitioner policy, including a peer evaluation of clinical performance, a cognitive examination, and a comprehensive history and physical examination every two years for physicians aged 75 and older [32].

However, <u>assessment</u> of older physicians is problematic for a number of reasons. In 2015, senior faculty members at Stanford Hospital and Clinics voted to reject the late-career practitioner policy on the grounds that it constituted age discrimination [33]. Among the difficulties with mandating these assessments is the lack of practical screening tools that are specific and easily utilized. Comprehensive neurocognitive and functional testing, which is currently available in only a few sites, incurs travel expenses and requires time away from practice for multiday, multispecialty testing. Variability in how age-associated cognitive changes manifest, uncertainty in interpreting psychomotor tests in physicians and in using the test results to predict care quality and patient outcomes are other concerns that have been raised [34].

A possible adjunct to clinical assessment is a system of <u>self-regulation</u>, wherein an individual physician is responsible for monitoring his or her own cognitive and physical functioning. Some professional organizations (e.g., the Royal Australasian College of Surgeons—The College of Surgeons of Australia and New Zealand) have developed tools for this kind of self- and peer-assessments of competence throughout surgeons' careers [35]. In 2015, the American Medical Association (AMA) [36] announced its intention to

address the need for guidelines and appropriate plans for screening senior physicians and assessing their competence. One important limitation of self-assessment, however, is the need for a high degree of self-awareness and honesty [37]. As noted above, individuals with cognitive decline or those in denial, because of concerns over loss of professional identity or livelihood, perhaps, might fail to recognize and act on critical signs of deteriorating functioning.

### Conclusion

As age-related changes in physicians' performance are evaluated, it is not simply chronological age that should be considered, but a physician's overall mental and physical abilities to provide safe and skillful care to a patient. Age cannot reliably be used as a proxy for competence or procedural skill. Implementing mandatory retirement ages or restricting privileges for physicians of specified ages could negatively influence individual practitioners in the ways discussed here without enhancing patient safety. Such action would also likely exacerbate some patients' access to health care, particularly in areas with physician shortages. However, developing realistic and practical methods to evaluate and demonstrate clinicians' abilities to practice safely poses challenges for health care organizations accreditation and licensure, certification, or credentialing bodies.

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# **AMA Journal of Ethics®**

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## **POLICY FORUM**

# Perspectives on the Meaning of "Disability"

Leslie Francis, PhD, JD, and Anita Silvers, PhD

### **Abstract**

The meaning of "disability" has shifted with changes in public policy. Half a century ago, Congress was convinced that narrow determinations of disability are easy for physicians to make. But with the advent of universal civil rights protection against disability discrimination in the US, deciding whether particular individuals are disabled became increasingly contentious, until Congress intervened. What should now be addressed in each case is not whether the functionally compromised person is severely disabled enough to exercise a right, but whether mitigating interventions and reasonable accommodations can together achieve equitable access for that person.

### Introduction

"Disability" is a term of art with different specialized meanings, each developed for the particular policy or program that uses it. How we conceptualize disability shifts relative to the methodologies used to learn about it and the contexts in which it is addressed. The criteria for judging people to be disabled likewise fluctuate over time and across different social and cultural contexts.

### **A Medical Perspective**

The history of the concept of disability illuminates its evolution. Before the nineteenth century, being disabled meant being disadvantaged by laws preventing participation in some areas of a community's social, political, or economic life. For example, according to legal theory of that day, successful domestic arrangements required husband and wife to be as one person, permitting only one decision-maker—the male. So married women were explicitly disabled by law from the management or disposition of property [1].

While legal disability's imposition of disadvantage was a result of a social arrangement, by the late nineteenth century, another kind of disabling disadvantage—associated with compromised health rather than legislative mandate—came to be portrayed as a natural fact. During this era, healthy and pathological states of organisms began to be distinguished through statistical investigation, with species typical functioning being conceived as a "norm" conducive to individual and species success [2]. As the nineteenth century turned to the twentieth, anomalous biological functioning began to be equated

as a general matter with disabling defectiveness that not only disadvantages the individual but also, unless ameliorated or eliminated, detracts from social stability and species survival [3, 4]. We examine social welfare and disability rights legislation in the US to consider additional shifts in views of disability during the twentieth century.

# A Pre-Civil Rights Perspective

A generalized characterization of persons with disabilities as functionally abnormal enabled them to be addressed collectively for purposes of policy formulation. On the one hand, persons with such anomalies could be discriminated against by policies denying them access to common services or by segregating them into institutions [5, 6]. On the other hand, aggregation of various kinds of biological dysfunction enabled a more positive policy effect: income-related benefits to individuals with impairments who, due to their past or potential social contribution, were judged deserving. For example, after the Civil War, Congress gave veterans with a variety of injuries and illnesses preference as a group for government employment [7]. Later, assistance programs such as the 1920 Civil Vocational Rehabilitation Act [8] were devised to return citizens with the potential to overcome their functional disabilities to the workforce, regardless of how the disability was acquired.

Between 1954 and 1964, a series of amendments to the 1935 Social Security Act added payment of benefits to persons with illness or injury too severe to work [9-11]. According to a US Social Security Advisory Board report, The Social Security Definition of Disability [12], "When the Social Security Disability Insurance (DI) program was enacted in 1956, it was intended for the 'totally and permanently disabled,' a population for whom work was not an option" [13]. To the Social Security Administration (SSA), persons with disabilities were people permanently unable to perform substantial gainful activity due to severe impairment. During Congressional hearings on the Social Security Act amendments, controversies arose about the definition of disability and its implementation through physicians' testimony [14]. Despite testimony from American Medical Association (AMA) leadership and many other physicians about their doubts that practitioners could deliver objective judgments about disability, as the amendments to the 1935 Social Security Act apparently presumed, federal legislators remained unshakably optimistic. As Georgia Senator Walter F. George declared, "[M]any American doctors are afraid that they cannot determine when a man or a woman is disabled, when the plain requirement is that the disability must be a medically determined physical or mental impairment. .... I think more of the medical profession in this country than to believe that they cannot determine when a man or a woman worker has a permanent and total disability" [15].

As the SSDI program functions today, to qualify for Social Security disability benefits, applicants' conditions must be severe enough to interfere with basic work-related activities. The SSA maintains a list of medical conditions that are so severe they

automatically mean that the person is disabled [16]. If the applicant's diagnosis is not on the list, there is a Social Security process that decides "if it is of equal severity to a medical condition that is on the list" [16]. To receive benefits if the condition is not considered as severe as those on the list, the applicant must demonstrate that the condition prevents executing both previous types of employment and other types of employment in the relevant labor market [16]. Demonstrating such inability to work in the relevant labor market is thus a critical aspect of disability determinations today for people whose conditions do not fall within the SSA list.

As the AMA warned, however, diagnosing individuals' inability to work has turned out to be much more problematic than Congress initially supposed. Physicians' assessments of the same patient's disability can be surprisingly varied, indicating that the theoretical foundation of this kind of diagnosis is far from robust [17]. Furthermore, clinical judgments of the impact of physiological or psychiatric medical conditions on ability to work can be skewed by implicit bias [18, 19]. Finally, barriers to employment extend beyond actually executing work. To illustrate, having to climb steep stairs to the workplace or restrooms can curtail employment for persons with even modest impairments such as compromised respiration or tendonitis [20].

# **A Civil Rights Perspective**

Recognizing that WWII veterans with disabilities could face exclusion from employment in the communities they had sacrificed to protect, Congress in 1944 gave them preference for government jobs. But such preferences did not prevent government employers' discrimination against workers with disabilities, even those with service-related impairments, so in 1948 Congress prohibited discrimination based on physical handicap in United States civil service employment [21]. Beginning in the 1970s, Congress expanded efforts to give people with disabilities equitable access to the public buildings, public transportation, and education in public schools that other citizens enjoyed. Although by no means abandoning programs entitling some persons with disabilities to various kinds of compensatory support, Congress added legislation with a civil rights perspective aimed at enabling persons with disabilities to combat discrimination that limited opportunity for them. These policies all were framed by an understanding that the disadvantages of disability emanate, to some degree, from social discrimination rather than biological deficiency.

In 1973, a greatly revised reauthorized Rehabilitation Act expanded civil rights to more meaningfully protect people with disabilities against exclusion from opportunity by prohibiting disability discrimination by federal contractors and in any program receiving federal support. The primary focus of the 1973 legislation was job training and reducing dependency on public funds, so the added language maintained the values and purposes of its origin. Congress defined "handicapped individual"—the language of the day—as "any individual who (a) has a physical or mental disability which for such individual

constitutes or results in a substantial handicap to employment and (b) can reasonably be expected to benefit in terms of employability from vocational rehabilitation services" [22]. The civil rights-conferring sections of the 1973 legislation are only a small part of the act, the bulk of which focuses on job training programs and other ways of getting more people with disabilities into the workforce and thus reducing dependency on public funds. In contrast, the 1990 Americans with Disabilities Act (ADA) expands civil rights in recognition of the intrinsic value of people with disabilities and as an expression of personal respect, not just in recognition of the instrumental value of reducing public expenditures.

Nevertheless, the definition of disability that was incorporated into the ADA has roots in the Rehabilitation Act's definition and remains standard in law today.

The term "disability" means, with respect to an individual—

- (A) a physical or mental impairment that substantially limits one or more major life activities of such individual;
- (B) a record of such an impairment; or
- (C) being regarded as having such an impairment [23].

The ADA aimed to provide "a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities" [24] and "to address the major areas of discrimination faced day-to-day by people with disabilities" [25]. Yet in the decades after enactment of the ADA, the US Supreme Court gradually curtailed the ADA's reach by adopting a strained and straitened understanding of what it means for a physical or mental impairment to substantially limit a major life activity. In a trilogy of cases in 1999, the Court held that individuals must be assessed in their corrected condition. Corrections may themselves be burdensome, however, such as medication side effects and even the regimen required to administer medication. The Supreme Court's analysis ignores these and other impacts such as the monetary costs or demands on time that the means of mitigating dysfunctions may impose [26-28]. Ironically, the more medical and mechanical intervention improved the functionality of people with disabilities, the more likely those people were, given the Court's jurisprudence, to lose protection against well-documented disability discrimination by being denied accommodation for such interventions at work after they have been hired [29]. Further, in 2002 the Court concluded that impairments do not substantially limit a major life activity unless they prevent or severely restrict the ability to execute fundamental activities people normally perform independently in daily life such as fixing simple meals [30], thus denying eligibility for accommodation to individuals who could care for themselves in executing activities of daily life but whose impairments prevented their overcoming barriers erected by an employer's particular arrangement of work activity or the condition of the work site [31, 29]. The upshot of these decisions was that many people with impairments who were able to engage in personal care for themselves

independently but could not overcome <u>workplace barriers</u> never cleared the initial hurdle of demonstrating that they were sufficiently disabled to claim the statutory protection of the ADA.

In response to these decisions, the ADA Amendments Act (ADAAA) was passed in 2008. Although Congress did not change the statutory definition of disability as substantially limiting a major life activity, it made clear that the ADA was to be construed in favor of broad coverage of individuals. Congress deleted reference to the number of Americans who had disabilities, a finding that had been used by the Court to deny coverage; made clear that the Supreme Court's and the Equal Employment Opportunity Commission's standards for "substantially limits" and "major life activities" were overly strict; rejected the Supreme Court's requirement that the effect of measures to mitigate the effects of the impairment must be weighed in deciding whether an impairment results in a disability; offered broadly construed and diverse examples of major life activities, and eliminated from the "regarded as" prong of the definition the demand that individuals show they are perceived to be substantially limited in a major life activity instead of being merely perceived as disabled [32]. Unlike the objective that prevailed more than half a century earlier when the program for social security disability benefits was devised, Congress's consideration of disability through a civil rights lens aimed to provide broad protections against disability discrimination throughout the community to all individuals who are victimized by it. This is a very different aim than the Social Security objective of providing monetary support, which is offered only to a narrow subset of the population who, due to severe impairment, are unable to work [33].

# **An Ethics Perspective**

As may be expected of terms of art developed to serve specific policy aims, "disability" does not possess a univocal definition. According to the US Census Bureau, changes in context shift the standard for being counted as disabled [34]. By the standard the Census Bureau applies to citizens' self-reports about their functional capacity, approximately one in five US citizens over age 15 has a disability [34]. The same document warns, however, that "health professionals, advocates, and other individuals use the same term in different contexts" [35]. To take an example, in a 1999 Supreme Court case, a stroke patient's physician supported her claim on a Social Security application that she was too disabled to work but testified in an ADA complaint that she would be capable of working if not for her employer's refusal to reasonably accommodate her impairment [36]. According to the Court, testimony that a person is or is not disabled is not always unconditional; both asserting and denying that a person is disabled need not be a contradiction because disability has different meanings in different contexts.

That the standard for having a disability remains so much in flux across contexts reveals a fundamental ethical difficulty that has become embedded in our discourse about

disability. The purported precision of these judgments is illusory, so much so that defining disability to achieve gatekeeping dependent on such judgments too easily devolves into an exercise in stereotyping—for example, by courts defining people with disabilities as unable to work and then by programs and commentators applying the courts' interpretation. By their very nature, such assessments of disability lack epistemic trustworthiness, especially when allocation of opportunity and (dis)advantageous social positioning are at stake [37]. Disregard for lack of epistemic reliability invites deceptively authoritative declarations about who has and does not have a disability, undercuts the effort to increase social participation by biologically anomalous people, and is antithetical to Congress's aim of broad coverage in the ADAAA.

Protection of civil rights under the ADA should not be impeded by difficulties in determining whether a person is sufficiently disabled to qualify. A common misunderstanding is that only those with disabilities, or severe disabilities, can be rights-bearers under that law. The basic issue in each case, however, pertains to whether a person has been subjected to disability discrimination—regardless of the existence or severity of disability—and thus to a violation of the right to equitable social opportunity through accommodations that do not impose undue hardship on other people.

The ADA mandate presents a challenge and an invigorating chance for health care organizations, which are tasked with responding to biological differences related to patients' compromised functioning, to come to grips with more nuanced, proactive, and contextualized understandings of disability. ADA compliance should focus broadly on devising ways for people who, for reasons of biological anomaly, do not function in species-typical ways to nevertheless access opportunities open to others—not on whether it is accurate to call these people disabled. (That is, ADA compliance should be based on whether the functional deficiency can be effectively mitigated by medical means or addressed by the proposed accommodation or by a combination of both.) Such a focus requires flexibility, as well as knowledge and open mindedness, to devise effective approaches for eliminating or reducing harm occasioned by inaccessible practice or other manifestations of disability discrimination.

The ADAAA facilitates shifting skilled medical judgment away from whether the functionally compromised person is severely disabled enough to exercise a right toward bringing medical knowledge and skills to bear on how to implement that right through a process of integrating mitigating interventions and reasonable accommodations to achieve equitable access for that person. This process involves physicians working with persons with disabilities to explore how workplace accommodations might be designed to allow people with different modes of functioning to perform jobs and otherwise increase their social participation. To do so, both the responsibility and the expertise of physicians should extend beyond improving biological functioning to support assuming a greater role in making progress toward social justice.

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## **MEDICINE AND SOCIETY**

Just and Realistic Expectations for Persons with Disabilities Practicing Nursing Patricia M. Davidson, PhD, RN, Cynda Hylton Rushton, PhD, RN, Jennifer Dotzenrod, MPP, Christina A. Godack, MA, Deborah Baker, DNP, CRNP, and Marie N. Nolan, PhD, RN

### **Abstract**

The Americans with Disabilities Act prohibits discrimination on the basis of disability and requires schools to provide reasonable accommodations for persons with disabilities. The profession of nursing is striving for diversity and inclusion, but barriers still exist to realizing accommodations for people with disabilities. Promoting disclosure, a supportive and enabling environment, resilience, and realistic expectations are important considerations if we are to include among our ranks health professionals who can understand, based on similar life experiences of disability, a fuller range of perspectives of the patients we care for.

### Introduction

The Americans with Disabilities Act (ADA) of 1990 provides civil rights protections to persons with disabilities similar to those provided on the basis of race, sex, national origin, and religion. More specifically, "the ADA prohibits discrimination on the basis of disability in employment, state and local government, public accommodations, commercial facilities, transportation, and telecommunications" [1]. The ADA Amendments Act (ADAAA) of 2008 clarifies that the ADA's definition of disability was to "be construed in favor of broad coverage of individuals ... to the maximum extent permitted by the terms of this Act" [2]. The ADA also mandates that employers provide reasonable accommodations to qualified employees with disabilities, unless providing such accommodations would result in "undue hardship" or "significant difficulty or expense incurred by a covered entity" [3]. Reasonable accommodation refers to assistance or changes to a position or workplace that will enable a person to undertake occupational tasks despite having a disability [1]. Schools of nursing are thus legally bound to provide reasonable accommodations to students, faculty, and staff.

In our experience, there is broad support for this goal within the nursing profession. The National Organization of Nurses with Disabilities (NOND), for example, advocates for an <u>inclusive workplace culture</u> and provides both a voice for disability and resources to promote inclusion through professional engagement and demonstration of financial

need [4]. Indeed, the nursing profession is striving for diversity through federal stipends and scholarship programs [5] and promotion of dialogue on the topic [6]. Nevertheless, more than 25 years after the passage of the ADA, there remain challenges in operationalizing the rights and responsibilities of students, nurses, and nursing faculty and administrators [7, 8]. In this article, we illuminate barriers to accommodations in the nursing profession and suggest how the culture of nursing can be made more inclusive of people with disabilities. To do so, we draw on a social model of disability that focuses attention on intentional or unconscious systemic barriers, negative attitudes, and prejudicial actions [2, 9, 10].

# **Challenges in Implementing Accommodations in Nursing**

There are four major barriers to implementing accommodations for persons with disabilities in nursing: the heterogeneity of practice settings; stereotypical views about the capabilities required to deliver safe care; clinician and patient expectations; and a professional environment where providing accommodations can be challenging.

Capacities needed for nursing care. There has been little research on which physical and mental capacities are essential for delivering safe nursing care, and, in some cases, there is a mismatch between the academy and the health system [11, 12]. The commonly applied technical standard of being able to stand for 12 hours, for example, is likely not relevant for someone wanting to work in a community or telehealth setting and is particularly fraught due to failure by nursing as a profession to address potential harmful consequences suffered by nurses who work 12-hour shifts [13]. It is possible to determine which skills and abilities are needed to administer medications, start intravenous infusions, and manage 3-10 patients by assessing patients' needs and prioritizing specific care tasks. Schools of nursing in academic health centers could be ideal settings to build interdisciplinary research teams to study such questions. Colleagues in biomedical engineering could measure gross and fine motor skills needed for nurses to complete certain tasks. Neuroscientists and cognitive psychologists could determine the scope of attention, memory, response time, and decision-making abilities needed from nurses working in particular settings. Teams could also develop technologies, such as smart phone applications that calculate doses and warn of medication contraindications, to enhance nurses' abilities or develop possible accommodations for nurses with disabilities in any of these areas. Although these are suggestions for future research, it is now possible to test professionals' functional capacities without identifying which ones are essential. Nurses and other team members in acute and critical care settings regularly practice resuscitation simulations of respiratory and cardiac arrest and even practice responding to mass casualty events with triage and coordination for treatment for large numbers of people. Notably, however, with the exception of recertification for cardiopulmonary resuscitation, in most cases, what's assessed is team rather than individual functioning.

Culture of nursing. Despite the protection provided by the ADA, many health care professionals, including nurses, physicians, and physician assistants, are reluctant to request access to resources and accommodations since they fear stigmatization and reprisals, such as exclusion from opportunities [14]. Reprisals can be sources of harm not only to individual health professionals but also to the patients, families, and communities those professionals serve. Many workplace injuries likely occur because employees do not seek assistance and are unwilling to disclose physical or psychological limitations that can place patients at risk. Promoting a health care workplace culture that is supportive, accommodating, and compliant with the ADA is critical for ensuring safety for everyone in health care environments. Moreover, as the nursing workforce ages, many employees will suffer from chronic and complex conditions and likely need accommodations [15]. For example, nurses have a high prevalence of disabilities from musculoskeletal disorders [16].

# Changing the Culture of Nursing to Support People with Disabilities

Students with disabilities and health care professionals who acquire a disability through accidents or aging face many challenges but also opportunities [9, 10]. Promoting a culture of open communication, compassion, ADA compliance, safety in disclosure of physical and psychological limitations, and support is critical to the health of individual health professionals and patients [17]. Below we discuss ways in which institutions and individuals can promote a culture of inclusiveness in their workplaces.

Foster resilience in persons with disabilities. Commonly, people with disabilities have already faced many challenges before they reach nursing schools, and we have much to learn from them in improving patient care and personal resilience. Kay Redfield Jamison, professor of psychiatry at Johns Hopkins School of Medicine, exemplifies resilience in the face of challenges. In writing about her own experience with bipolar disorder, she has demonstrated that a physician can not only manage this illness but also flourish as an international expert who has shattered stereotypes that limit career aspirations of those with similar illnesses [18]. Providing such persons with mentorship, awareness of their rights and resources, and strategies for promoting resilience are important for their success and happiness in the workplace [19].

Foster meaningful engagement. Discussions of disability and illness are often shrouded in fear, prejudice, stigma, and inappropriate use of power [20-22]. Fear of the unknown, litigation, and failure can all conspire to create less meaningful and inclusive work environments. We believe that these fears can be overcome by effective communication and engagement with disability experts—and, importantly—with people with disabilities [5]. For example, close communication between nursing schools and health systems can help to forge realistic expectations about career opportunities and appropriate practice settings. Acceptance of diversity and disability requires not only good communication but also that each of us appraise our own values and beliefs in the

context of how we understand professionalism and norms of respect, which are needed to create cultures of ethical practice [23].

Work with students with disabilities. Promoting environments that enable academic success, professional satisfaction, and achievement of career aspirations should be important goals of student admissions and academic services. Less clearly stated, but likely more important than providing accommodations, is providing students with realistic expectations about work environments and exposure to nursing roles not limited to the bedside, such as those in organizational oversight and administration [24, 25]. By failing to provide students with disabilities with realistic expectations for different health care work environments, health care professionals and organizations neglect their responsibilities as employers and educators [26]. For example, allowing shadowing in a range of career settings can be useful in promoting exposure to and shared understandings of requirements needed for a range of nursing roles. All too often, disability is made invisible and excluded from broader discourse and debate about workforce composition, which should be a key feature of diversity and inclusion conversations [27]. As schools of nursing move toward models of holistic and diverse admission, the focus should be on disability as an opportunity for nursing as a profession [28].

### **Conclusion**

Diversity and inclusion debates about the nursing workforce should accommodate a range of perspectives. The American Nurses Association's *Code of Ethics for Nurses with Interpretative Statements* [29] should be our guide in ensuring that we promote quality care within a culture of ethical practice that encompasses not only our patients but also fellow professionals and students. Much cultural work remains to be done beyond writing white papers and issuing policy statements. For example, increasing tolerance and respect for diverse abilities and views of difference are just as important as lists of accommodations and procedures for leveraging cultural change, which is not easy but achievable when professions are committed to person-centered care, equity, diversity, and social justice.

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## **MEDICINE AND SOCIETY**

Why Increasing Numbers of Physicians with Disability Could Improve Care for Patients with Disability

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#### **Abstract**

Erroneous assumptions among health care professionals about the daily lives, preferences, values, and expectations of persons with disability can contribute to documented health care disparities, faulty communication, and substandard quality of care affecting this heterogeneous population. Efforts to reduce racial and ethnic disparities have focused on expanding diversity in the physician workforce. Would expanding the numbers of physicians with disability benefit patients with disability? Increasing the number of physicians who identify as "disabled" is one strategy for proactively confronting disability-related barriers affecting patients, but such efforts will likely face substantial challenges. Nonetheless, physicians who require accommodations to practice (e.g., a height-adjustable examination table) could plausibly benefit patients needing similar accommodations and perhaps be well-positioned to provide patient-centered care to persons with comparable disability.

## Introduction

Able-bodied images, such as "walking tall" and "seeing is believing," suffuse our language. Although it has several variants, one popular aphorism typically asserts: "You can't really understand another person's experiences until you've walked a mile in their shoes." Recognizing irony in this ambulatory metaphor, many persons with disability might nonetheless endorse this sentiment, even when considering health care. Health care professionals' erroneous assumptions about the daily lives, preferences, values, and expectations of persons with disability—a diverse population encompassing people of all ages—can reduce the quality of the health care that persons with disability receive [1]. In particular, frequent misconceptions about persons with disability can contribute to troubling health care disparities, especially an underemphasis on health promotion [2]. For example, clinicians might not think that persons with disability are interested in exercise or that women with certain types of disability are sexually active and thus put the latter at risk for human papillomavirus exposure and cervical cancer development. According to the World Report on Disability, this problem of erroneous assumptions extends globally, as stigmatized views of disability infiltrate patient-physician communication and can compromise patients' care [3].

Little is known about whether increasing the numbers of physicians with disability would reduce health care disparities and improve quality of care among patients with disability. Some suggest that increasing racial and ethnic diversity of the physician workforce can reduce both health disparities and health care disparities for racial and ethnic minorities [4]. One strategy for reducing racial and ethnic disparities in health care involves increasing physician-patient concordance with respect to race and ethnicity. Research suggests that racial and ethnic concordance between patients and physicians can significantly enhance cross-cultural communication and patients' health care experiences, participation in clinical decision making, intentions to adhere to clinicians' recommendations, and satisfaction with care [5, 6]. Perhaps concordance improves these outcomes because many minority patients distrust clinicians from racial or ethnic backgrounds who do not share their daily experiences—that is, who have not "walked in their shoes" [7]. Could concordance in disability status between physicians and patients eliminate disparities in health status, access to health care, and quality of health care, and generate better health outcomes?

Empirically, this question has not yet been addressed. Indeed, some might be puzzled or troubled by the notion of having a substantial number of physicians with disability in the physician workforce [8, 9]. Historically, physicians with recognized disability have been persons with singular personal qualities (such as having an attractive demeanor or personality, being highly personable, or having extraordinary intellectual gifts or professional achievements) who have found mentors who have recognized their talents and intervened or advocated for them [10]. Approximately 57 million Americans (almost 20 percent) currently live with disability [11], and finding sufficient numbers of physicians with disability to serve even a small fraction of this growing population would be difficult. Increasing the workforce of physicians with disability would require major changes in medical training programs and, for physicians who become disabled during their careers, systematically providing reasonable accommodations so they could continue productive practice. Improved accommodations for medical students who are <u>deaf or hard of hearing</u> appears to have contributed to the number of physicians serving persons with hearing disability, which will likely dramatically improve patientphysician communication for this underserved group [12]. However, benefiting large and heterogeneous populations of patients with disability would require two major steps: (1) expanding the number of physicians with disability and (2) ensuring that their practices actually enhance care for patients with disability.

## **Motivating Change**

Both steps face considerable challenges. As Melnick argues, increasing the number of physicians with disability requires recognizing the absolute primacy of patient safety [8]. But there are other challenges to increasing the number of physicians with disability. One might wonder, how much and what kind of concordance is needed? Indeed, achieving

disability status concordance between physicians and patients is illusory for some disability types. Given the cognitive, professional, and personal demands of medical practice, expanding the physician workforce to include persons with significant intellectual and cognitive disability, major communication disorders, and some mental illnesses, particularly if untreated, is likely unrealistic. However, depending on clinical practice demands, reasonable accommodations are now possible to support safe and productive practice by physicians with vision, hearing, mobility, or mental health disability. Below, I discuss challenges to expanding the number of physicians with disability and possible effects of physicians' disability on their attitudes toward and care of patients with disability.

## Challenges to Expanding the Number of Physicians with Disability

Expanding the number of students with disability matriculating at and graduating from medical schools confronts several challenges, as does retaining physicians who acquire a disability during their career.

Despite the 1990 passage of the Americans with Disabilities Act (ADA) [13], medical schools and practice settings have been slow to recognize their legal obligations to make reasonable accommodations for persons with disability [10, 14]. Most notably, accommodations are not explicitly supported in many schools' technical standards [15]. In 1979, the Association of American Medical Colleges Report of the Special Advisory Panel on Technical Standards for Medical School Admission specified five categories of skills required for medical school matriculation and graduation: observation; communication; motor; conceptual, integrative, and quantitative; and behavioral and social [16]. These technical standards have changed little since 1979 and—especially the standards for motor and sensory skills—have effectively prevented qualified students with disability from becoming physicians [14-16]. Not surprisingly, young adults with disability are underrepresented in medical schools, and their graduation rates are lower than those of students without disability [16]. Nonetheless, more deaf and hard of hearing applicants [8] are entering medical school today than before passage of the ADA.

Keeping physicians who acquire disability later in life in the practitioner workforce also poses important challenges. Physicians experience the same potentially disabling disorders over their life course as others do, with prevalence increasing with age. Given the potentially career-ending consequences of some disabilities, whether and when physicians recognize or openly acknowledge disability raises several questions, including about ensuring safe practice [10]. In some situations, physicians might be "in denial" about whether they can practice safely [9]. They "appear reluctant to identify themselves as disabled or use available accommodations, in part out of fear of reprisal" [17]. State licensure boards, which ultimately make determinations about whether health care professionals can practice safely, might not yet fully understand ADA requirements, such

as whether it is permissible to ask questions about physical or mental health that have no bearing upon professional competence [18]; the ADA prohibits such questions. Safe practice deliberations can be complex: "Resolving the tension between protecting the public and protecting the rights of impaired individuals [i.e., physicians with disability] requires Solomonic wisdom" [19]. As Altchuler observed, medical licensure boards must walk a fine line between identifying physicians with impairments that compromise their abilities to practice safely with the boards' obligation to uphold ADA provisions by limiting investigations to topics relevant to professional competence and not imposing an undue burden on physicians with disability [9].

## The Effects of Physicians' Disability on their Attitudes toward Patients with Disability

The small group of physicians with pre-existing disability who graduated and trained since the ADA went into effect and the much larger group who age into disability likely approach caring for patients with disability differently.

Young physicians who explicitly needed to invoke their rights under the ADA or who received specific accommodations during training can carry a disability identity [20] that informs their clinical practice, giving them more disability cultural competence [21-23] or empathic understanding of disability experiences. This is one potential benefit of disability concordance in patient-physician relationships that could motivate good outcomes or health care experiences for patients.

In contrast, older physicians who have developed chronic disabling conditions might not identify as "disabled" or might even actively deny their limitations [10]. It is unclear whether a clinician's denial of disability might affect his or her views of patients with disability. Today's aging physician workforce—and some physicians' erroneous assumptions about the values and preferences of their patients with disabilities [1, 2]—are two factors partially responsible for current health care disparities. Health care disparities are exacerbated by discriminatory structural features of health care delivery systems (e.g., inaccessible facilities and equipment) and the health care system as a whole (e.g., inadequate insurance coverage). It is unclear whether these older physicians will significantly alter and improve their current practices or become more knowledgeable about their legal obligations to accommodate patients with disability if and when they become disabled themselves.

## How Physicians with Disability Can Affect Health Care

Patients report that many physicians "just don't get disability"—they have little understanding about living with disability or the consequences for daily life or health-related behaviors [1, 3, 24, 25]. A question is whether one can assume—based on disability concordance—that physicians with disability will proactively "get it" and thus improve care for this population. In particular, will physicians with disability be more likely to provide patient-centered care—a "true North" to guide improvements in health

care quality [26, 27]—to patients with disability? After all, "nothing about me without me," a key maxim defining patient-centeredness [28], precisely echoes one rallying cry of the disability rights movement: "nothing about us without us" [29].

Certainly, if physicians themselves need accommodations—for vision correction, being deaf or hard of hearing, or mobility disability, for example—those very accommodations could help their patients with the same disabling conditions. For example, physicians who use wheelchairs would benefit from height-adjustable examination tables, which automatically raise and lower. Their patients with mobility disability would also find that "high-low" tables improve accessibility (i.e., a physician who lowers a height-adjustable exam table to facilitate his or her performance of physical exams would similarly position the table's height to best assist patients in getting on and off the table). However, height-adjustable examination tables are not yet widely available. A study of 2,389 California primary care facilities found that just 8 percent had a height-adjustable examination table [30]. Another study conducted a telephone survey of 256 practices in four US cities to assess the willingness of subspecialty clinicians to care for a fictional patient with hemiparesis (weakness on one side of the body) and obesity who used a wheelchair and could not self-transfer onto an examination table [30]. The researchers reported that 22 percent of practices could not accommodate the patient and 18 percent of practices could not transfer the patient onto an examination table [31]. One striking finding among clinicians who refused to accommodate this fictional patient was that they failed to recognize that their refusal was illegal under the ADA [13] and Section 504 of the Rehabilitation Act [32]. Most importantly, practices staffed by physicians with mobility disability would probably have accessible equipment and better understand their legal obligations to serve patients with mobility disability.

Other factors that contribute to disparities and poor care—and that possibly could be contravened by physician-patient concordance—are erroneous assumptions and stigmatized attitudes about the lives, preferences, values, and expectations of persons with disability. These explicit and implicit negative biases do vary by disability type (e.g., often persons with intellectual disability generate the most negative perceptions) [33-35], and physicians can share these prejudices [36-38]. However, physicians' attitudes toward persons with mobility disability can improve with greater experience with these patients, especially through interacting with wheelchair users whose full lives and extensive daily activities contradict stereotypes about the limitations imposed by wheelchair use [39]. In 1994, a seminal study of three Level I trauma centers compared the attitudes of 233 physicians, nurses, and emergency medical technicians toward treating persons with spinal cord injury (SCI) with responses of people with SCI from a previous study [40]. Among clinicians, 22 percent reported they would not want lifesustaining treatment if they had a SCI; 18 percent imagined being glad to be alive after SCI; and 41 percent felt that staff in their emergency departments tried "too hard to resuscitate or save" persons with new SCIs [41]. In contrast, 92 percent of respondents with SCI said they were glad to be alive. Physicians who themselves have SCI—or exposure of physicians to colleagues or patients with SCI—could likely dispel these negative impressions.

#### Conclusion

Plausible scenarios do exist that suggest why increasing the number of physicians who actively identify as having a disability and who require accommodations to practice could improve health care experiences and outcomes for patients with disability. Increasing the representation of physicians with disability in the clinical workforce will be challenging for reasons explored here but could potentially offer benefits to the growing population of patients with disability [42]. However, physicians with disability should not be burdened by unrealistic expectations about what they can accomplish. As a physician who became deaf wrote:

The single most important insight I have gained from being a disabled doctor is that I really have no idea what life is like for my patients.... The disability I know best is deafness. The profession I know best is medicine. So I accept that I've no idea how life is for, say, an accountant with cerebral palsy. But I do at least know what not to do if I should meet such a person. I won't automatically assume that they can't do certain things—nor will I blithely reassure them that they can. I'll ... try to build up a picture of a more complex reality. Above all, I will let them tell me how it is [43].

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## **SECOND THOUGHTS**

Technical Standards and Deaf and Hard of Hearing Medical School Applicants and Students: Interrogating Sensory Capacity and Practice Capacity

Michael Argenyi, MD

#### **Abstract**

Applicants to medical schools who are deaf and hard of hearing (DHoH) or who have other disabilities face significant barriers to medical school admission. One commonly cited barrier to admission is medical schools' technical standards (TS) for admission, advancement, and graduation. Ethical values of diversity and equity support altering the technical standards to be more inclusive of people with disabilities. Incorporating these values into admissions, advancement, and graduation considerations for DHoH and other students with disabilities can contribute to the physician workforce being more representative of the diverse patients it serves and better able to care for them.

#### Introduction

People who are deaf and hard of hearing (DHoH) are increasingly entering health care fields [1]. Yet, despite the fact that more than 15 percent of the general population experiences trouble with hearing loss [2], medical students with hearing loss represented a mere 0.01 percent of United States medical school graduates during the years 2001-2010 [3]. This statistic shows that DHoH medical students still face barriers to matriculation and graduation. One common barrier that DHoH and other candidates with disabilities face is the medical school technical standards (TS). The TS specify minimum abilities not necessarily related to acquisition of medical knowledge, including sensory and motor capabilities, thought by some to be necessary to function as a physician [4]. Candidates who are unable to demonstrate these requirements can be disqualified from matriculation and graduation. Because medical schools set their own TS, they differ widely both in the actual capacities required and how students can demonstrate them. Therefore, the importance of the TS cannot be underestimated, as it is difficult to predict how schools will interpret their own TS and how these interpretations might affect whether DHoH applicants are able to matriculate and receive any necessary accommodation.

The inherent difficulty in interpreting the TS when reviewing candidates for matriculation and graduation raises ethical issues concerning equity for individuals and diversification of medical school cohorts. However, some programs use alternative TS that enable

DHoH and other matriculants with disabilities to become successful physicians-in-training by incorporating inclusive language, such as explicit provisions for using accommodations, and by eliminating the unrealistic and outdated concept of the "undifferentiated physician" to better reflect the availability and technological capacity of accommodations and the larger roles of technology and specialization in health professions training.

## Variations in Medical Schools' Technical Standards

The Association of American Medical Colleges (AAMC) published guidelines for the TS in 1979 [5] in response to Section 504 of the Rehabilitation Act of 1973, which prohibits discrimination on the basis of handicap [6]. The guidelines called for "certain minimal technical standards for physicians that must be examined and enforced in the admissions process" that would enable physicians "to function in a broad variety of clinical situations and to render a wide spectrum of patient care" [7]. The report described the MD degree as "a broad *undifferentiated* degree attesting to the acquisition of general knowledge in all fields of medicine and the basic skills requisite for the practice of medicine" [8; italics added]. The AAMC subsequently published a handbook on students with disabilities in 2004 to encourage medical schools' compliance with the Americans with Disabilities Act of 1990 (ADA) [9], which expanded protections for people with disabilities by requiring programs receiving federal funding to provide reasonable accommodations or to make reasonable modifications to its policies, practices, or procedures [10].

Despite issuance of the AAMC handbook on students with disabilities, the AAMC guidelines left it up to schools to design their own institutional TS. For example, the AAMC 2005 TS guidelines [11] do not specify the skills required, merely stating that "technical standards should include those skills and abilities that are essential to the completion of the educational program" [12]. Moreover, the guidelines do not specify accommodations to be provided, stating, for example, "Institutions are afforded flexibility in how to provide auxiliary aids as long as students are not denied access to materials" [13]. Unsurprisingly, the TS are not consistent across institutions. In a 2014 review, Sandhouse concludes that there are no universal TS in any health care field [14]. Moreover, in a 2010 survey, 38.4 percent of medical schools reported having last revised their TS between 2001 and 2005 [3]. These findings highlight the challenge of using TS that might not have been updated in accordance with the AAMC guidelines for candidates with disabilities, including those who are DHoH. As a result, candidates with disabilities might not be able to gauge whether a medical school will, in fact, be willing to allow them to fulfill the technical standards using accommodations as intended by the ADA. In what follows, some institutions' TS were selected to briefly illustrate variations in the formulations of technical standards as well as in the allowed accommodations. These posted TS might not reflect the actual current practices of each medical school in admission and accommodation provision.

For example, some schools' TS, like those of the University of Central Florida College of Medicine (UCF) and Dartmouth University Geisel School of Medicine, use inclusive language. In its TS, UCF states that candidates must be able to "perceive relevant nonverbal communications such as changes in mood, activity, and posture as part of a physical examination of a patient," but the school allows that "accommodation through use of a trained intermediary or other communications aide may be appropriate when this intermediary functions as an information conduit" [15]. A candidate needs only "sufficient use" of the senses for physical examinations at UCF, and the TS do not specify which sense is to be used for which physical examination components. While UCF's TS are broader, Dartmouth specifically names different possible accommodations for students to demonstrate essential capacities for matriculation and graduation [16]. For DHoH students at Dartmouth:

Some intermediaries that may be acceptable include sign language interpreters—provided the interpreters offer only translation, and do not perform selective, analytic, interpretive, or integrative functions for the student—or transcriptionists who provide a similar function. In this way, a deaf student is simply enabled to "listen," but is still responsible for essential communication elements of the curriculum [16].

Inclusivity is demonstrated in both UCF's and Dartmouth's TS, as both explain the student's responsibility to evaluate sensory input and are open to the use of accommodations for students to receive that input and thus demonstrating the capacity to evaluate it. Under these TS, a DHoH student may receive traditionally auditory information (e.g., the patient history, heart sounds) through different "conduits" and still assumes the responsibility for demonstrating the knowledge required to translate that information into good clinical practice.

These aforementioned TS models also reflect an evolution away from the concept of the "undifferentiated graduate" that was briefly introduced and problematized earlier. DeLisa and Thomas argue that given medicine's increased specialization and the fact that inherent personal qualities can often be associated with medical specialties, some students might be simply better suited for certain specialties than others [17]. For example, a DHoH student who requires more communication accommodations might do less well in a fast-paced environment like the emergency department. Similarly, students with weaker hand-eye coordination might not naturally excel in surgery. Medical students tend to naturally gravitate toward specialties that augment their strengths and minimize their weaknesses, and those with disabilities are no different. While accommodations might enable students to train according to the ideal of an undifferentiated student and meet the TS, Van Matre and colleagues argue that students, with or without disabilities, will choose specific specialties according to their

aptitudes [18]. Therefore, the belief that students must somehow succeed equally across every rotation, an ideal embraced by many medical schools' TS, is less relevant as medical practices continue to specialize.

Conversely, many schools do not explicitly support accommodations [19], and some reject certain accommodations or have more exacting and exclusionary TS. For example, the University of Maryland School of Medicine (UMD) requires in their TS that candidates "must be able to ... hear adequately" for communication and auscultation and state that an intermediary is never appropriate [20]. This language is exclusionary because it could preclude DHoH candidates from matriculating. Similarly, Albert Einstein College of Medicine (AECOM) sets forth that "Under the law, a school need not approve any proposed 'accommodation' that may reasonably compromise patient health or safety" [21] and, more specifically, that "an impairment or disability may be such that despite reasonable accommodation the TS cannot be met" [21]. Furthermore, AECOM's TS penalize students for failing to report a "significant" disability:

Significant impairments or disabilities which are reasonably likely to affect a prospective student's capacity to satisfy the TS, or which represent a condition reasonably likely to prevent completion of the curriculum, may not be concealed or otherwise misrepresented. Doing so would be grounds for immediate suspension, dismissal, and/or other disciplinary considerations as per the by-laws [21].

What is understood by "significant" disability, however, can vary from person to person; one admissions committee might deem a specific disability to be significant, while another does not. This potential variation in interpretation of the TS leaves applicants at the mercy of each committee's definition of impaired capacity and reasonable accommodation, since standards are not consistently drafted or interpreted. Thus, programs with such noninclusive stipulations, like UMD and AECOM, might be perceived by DHoH applicants as unwelcoming, and possibly intimidating; these institutions' TS might deter DHoH and other persons with disabilities from applying.

## **Hearing Loss and Technical Standards**

Hearing loss is currently the most common physical and sensory disability encountered in medical school [3], and, in one survey, respondent schools reported providing accommodations for students with hearing loss almost as frequently as accommodations for students with motor and learning disabilities [3]. Once admitted, most DHoH medical students require at least one accommodation. The most commonly requested accommodation is a special stethoscope that allows either amplified or visual auscultation of heart and lung sounds, but other accommodations have included sign language interpreters, note-taking services, and modified surgical masks [1]. Hearing loss represents a wide spectrum of severity and accommodation needs for different

language modalities, including spoken English, American Sign Language, or mixed modalities. DHoH students and health care professionals potentially benefit from access to a unifying organization, the Association of Medical Professionals with Hearing Losses (AMPHL) [22], which gives legitimacy and support to those who are DHoH and are aspiring health care professionals or in related fields.

Despite the commonality of hearing loss in medical school and requests by DHoH students for accommodations, many DHoH applicants to medical schools have shared personal stories of being "cautioned" by schools to evaluate the TS to ensure that they could meet the TS. These stories were shared with AMPHL members at conferences and on now-defunct online forums. For students without disabilities, signing a TS compliance agreement is a formality. For DHoH students, it begins a conversation with the school and possibly the legal system about whether they will qualify for admission or graduation and whether necessary accommodations will be provided. If that conversation becomes adversarial, or if the school uses a "caution" or the TS as a de facto warning not to apply or matriculate, then it puts the applicant at a disadvantage before beginning medical school. Students subsequently feel pressured to not disclose their disability early in the process, which might cause medical schools to feel that the student has matriculated dishonestly.

### Case Law

There are several <u>legal cases</u> of <u>alleged disability discrimination</u> by medical schools involving TS in which a federal court decision permitted the plaintiffs to continue their training with accommodations [23, 24]. Although some survey participants have voiced concerns that DHoH applicants pose a danger to patient safety or a financial burden on medical schools and health systems [4, 17, 19], these concerns have not stood up to legal scrutiny [1, 11]. Two cases are especially notable as the plaintiffs were medical students. *Featherstone v Pacific Northwest University* held that safety concerns were unfounded given the long history of successfully practicing DHoH health care professionals and the routine presence of interpreters in the health care setting [23]. *Argenyi v Creighton* concluded that accommodations must be provided in order for the DHoH student to have the same educational access as peers without disabilities and that cost cannot be a factor given the overall operating budget of the university [24].

## Inclusivity and Service to Patients as Goals of Medicine

After thoughtfully considering the effects of the TS on enrollment and how students with disabilities can demonstrate their capacities, several commentators on the TS have focused on <u>promoting inclusivity</u>. These commentators have encouraged taking steps to promote enrollment of students with disabilities because of the perceived benefits of representative physicians [17, 25]. In 2004, Jordan J. Cohen, then serving as president of the AAMC, called upon medical schools to increase the enrollment of students with disabilities with the understanding that, like ethnic and racial minorities, physicians with

disabilities are more likely to provide care in their own communities [26]. Moreover, evidence supports the preference of DHoH patients for concordant clinicians because of shared empathy, culture, and communication [26-28]. However, if the TS require DHoH students, without the use of accommodations, to conform to standards for students without disabilities, then the opportunities for DHoH applicants to be seriously considered for admission to health care training programs and to serve their own communities remain limited.

## Ethical Implications of the TS's Sensory Capacity Assumptions

Equity is a concept that transcends the liberal value of equal opportunity to encompass outcomes [29]. In the more than 25 years since its passage, the ADA has enabled many students with disabilities to gain admission to and accommodations at institutions of higher learning. However, people with disabilities, including members of the DHoH community, continue to be underrepresented in the health professions, including medicine, because of the disconnect between the intention of the ADA to expand equality of opportunity and some medical schools' TS, which create inequities. Although DHoH persons can apply to any medical school, not all programs are fully accessible because of the various ways in which the TS are written, interpreted, and administered.

Pollard encourages the development of "functional" TS, which focus on the outcome of tasks rather than on the organic process by which they are accomplished [4]. A classic example is the need to evaluate heart sounds. "Organic" TS require a DHoH student to have the capacity to hear heart sounds, which rests on the erroneous assumption that hearing is the only way to assess heart sounds [4]. By contrast, functional TS, such as those employed at Dartmouth and UCF, require a DHoH student to be able to evaluate the heart but allow the use of different accommodations, including an amplified stethoscope, a visual stethoscope, or ultrasound, to do so. Under this model of TS as functional rather than organic, DHoH applicants could be treated equitably, and, if provided access to training with accommodations, they would help diversify the physician workforce and bring a wider diversity of clinicians' strengths, aptitudes, and life experiences to the clinical care of patients. A commitment to equity involves removing educational inequalities and barriers to admission—for example, by modifying the TS to allow accommodations and draw focus to functional outcomes. Such modifications in policy and practice would likely increase enrollment and graduation of DHoH candidates.

## Recommendations for Increasing Enrollment of Students with Disabilities

DeLisa and others have made a number of recommendations about how to increase the enrollment of students with disabilities, several still unheeded [17, 25]. In the interests of equity, I put forth several recommendations here. First, the AAMC graduation questionnaire routinely collects information regarding social demographics but currently does not include disability information [17]. Including this information would provide annual data on the number of graduates with disabilities and help illuminate institutional

attitudes toward disabilities through the concordance or discrepancy between student questionnaire responses and their written TS. Second, a committee—possibly under the AAMC—could develop universal functional TS that allow for appropriate accommodations for students with disabilities, applicable across all schools. These TS would specify the minimum necessary capacities in medical schools in the current age of practice. Given the expanding availability of technology and appropriate accommodations, medical students with disabilities might be able to demonstrate these necessary capacities. Third, an ethical and legal inquiry into what constitutes reasonable accommodations in the medical setting, involving disability specialists, ethicists, student representatives, and legal consultants or lawyers, could be initiated. Such an inquiry might be an ongoing process given the evolving nature of legal rulings and technology (for both disability accommodations and medical practice). Fourth, the AAMC or disability organizations like AMPHL could offer training to admissions committees that would facilitate their understanding of and appreciation for the differing educational stories of applicants. DHoH health care practitioners have all benefited from institutions that have been compassionate in their assessments, recognizing the benefits that we have to offer an underserved population and appreciating the challenges specific to hearing loss and their impact on our educational and social opportunities. For instance, a DHoH applicant might not gain the same experience from shadowing physicians if communication accessibility is unavailable and instead engage in extracurricular activities to compensate. If these recommendations are pursued, DHoH applicants and matriculants will continue their ascendency in higher education and professional fields. In return, many of us will serve DHoH patients or in organizations to bolster the advancement of the DHoH [1, 21]. Only then can the physician workforce truly represent our patient population and show equity in the opportunities seized, not merely available, to applicants.

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