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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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