Published in final edited form as:

JAMA. 2016 November 1; 316(17): 1767–1768. doi:10.1001/jama.2016.9956.

Moving from Disability to Possibility

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When I was in the first grade, an astute teacher noticed that I had trouble seeing the blackboard. This finding was quickly confirmed by a vision test. Formal evaluation by an ophthalmologist revealed that I had a rare degenerative retinal disease. Worse than that diagnosis was the ophthalmologist's devastating prognosis for my life: attending college would be very challenging, sports and certain activities would be difficult or impossible, and it was unlikely that I would ever have a professional career.

With the support of my family, I strove to not live out the dystopia of my ophthalmologist's predictions. This formative patient experience also shaped my future. Years later, as a college premedical student shadowing physicians in the hospital, I became convinced that patients in particular and individuals in general deserve to be defined by their strengths and not by a discouraging perspective of disability, such as the one that my family and I received.

When applying to medical school (and disclosing that I had a disability), I once again encountered a myopic view, sometimes receiving unsolicited advice that medicine was unrealistic given my visual disability and to consider other careers. This appears to be the norm, as recent research suggests that only one third of U.S. medical schools would explicitly provide accommodations to a qualified student with a disability.¹

Society as a whole and, I feel, education and health care professionals have, for too long, viewed students with disabilities as a problem to be managed. As a first year medical student, I repeatedly heard William Osler's maxim that the good physician treats the disease, but the great physician treats the patient. Osler's caution, I believe, was to not rely exclusively on a biomedical model. I fear that sometimes when medical schools encounter applicants or students with disabilities, they do not see the whole individuals; they do not see possibilities. Instead, looking through the lens of that same biomedical model, they focus narrowly on the disabilities and, as a result, see only impairments.

In 2015, the United States celebrated the 25th anniversary of the Americans with Disabilities Act (ADA). As a nation, we have made important progress toward improving the education and employment opportunities for Americans with disabilities. Nevertheless, disparities in education and employment remain—particularly in the health professions.² In recent years,

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Conflict of Interest Disclosures: Dr. Herzer has no potential conflicts of interest to disclose.

several notable lawsuits have been filed against medical schools related to the schools' failure to provide accommodations to students with disabilities. In some instances, these cases involved overt discrimination. But, more broadly, these lawsuits are emblematic of the need for a new lens with which to look at the inclusion of individuals with disabilities in medical education. That new lens should emphasize possibility.

Defining technical standards—those capabilities required of students for admission, promotion, and graduation from medical school—is important, but accommodations and currently available assistive technology offer many opportunities for students with disabilities to fulfill technical standards.³ In the preclinical years, I used large-print versions of lecture slides and handouts for didactic coursework. In anatomy lab, I wore custom-made optical surgical loupes—the same kind of magnifying lenses worn by surgeons when operating—to magnify dissections. On the clinical wards, I carry and use various pocket-sized magnifying devices in order to read small print on medicine vials, to more clearly see patients' pupillary responses, or to magnify skin rashes.

Prospectively, one of the greatest barriers identified by my ophthalmologists, low-vision specialists, and advisors was the accessibility of clinical workstation computers. As my transition to the clinical wards neared, I approached my institution's chief medical information officer—with the support of my advisors—to determine how to make the more than 5,000 clinical workstation computers visually accessible, regardless of the location of my assigned clerkships. Working with institutional technology leaders, we devised a solution that provided customized computer screen magnification across our health system—a solution that can be scaled to assist other low-vision employees and patients. This partnership focused not on disability but on possibility, and the solution was imaginative in how it pushed the limits of currently available virtualization technology. Moreover, this approach embodied the concept of “universal design,” which seeks to create environments that are intrinsically accessible to all individuals regardless of disability status.

The collaborative experience that I have described—which involved my personal physicians, academic advisors, disability services experts, and technology engineers—is what the ADA mandates, but in practice may be the exception and not the rule. In addition, my experience likely does not generalize to students with other types of disabilities or at other institutions, and this is why the ADA requires that accommodation decisions be made on a case-by-case basis. In my case, technical solutions exist that make medical school possible. Technical solutions also exist to extend the opportunity to go to medical school to students with other disabilities. For example, hard-of-hearing individuals can auscultate with electronic stethoscopes that dramatically amplify sounds. Individuals with spinal cord injuries can use standing wheelchairs to work at the operating table. Universities across the United States are required to have institutionally designated disability experts to determine eligibility for services and to assist students and faculty with identifying and acquiring assistive technology and implementing accommodations.

Although more advanced technology is still needed as well as dissemination of the knowledge as to what disability accommodations currently exist, today the barriers to inclusivity of students with disabilities are predominantly attitudinal and cultural in nature.

Medical education and training is imbued with a culture of perfection, as well as with a rigid hierarchy that reinforces power differences between students, residents, and attending physicians; these barriers may deter students from disclosing their disabilities for fear of appearing less than perfect or undeserving of respect. In conversing with students with disabilities at a number of U.S. medical schools, I have found that this fear of disclosure is real and prevalent. Some students report being wholly unsupported after disclosing their disabilities. Students with disabilities who find themselves in this position may perform below their capabilities because they choose not to disclose and therefore do not receive the accommodations they need. The end result serves neither the students, medical schools, nor patients well. This stands in contrast to my experience, but it underscores the current challenges faced by some students and the disparate acceptance of disability across schools. I have openly disclosed my visual impairment to the clinical teams I work with; this disclosure has been met with curiosity, but also with respect and support from fellow students, residents, and attending physicians. They ask what they can do to help. Small, relatively simple changes can make an outsized difference, such as verbalizing the location and characteristics of MRI findings during rounds rather than simply pointing to a lesion on the monitor.

This discussion is not intended to suggest that any individual with a disability is necessarily qualified to enter medical school and practice medicine, nor is it the case that students with disabilities will be able to specialize in any field of their choosing. In the same way that all medical students consider and weigh their underlying temperaments, strengths, and future goals when choosing a specialty—with no person being optimally suited for all specialties—students with disabilities face additional but realistic constraints on their choices. For instance, it would be unwise for me to pursue medical specialties that are especially demanding visually, such as surgery, pathology, or radiology. It is the professional responsibility of all prospective physicians to understand their strengths and limitations and choose specialties where they will serve their patients well while upholding the ethical precepts of beneficence and non-maleficence.

Despite these considerations, the path forward is to recognize that both students and physicians with disabilities can share in the essential ethos of the medical profession: a devotion to relieving human suffering and curing disease.⁴ Encouraging efforts are already under way. There is a growing interest in studying medical students with disabilities,^{5,6} about which little is known. This research agenda can emphasize the prevalence and types of disabilities represented in U.S. medical schools, how best to support medical students with disabilities, the efficacy of accommodations, and the performance of these students when they are appropriately accommodated. In 2013, a group of experts formed the Coalition for Disability Access in Health Science and Medical Education; in addition to leading research, this group seeks to develop and disseminate best practices for supporting students with disabilities who are in graduate health science and medical education programs.⁷ The Coalition has created a learning community that allows medical schools to identify and share solutions to best support students with disabilities and to cultivate institutional expertise. The Coalition and the Association of American Medical Colleges (AAMC) have together hosted a series of webinars—the most popular ever hosted by the AAMC—on disability topics for medical educators. There is a growing interest among medical schools across the U.S. to

improve disability services for students and an increasing appreciation for how these students contribute to the diversity of the physician workforce. These developments suggest a bright future, one grounded in collaboration rather than litigation.

There are undoubtedly easier career paths than medicine for students with disabilities to pursue. These students choose medicine knowing the barriers they could face. Yet these students undoubtedly feel great devotion and enthusiasm and want to commit their lives to a noble cause—to serve others through the practice of medicine. Their inclusion should not be viewed as a problem, but rather as an opportunity to be welcomed and embraced.

Acknowledgments

I am grateful to Lisa Meeks, PhD, Lynette Mark, MD, and Susan Turley, MA, BSN, RN, for their comments to an earlier version of this article. I also thank Emily Frosch, MD, Thomas Koenig, MD, Peter Greene, MD, Steve Sears, Scott Rabalais, Peter Donnell, and countless others at Johns Hopkins Medicine for their leadership and support. These individuals were not compensated.

Funding/Support: Dr. Herzer is supported by Medical Scientist Training Program grant T32GM007309-41 from the National Institute of General Medical Sciences and National Institute on Aging Grant R36AG051727.

Role of the Funders/Sponsors: The funding agencies had no role in the design and conduct of the study; collection, management, analysis, and interpretation of the data; preparation, review, and approval of the manuscript; or decision to submit the manuscript for publication.

References

1. Zazove P, Case B, Moreland C, et al. U.S. medical schools' compliance with the Americans with Disabilities Act: findings from a national study. *Acad Med*. 2016
2. Gostin LO. The Americans with Disabilities Act at 25: the highest expression of American values. *JAMA*. 2015; 313(22):2231–2235. [PubMed: 26057283]
3. Meeks, L.; Jain, NR. *The Guide to Assisting Students with Disabilities: Equal Access in Health Science and Professional Education*. New York: Springer Publishing Company; 2015.
4. Cassel EJ. The nature of suffering and the goals of medicine. *N Engl J Med*. 1982; 306(11):639–645. [PubMed: 7057823]
5. Meeks LM, Herzer KR. Accommodated MCAT time and performance measurements. *JAMA*. 2015; 314(14):1517–1518. [PubMed: 26462002]
6. Searcy CA, Dowd KW, Hughes MG, Baldwin S, Pigg T. Association of MCAT scores obtained with standard vs extra administration time with medical school admission, medical student performance, and time to graduation. *JAMA*. 2015; 313(22):2253–2262. [PubMed: 26057286]
7. University of California San Francisco. The Coalition for Disability Access in Health Science and Medical Education. 2015. <http://meded.ucsf.edu/msds/coalition>. Accessed February 13, 2016