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## Disability Cultural Competence in the Medical Profession

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## DISABILITY CULTURAL COMPETENCE IN THE MEDICAL PROFESSION

MARY CROSSLEY\*

### I. INTRODUCTION

People with disabilities make up an estimated nineteen percent of the United States (U.S.) population,<sup>1</sup> and many of them are heavier consumers of health care than people without disabilities.<sup>2</sup> Yet relatively few physicians—the persons responsible for providing medical care to this significant fraction of the patient population—have disabilities themselves, and the percentage of medical students with disabilities is even smaller.<sup>3</sup>

Although the needs of people with disabilities for health care are diverse, varying with the type of impairment experienced and any underlying condition, many have significant health needs.<sup>4</sup> But as a group, people with disabilities experience health care disparities, receiving some health services at a lower rate than non-disabled patients and facing barriers to accessing needed health

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1. Lisa I. Iezzoni, *Eliminating Health and Health Care Disparities Among the Growing Population of People with Disabilities*, 30 HEALTH AFF. 1947, 1947 (2011) (citing 2010 Census Bureau Data). The Institute of Medicine projects substantial growth in the coming decades in the number of people with disabilities in the United States. INST. MED., *THE FUTURE OF DISABILITY IN AMERICA* 1 (National Academies Press 2007).

2. Wayne L. Anderson et al., *Estimates of State-Level Health-Care Expenditures Associated with Disability*, 125 PUB. HEALTH REPS. 44, 45 (2010); Gerben DeJong et al., *The Organization and Financing of Health Services for Persons with Disabilities*, 80 MILBANK Q. 261, 269-70 (2002).

3. Demetrius Moutsiakakis & Thomas Polisoto, *Reassessing Physical Disability Among Graduating US Medical Students*, 89 AM. J. PHYSICAL MED. & REHABILITATION 923, 926 (2010); Sarah M. Eickmeyer et al., *North American Medical Schools' Experience With and Approaches to the Needs of Students with Physical and Sensory Disabilities*, 87 ACAD. MED. 567, 567 (2012); Joel A. DeLisa & Peter Thomas, *Physicians with Disabilities and Physician Workforce: A Need to Reassess Our Policies*, 84 AM. J. PHYSICAL MED. & REHABILITATION 5, 6 (2005); Stanley F. Wainapel, *Physical Disability Among Physicians: An Analysis of 259 Cases*, 9 INT'L DISABILITY STUD. 138, 138 (1987); Sam S. Wu et al., *Physical Disability Among American Medical Students*, 75 AM. J. PHYSICAL MED. & REHABILITATION 183, 187 (1996).

4. Gloria L. Krahn et al., *Persons with Disabilities as an Unrecognized Health Disparity Population*, 105 AM. J. PUB. HEALTH S198, S198 (2015).

services.<sup>5</sup> They also exhibit health disparities,<sup>6</sup> far more often reporting being in poor or fair health than people without disabilities.<sup>7</sup>

The under-representation of people with disabilities in the medical profession and the disparities they experience reflect just two aspects of a health care system that fall short of the goals of the Americans with Disabilities Act (ADA), passed twenty-five years ago with the purpose of “provid[ing] a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities.”<sup>8</sup> In passing the ADA, Congress understood that discrimination against people with disabilities takes diverse forms, including “the discriminatory effects of architectural, transportation, and communication barriers, overprotective rules and policies, exclusionary qualification standards and criteria, segregation, and relegation to lesser services, programs, activities, benefits, jobs, or other opportunities.”<sup>9</sup> Yet a quarter century later, people with disabilities pursuing careers in the health professions continue to face exclusionary qualification standards. And people with disabilities continue to face avoidable barriers to the receipt of effective health care.

Much could be written about how these two problems relate to one another and how they relate to broader challenges in achieving the ADA’s goals. This essay highlights one likely connection: the relative rareness of doctors with disabilities may contribute to a generally low level of understanding within the medical profession of the social context of disability and how non-medical factors affect the health of people with disabilities. This lack of understanding, in turn, contributes to less effective medical care for people with disabilities.

The observation that providers’ limited understanding of the lived experience of people with disabilities contributes to poor health outcomes is far

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5. See generally Iezzoni, *supra* note 1 (discussing health care disparities including low screening rates and difficulty accessing services).

6. Although usages vary somewhat, the term “health disparities” generally refers to “differences in health outcomes at the population level, that . . . are linked to a history of social, economic, or environmental disadvantages, and that . . . are regarded as avoidable.” Krahn et al., *supra* note 4, at S198. By contrast, “health care disparities” refers to differences in the level and type of health care received, in access to health care, and in insurance coverage. See *id.* at S203.

7. Iezzoni, *supra* note 1, at 1949-50; Krahn et al., *supra* note 4, at S201 (listing documented disparities). See also Michelle A. Meade et al., *The Intersection of Disability and Healthcare Disparities: A Conceptual Framework*, 35 DISABILITY & REHABILITATION 632, 632-33 (2015) (distinguishing health care disparities from health disparities and noting that the former is one component of the latter).

8. 42 U.S.C. § 12101(b)(1) (2012). In its findings, Congress stated that “discrimination against individuals with disabilities persists in such critical areas as . . . health services.” *Id.* § 12101(a)(3).

9. *Id.* § 12101(a)(5).

from novel.<sup>10</sup> This essay, however, asserts that better educating medical students and doctors about the disability experience by treating disability as an element of cultural competence could produce benefits on two fronts. First, by equipping doctors to provide the culturally competent and accessible services that people with disabilities need, it could help mitigate that group's health and health care disparities. Second, expanding the medical profession's understanding of disability could, over time, lead to more accessible programs of medical education and accommodating health care employment settings, thus smoothing the path for more people with disabilities to enter the medical profession.

This essay first describes the concept of cultural competence and its place within medical education and considers briefly whether a "disability culture" exists and should be an element of cultural competence training for doctors. A core element of disability culture is people with disabilities' common history of social exclusion, stigmatization, and oppression. This history undergirds a contemporary understanding of disability defined in part by its rejection of a medical model of disability. The "social model" of disability rejects the "medical model," and both historical and contemporary evidence explain the distance and distrust that still stretch between many people with disabilities and the medical profession.

The essay proceeds to review some recent signs of progress, including increased attention to the health and health care disparities experienced by people with disabilities and expanded discussions about health care providers' role in addressing these disparities. Moreover, some medical educators have begun developing curricula that emphasize competencies doctors need to care effectively for people with disabilities. The essay concludes by suggesting how disability cultural competence education may both benefit patients with disabilities and contribute to increased representation of people with disabilities within the medical profession.

## II. DISABILITY CULTURAL COMPETENCE

### A. *Cultural Competence and Medical Training*

Any discussion of disability cultural competence requires first an understanding of cultural competence as a concept. The phrase refers to an understanding developed in "caring" professions like medicine, nursing, and social work over the past few decades that, in order to provide high quality and effective care, provider interactions with service recipients must recognize and

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10. See Krahn et al., *supra* note 4, at S204 ("Every major report addressing the poor health of people with disabilities has called for improvements in training of health care providers about adults with disabilities.").

respect aspects of the recipient's culture relevant to her receipt of services.<sup>11</sup> Depending on the situation, this might include a person's values, traditions, beliefs, and other cultural dimensions of her identity.<sup>12</sup> Achieving cultural competence requires a provider to learn both to recognize how his own culture informs the care provided and to adapt his practice to address cultural differences.<sup>13</sup> In effect, adapting systems and methods of providing care to patients' cultural understandings is a way of making systems of care more inclusive. Inclusion's characterization as "the active, intentional, and ongoing engagement with diversity . . . [to] increase [one's] awareness, content knowledge, cognitive sophistication, and empathic understanding of the complex ways individuals interact within systems and institutions"<sup>14</sup> describes cultural competence as well.

As a result of increasing cultural diversity in the U.S. and a growing recognition of how important patient trust and compliance are to effective treatment, the value of cultural competence and the need for effective training have gained wide acceptance.<sup>15</sup> Increased recognition of racial and ethnic health disparities also prompted greater attention to the role of culture in health care.<sup>16</sup> In 2000, the Liaison Committee on Medical Education (the accrediting body for medical schools in the U.S.) introduced a standard requiring that faculty and students demonstrate "an understanding of the manner in which people of diverse cultures and belief systems perceive health and illness and respond to various symptoms, diseases, and treatments."<sup>17</sup> As a result, medical

11. *E.g.*, NAT'L ASS'N OF SOC. WORKERS, CODE OF ETHICS § 1.05(b) (2008) ("Social workers should have a knowledge base of their clients' cultures and be able to demonstrate competence in the provision of services that are sensitive to clients' cultures and to differences among people and cultural groups."). *See also* Lisa C. Ikemoto, *Racial Disparities in Health Care and Cultural Competency*, 48 ST. LOUIS U. L. J. 75, 75 (2003) ("Cultural competence efforts aim at changing the institutional culture of health care and accompanying social services. The efforts include enabling health care and social service workers to provide effective access and care to patients with diverse values, beliefs, and practices.").

12. Gary E. Eddey & Kenneth L. Robey, *Considering the Culture of Disability in Cultural Competence Education*, 80 ACAD. MED. 706, 706 (2005).

13. *Id.*

14. *Making Excellence Inclusive*, ASS'N AM. COLLEGES & U., <https://www.aacu.org/making-excellence-inclusive> (last visited Dec. 18, 2015). *See generally* J. MILEM ET AL., MAKING DIVERSITY WORK ON CAMPUS: A RESEARCH-BASED PERSPECTIVE (Ass'n of Am. Colls. & Univs. 2005).

15. *See* Joseph R. Betancourt et al., *Cultural Competence and Health Care Disparities: Key Perspectives and Trends*, 24 HEALTH AFF. 499, 502 (2005).

16. *Id.* at 503.

17. ASS'N OF AM. MED. COLLS., CULTURAL COMPETENCE EDUCATION 1 (2005).

schools have introduced diverse cultural competency education as part of their curricula.<sup>18</sup>

But developing cultural competence curricula requires defining the project's scope. Whose culture should be taught? And what even counts as "culture"? In 2005, the Association of American Medical Colleges (AAMC) provided its view of what cultural competence actually entails:

Cultural and linguistic competence is a set of congruent behaviors, knowledge, attitudes, and policies that come together in a system, organization, or among professionals that enables effective work in cross-cultural situations. "Culture" refers to integrated patterns of human behavior that include the language, thoughts, actions, customs, beliefs, and institutions of racial, ethnic, social, or religious groups.<sup>19</sup>

The AAMC's statement reflects a common early understanding as to the appropriate scope of cultural competence, an understanding that utterly failed to consider that having a disability might be part of a patient's cultural identity to which health care providers should be attuned.<sup>20</sup>

#### B. *Disability Culture*

Questioning the omission of disability from common understandings of cultural competency, however, provokes the question: Is there such a thing as "disability culture"? Many find it hard to conceive of disability culture because the term "disability" encompasses a wide range of conditions experienced by a heterogeneous mix of people.<sup>21</sup> People with disabilities come from diverse backgrounds, experience a variety of impairments and resulting disabilities, and may seem at first blush to have little in the way of shared life experiences. Consequently, viewing them as sharing a culture of which professionals should somehow be aware may seem improbable.

"A shared way of life" is a common definition of culture.<sup>22</sup> So how can the huge group of people (about fifty-four million, just in the U.S.<sup>23</sup>) with a broad range of disabilities be understood to share a culture? A team of pharmacy educators considering whether persons with disabilities share a cultural identity identified the following markers, including the sharing of "(1) a collective

18. See Betancourt et al., *supra* note 15, at 502 ("[A]cademe has seen robust advances in cultural competence.").

19. ASS'N OF AM. MED. COLLS., *supra* note 17, at 1.

20. See W. Thomas Smith et al., *Disability in Cultural Competency Pharmacy Education*, AM. J. PHARMACEUTICAL EDUC., Mar. 10, 2011, at 1, 3 (suggesting that health professions educators may not recognize the barrier experienced by people with disability or "maybe they are overwhelmed by a seemingly infinite number of other cultures that exist").

21. *Id.* at 3.

22. See *id.* at 1; see also Eddey & Robey, *supra* note 12, at 706 (quoting definition from anthropology).

23. Smith et al., *supra* note 20, at 2.

identity; (2) common history; (3) common experiences; (4) shared beliefs, values, and norms; and (5) distinctive material goods originating from a shared identity, like arts [and] music.”<sup>24</sup>

Using these markers, a strong case can be made that people with disabilities do have a distinctive culture, founded on their shared history of discrimination and common experiences of stigmatization, poverty, social isolation, lack of self-determination, and “imposed immobility”—all of which combine to produce a common sense of identity.<sup>25</sup> Moreover, commentators observe that people with disabilities share a number of core values. These include “an acceptance of human differences, . . . a matter-of-fact orientation toward helping and being helped, . . . and a sense of humor about disability.”<sup>26</sup> These core values inform the growing music, art, and literature created by individuals with disabilities to express and interpret their experiences of living with disability.<sup>27</sup> The emergence of disability cultural centers at universities<sup>28</sup> further cements the recognition of disability culture.

Not every individual living with a disability shares in all aspects of this culture—just as not every member of a racial, ethnic, or religious group will share in that group’s culture. But unlike other cultures, disability has an element of universality, in the sense that anyone can become disabled at any time and most people will experience some degree of disabling limitation during their lives.<sup>29</sup> Moreover, subgroups of people with the same disability may share a distinctive sub-culture, as in the case of Deaf culture.<sup>30</sup> Nonetheless, recognition is growing that many people with disabilities have forged some level of group identity, based on common history of oppression and a common bond of resilience.

24. *Id.* at 1-2.

25. *Id.* at 2; Laurie J. Woodard et al., *An Innovative Clerkship Module Focused on Patients with Disabilities*, 87 ACAD. MED. 537, 537 (2012).

26. Eddey & Robey, *supra* note 12, at 709 (noting Carol J. Gill, *A Psychological View of Disability Culture*, 15 DISABILITY STUD. Q. 16, 17 (1995)).

27. See Steven E. Brown, *Disability Culture: A Fact Sheet*, INDEP. LIVING INST. (1996), <http://www.independentliving.org/docs3/brown96a.html>; see also Eddey & Robey, *supra* note 12, at 706-07.

28. The following universities have established disability cultural centers: *Disability Cultural Center*, SYRACUSE U., <http://sudcc.syr.edu/> (last visited Dec. 22, 2015); *Campus Disability and Programs*, U. WASH., <http://www.washington.edu/doit/campus-disability-centers-and-programs> (last visited Dec. 22, 2015); *Disabled Student Cultural Center*, U. MINN., <http://sua.umn.edu/groups/directory/group/230/> (last visited Dec. 22, 2015). The student government organization at Georgetown University voted in favor of a proposed Disability Cultural Center. Max Harris and Jenna Galper, *GUSA Executive Endorses Establishment of Disability Cultural Center*, GEORGETOWN U. STUDENT ASS’N (Feb. 23, 2015), <http://www.gu-studentassociation.org/wp-content/uploads/2015/02/Press-Release-GUSA-endorses-DCC.pdf>.

29. Smith et al., *supra* note 20, at 2.

30. See Eddey & Robey, *supra* note 12, at 707.

### C. *Rejecting the Medical Model*

Recognizing people with disabilities' shared history of social exclusion and oppression supports an understanding of disability that has gained increasing acceptance in the disability community and more broadly. This contemporary "social model" of disability stands in contrast to the historically prevalent "medical model" of disability.<sup>31</sup> The medical model views the problem of disability as lying in a deficit or pathology residing in a person's body.<sup>32</sup> Accordingly, the preferred response to disability under the medical model is to "fix" the person's body.<sup>33</sup> By contrast, the social model understands disability as a problem resulting from the interaction of social and environmental conditions (like prejudices and physical barriers) with a person's impairment.<sup>34</sup> Thus, because the disadvantages and challenges associated with disability flow at least in part from how physical, social, and economic environments are built, changing those environments can ameliorate disability's disadvantages.<sup>35</sup> This contrast can be overstated, of course, since disability also results from a physical or mental impairment that may require medical care.<sup>36</sup> Advocates of the social model, though, caution that focusing on medical needs may divert attention from how structures produce disability.<sup>37</sup>

Beyond this basic contrast between the two models, it bears noting that the medical model is strongly (and negatively) associated with the medical profession.<sup>38</sup> One disability studies<sup>39</sup> scholar, after acknowledging that other "helping fields" may also pathologize disability, goes on to conclude: "There

31. *But cf.* Krahn et al., *supra* note 4, at S199 (referring to the medical model as "still predominant in the United States").

32. Iezzoni, *supra* note 1, at 1948.

33. Tom Shakespeare et al., *The Art of Medicine: Disability and the Training of Health Professionals*, 374 LANCET 1815, 1815 (2009); *see* Iezzoni, *supra* note 1, at 1948 (describing the medical model).

34. Iezzoni, *supra* note 1, at 1948.

35. *Id.* at 1948-49.

36. Shakespeare et al., *supra* note 33, at 1815.

37. *Id.*

38. *See id.*

39. A legal scholar describes the field of Disability Studies as:

[A]pp[ly]ing social, cultural, historical, legal, philosophical and humanities perspectives to understanding the place of disability in society. It explores disability as a social and cultural construct and as a phenomenon reflecting and constituting identity formation by incorporating the "real-lived" experiences of people with disabilities. Furthermore, Disability Studies adopts a cross-disability perspective and explores differences and commonalities in the experiences of the diverse groups of people society has defined as "the other" based on their disability.

Arlene Kanter, *The Law: What's Disability Studies Got to Do with It or An Introduction to Disability Legal Studies*, 42 COLUM. HUM. RTS. L. REV. 403, 404 (2011).



are few, if any places where a [Disability Studies] perspective is more crucial than in the medical fields, whose name disability studies has appropriated to represent the model our field most opposes.”<sup>40</sup> Several factors have contributed to a sense of distance and distrust between the medical profession and many people with disabilities. First, society has long relied on medical expertise to make judgments about the extent and severity of a person’s disability—judgments determining who will receive material assistance from society and who must bear any burdens associated with their impairment without assistance.<sup>41</sup> This reliance, as well as the authority generally granted to physicians, elevated them and gave them significant power over the lives of people with disabilities. At the same time, it undermines the agency and power of people with disabilities. As Susan Wendell writes: “The authority of medicine tends to delegitimize our experiences of our bodies as sources of knowledge about them, because the authoritative, that is, the medical and scientific, descriptions of our bodies are third-person descriptions of physical conditions.”<sup>42</sup>

But the reasons for distrust include starker and darker harms that physicians historically visited on people with disabilities. For many years, physicians were complicit in the history of mistreatment of people with disabilities, including involuntary institutionalization and forced medical procedures.<sup>43</sup> Willowbrook State School, with its history of abuses of and experimentation on children with disabilities,<sup>44</sup> is deemed emblematic of physician devaluation of disabled people, much as the Tuskegee Syphilis Study is for African Americans.<sup>45</sup> Physicians pursuing eugenic agendas involuntarily sterilized women judged to be disabled;<sup>46</sup> others advocated the denial of life-saving medical treatment for infants believed to have disabilities.<sup>47</sup>

40. Alex Lubet, *Can Disability Studies Survive and Prosper Within Medically-Modeled Curricula?*, DISABILITY STUD. Q., Fall 2004, <http://dsq-sds.org/article/view/891/1066>.

41. See Lisa I. Iezzoni & Linda M. Long-Bellil, *Training Physicians About Caring for Persons with Disabilities: “Nothing About Us Without Us!”* 5 DISABILITY & HEALTH J. 136, 136 (2012).

42. SUSAN WENDELL, *THE REJECTED BODY: FEMINIST PHILOSOPHICAL REFLECTIONS ON DISABILITY* 119 (Routledge 1996).

43. E.g., PAUL A. LOMBARDO, *THREE GENERATIONS NO IMBECILES: EUGENICS, THE SUPREME COURT, AND BUCK V. BELL* (The Johns Hopkins U. Press 2008).

44. DAVID GOODE ET AL., *A HISTORY AND SOCIOLOGY OF THE WILLOWBROOK STATE SCHOOL* (Am. Ass’n Intellectual & Developmental Disabilities 2013).

45. See Clarence J. Sundram, *In Harm’s Way: Research Subjects Who Are Decisionally Impaired*, 1 J. HEALTH CARE L. & POL’Y 36, 64 (1998).

46. See Lombardo, *supra* note 43, at ix.

47. See Mary A. Crossley, *Of Diagnoses and Discrimination: Discriminatory Nontreatment of Infants with HIV Infection*, 93 COLUM. L. REV. 1581, 82-84, 1605 n.86 (1993).

Disability studies scholars offer medicine's "myth of control" as one explanation of medicine's devaluation of disabled life.<sup>48</sup> This phrase captures the idea that doctors historically have sought to control and fix dysfunctional and defective bodies,<sup>49</sup> but often reject or lose interest in unfixable bodies.<sup>50</sup> According to this explanation, physicians may find it demoralizing to care for people with incurable, disabling conditions and seek to avoid them. Or, like many people in American society, doctors may feel social discomfort around people with disabilities and thus avoid addressing the relevance of a patient's disability.<sup>51</sup>

Even today, many offices of physicians and other health care providers seem to be in a "land that time forgot" when it comes to accessibility for people with disabilities.<sup>52</sup> The *New York Times* recently described a study in which a physician called more than 250 specialists, seeking to refer a hypothetical patient who was partially paralyzed, used a wheelchair, and weighed 200 pounds.<sup>53</sup> The responses to the call illustrate the problem:

One out of five offices refused to even book an appointment. Some explained that their buildings were inaccessible to people in wheelchairs, but most refused simply because they had no equipment like height-adjustable examining tables and chairs, specially designed weight scales or trained staff members to help move the patient out of the wheelchair.

But even the offices that agreed to see the patient were not necessarily offering appropriate care. When pressed, some acknowledged that they had no plans or equipment for moving the patient. Others said that they would complete only the parts of the exam that they could — and forgo the rest. Fewer than 10 percent of these offices had appropriate equipment or employees trained to help patients with disabilities.<sup>54</sup>

48. See WENDELL, *supra* note 42, at 94-96.

49. Cf. Stephanie M. Vertrees, *Medical Humanities, Ethics, and Disability*, 21 CAMBRIDGE Q. HEALTHCARE ETHICS 260, 263 (2012) ("[I]t is the abolition of illness that motivates physicians . . . [and] the concept of beneficence fundamentally assumes that there is 'badness' on which 'goodness' must be affected.").

50. Cf. Lisa I. Iezzoni, *Going Beyond Disease to Address Disability*, 355 NEW ENG. J. MED. 976, 977 (2006) ("Chronic disability can thwart physicians' motivation to cure diseases.").

51. *Id.* ("Disability becomes the elephant in the room — present but unmentioned.").

52. See Meade et al., *supra* note 7, at 637 (citing to studies showing that "a significant number of healthcare offices remain both inaccessible . . . with regard to physical barriers as well as training provided to office staff" and that "the majority of primary care physicians, dentists and psychologists continue to work out of offices that are minimally accessible").

53. Pauline W. Chen, *Disability and Discrimination at the Doctor's Office*, N.Y. TIMES (May 23, 2013, 3:56 PM), [http://well.blogs.nytimes.com/2013/05/23/disability-and-discrimination-at-the-doctors-office/?\\_r=0](http://well.blogs.nytimes.com/2013/05/23/disability-and-discrimination-at-the-doctors-office/?_r=0).

54. *Id.*; The results of the research were published in the *Annals of Internal Medicine*. Tara Lagu et al., *Access to Subspecialty Care for Patients with Mobility Impairment: A Survey*, 158 ANNALS INTERN. MED. 441, 443-44 (2013).

Curiously, the researcher found that many specialists' offices apparently did not realize that their failure to make services available to a person with a disability could violate federal law.<sup>55</sup> Other sources confirm that people with disabilities continue to face pervasive problems of access when they seek medical care.<sup>56</sup> This challenge in finding accessible services and a widespread lack of trust in the medical profession are among the reasons for the serious health and health care disparities experienced by people with disabilities, a phenomenon generating increased public attention in the past decade.

### III. DISABILITY AND DISPARITIES

Despite this history of people with disabilities too often experiencing neglect, condescension, and even coercion from physicians, the past decade has witnessed high-profile recognitions of the health and health care disparities experienced by this group. In 2005, the Surgeon General issued a *Call to Action to Improve the Health and Wellness of Persons with Disabilities*.<sup>57</sup> As a corollary to the federal government's broader "New Freedom Initiative," which sought fuller inclusion of persons with disabilities in all aspects of society, the *Call to Action* recognized good health as a precondition to an individual's "freedom to work, learn and engage actively in . . . families and . . . communities."<sup>58</sup> To that end, the *Call to Action* articulates four goals, including health care providers having the knowledge and tools to treat persons with disabilities holistically and with dignity.<sup>59</sup>

Other organizations issued similar reports. In 2009, the National Council on Disability's (NCD) Report on the Current State of Health Care for Persons with Disabilities<sup>60</sup> succinctly summarized its findings regarding the nature and causes of disparities:

People with disabilities tend to be in poorer health and to use health care at a significantly higher rate than people who do not have disabilities. They also experience a higher prevalence of secondary conditions and use preventative

55. Chen, *supra* note 53.

56. Nancy R. Mudrick et al., *Physical Accessibility in Primary Health Care Settings: Results from California On-site Reviews*, 5 DISABILITY & HEALTH J. 159, 161-65 (2012) (reporting significant access barriers from survey of facilities serving Medicaid patients in California).

57. U.S. SURGEON GEN., U.S. DEP'T HEALTH & HUMAN SERVS., THE SURGEON GENERAL'S CALL TO ACTION TO IMPROVE THE HEALTH AND WELLNESS OF PERSONS WITH DISABILITIES V (2005) [hereinafter U.S. SURGEON GEN.].

58. *Id.* at 2, 8.

59. *Id.* at 2 ("Goal 2: Health care providers have the knowledge and tools to screen, diagnose and treat the whole person with a disability with dignity."); U.S. SURGEON GEN., *supra* note 57, at 2 ("Goal 4: Accessible health care and support services promote independence for persons with disabilities.").

60. See generally NAT'L COUNCIL ON DISABILITY, THE CURRENT STATE OF HEALTH CARE FOR PEOPLE WITH DISABILITIES (2009).

services at lower rates . . . . People with disabilities are affected disproportionately by such barriers [to care], including health care provider misinformation, stereotypes about disability, and lack of appropriate provider training; limited medical facility accessibility and lack of examination equipment that can be used by people with diverse disabilities; lack of sign language interpreters; lack of materials in formats that are accessible to people who are blind or have vision impairments; and lack of individualized accommodations.<sup>61</sup>

In 2010, the Department of Health and Human Services (HHS) issued its *Healthy People 2020* document, the fourth in a series of documents establishing public health goals for the nation.<sup>62</sup> *Healthy People 2020* lists areas in which people with disabilities experience disparities and includes several disability-related goals for ensuring that public health programs include persons with disabilities and that barriers to effective care are eliminated.<sup>63</sup> And a broader, global perspective on the health status of people with disabilities emerged the following year with the World Health Organization's (WHO) *World Report on Disability*.<sup>64</sup> Framed as lying at "the intersection of public health, human rights and development," the Report finds that more than a billion people worldwide have some disability and that the disproportionate barriers they face to good health can be overcome.<sup>65</sup>

These reports provide diverse perspectives on the health challenges experienced by persons with disabilities and propose varying remedial responses. Several themes relevant to this essay, however, emerge from these reports and other literature following in their wake. Persons with disabilities receive lower levels of health care<sup>66</sup> and suffer from poorer health outcomes<sup>67</sup> than people without disabilities. But, although many people with disabilities have significant health needs, "disability [itself] does not necessarily equate to poor health."<sup>68</sup> Instead, the health disparities experienced by people with

61. *Id.* at 23.

62. U.S. DEP'T HEALTH & HUMAN SERVS., *HEALTHY PEOPLE 2020* 2-3 (2010), [http://www.healthypeople.gov/sites/default/files/HP2020\\_brochure\\_with\\_LHI\\_508\\_FNL.pdf](http://www.healthypeople.gov/sites/default/files/HP2020_brochure_with_LHI_508_FNL.pdf).

63. U.S. Dep't Health & Human Servs., *Disability & Health*, HEALTHYPEOPLE.GOV, <http://www.healthypeople.gov/2020/topics-objectives/topic/disability-and-health> (last updated Sept. 4, 2015).

64. WORLD HEALTH ORG., *WORLD REPORT ON DISABILITY* (2011).

65. *Id.* at 3, 261, 263.

66. See Iezzoni et al., *supra* note 1, at 1951 (reporting studies finding disparities in treatment for early stage breast and lung cancers).

67. See generally Meade et al., *supra* note 7, at 633 (describing evidence of a range of disparities).

68. Donald J. Lollar & John E. Crews, *Redefining the Role of Public Health in Disability*, 24 ANN. REV. PUB. HEALTH 195, 200 (2003).

disabilities result in large part from environmental and attitudinal barriers baked into the health care system.<sup>69</sup>

According to this literature, several strata of barriers impede access to effective care. Central among the barriers are the medical profession's lack of awareness of the disability experience, and negative attitudes toward and assumptions about disability.<sup>70</sup> Because of humiliating or unhelpful experiences with the health care system, people with disabilities may avoid seeking medical care, relying instead on self-treatment.<sup>71</sup> Layered onto attitudinal barriers are communication barriers that can pose significant obstacles to effective care for patients with hearing, visual, or cognitive impairments, or developmental disabilities.<sup>72</sup> And yet another layer lies in providers' widespread failure to ensure physical accessibility in their equipment and facilities.<sup>73</sup> Finally, as a group, people with disabilities are particularly affected by social determinants of health such as poverty, low employment levels, poor housing, and social isolation,<sup>74</sup> compounding their burden of poor health.

None of these barriers is inevitable, though. Accordingly, the differences in health and health care experienced by persons with disabilities are largely avoidable. Limited data prevents precisely measuring the disparities existing for people with disabilities.<sup>75</sup> But the reports from the Surgeon General, NCD,

69. See Tara Lagu et al., *The Axes of Access — Improving Care for Patients with Disabilities*, 370 NEW ENG. J. MED. 1847, 1847 (2014) (identifying domains of physical access, policies and procedure to facilitate access, and communication access); see also Mari-Lynn Drainoni et al., *Cross-Disability Experiences of Barriers to Health-Care Access*, 17 J. DISABILITY POL'Y STUD. 101, 105 (2006) (classifying barriers as structural, financial, and personal/cultural).

70. Cf. Iezzoni, *supra* note 1, at 1952 (regarding physicians' failure to ask women of child-bearing age about contraception).

71. Iezzoni & Long-Bellil, *supra* note 41, at 136; cf. Cecelia Roscigno, *Challenging Nurses' Cultural Competence of Disability to Improve Interpersonal Interaction*, 45 J. NEUROSCIENCE NURSING 21, 22, 31 (2013) (reviewing narratives of negative encounters with health care professionals that patients with disabilities perceived as insensitive and synthesizing six themes describing those encounters).

72. Iezzoni, *supra* note 1, at 1948.

73. *Id.* at 1952; Elizabeth Pendo, *Shifting the Conversation: Disability, Disparities and Health Care Reform*, 6 FIU L. REV. 87, 89 (2010).

74. Cf. Dep't of Health & Human Servs. *Disability and Health*, HEALTHYPEOPLE.GOV, <http://www.healthypeople.gov/2020/topics-objectives/topic/disability-and-health/objectives>, (last updated Sept. 4, 2015) (including objectives regarding employment, housing, and community participation for people with disabilities). In addition, people with disabilities are disproportionately female and from racial and ethnic minority backgrounds, suggesting the possibility that "multiple minority status" may play some role in disparities. See Meade et al., *supra* note 7, at 633.

75. Iezzoni, *supra* note 1, at 1951 ("Beyond survey data little information is available to explore disparities among people with disabilities."). In addition, what data do exist pose

HHS, and the WHO consistently find that disparities exist, are avoidable, and thus are unjust.<sup>76</sup> As a result, the call to act to improve the health of people with disabilities has resounded clearly in the past decade.

As part of the growing chorus proclaiming the existence of disparities and the imperative to address them, discussions about the role that physicians and other health care providers can play in addressing those disparities have begun. In particular, commentary has recognized the contribution of the failure to train physicians to care for people with disabilities, and thus has emphasized the importance of improving the training that providers receive in how to provide effective care and treatment to people with disabilities.

#### IV. DISABILITY CULTURAL COMPETENCY AND MEDICAL TRAINING

##### A. *A History of Inattention*

This increased attention to the distinctive aspects of caring for people with disabilities, while encouraging, has emerged against a backdrop of enduring inattention. Even as the medical academy and profession increasingly recognized the importance of physicians' cultural competence in the 1990s and 2000s,<sup>77</sup> disability was not invited to the cultural competence party. As noted above, the AAMC's 2005 articulation of cultural competence referred to "racial, ethnic, social, or religious groups," but made no mention of persons with disabilities.<sup>78</sup> Even beyond a cultural competence approach, few medical schools formally attended to disability in their curricula.<sup>79</sup> And to the extent that training on caring for persons with disabilities was absent from the formal curriculum, medical students and junior doctors learned from the "hidden curriculum"—the day-to-day practical experiences of interacting with more

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problems of comparability because of varying definitions of disability used by federal agencies and researchers. See Krahn et al., *supra* note 4, at S199.

76. Krahn et al., *supra* note 4, at S198, S200, S202-S203.

77. See generally CARMEN J. BEAMON ET AL., A GUIDE TO INCORPORATING CULTURAL COMPETENCY INTO HEALTH PROFESSIONALS' EDUCATION AND TRAINING 18 (2006).

78. See ASS'N OF AM. MED. COLLS., *supra* note 17.

79. Woodard et al., *supra* note 25, at 537 (citing to a Special Olympics survey finding that only 25% of medical schools have curricula covering caring for people with intellectual/developmental disabilities); cf. Letter from the Nat'l Council on Disability, to The President of the U.S., Report on The Current State of Health Care for People with Disabilities 1 (Sept. 30, 2009) (on file with the National Council on Disability) ("The absence of professional training on disability competency issues for health care practitioners is one of the most significant barriers preventing people with disabilities from receiving appropriate and effective health care."); Krahn et al., *supra* note 4, at S204 ("[D]isability competency is not currently a core curriculum requirement for medical school accreditation or for receipt of federal funding.").

senior colleagues, many of whom displayed regressive attitudes and assumptions about people with disabilities.<sup>80</sup>

Thus, only after the Surgeon General's *Call to Action* in 2005 did discussions of disability-related competencies begin to occur more frequently.<sup>81</sup> Since that time, a small cadre of health educators has undertaken the project of articulating these competencies for providers.<sup>82</sup> The suggested competencies are wide-ranging, from the need to ask patients about their preferred method of communication, to being able to recognize how examination and diagnostic equipment may pose accessibility issues, to appreciating the value that people with disabilities attach to maintaining functioning and their lifestyles.<sup>83</sup> This project is still in its infancy, with neither medical educators nor accreditors having yet adopted any set of competencies.<sup>84</sup>

### B. *Cultural Competence for Disability*

Not all these discussions approach the need for improved medical training regarding disability as a matter of cultural competence.<sup>85</sup> Some advocates of improved training describe the need to understand disability as a human rights imperative.<sup>86</sup> Other presentations of disability-related offerings treat the knowledge and skills addressed as more technical than cultural in nature.<sup>87</sup> By focusing primarily on technical aspects of care, this approach risks reinforcing

80. Shakespeare et al., *supra* note 33, at 1815; *see also* Vertrees, *supra* note 49, at 262-63 (describing how early professionalization produced one doctor's assumptions regarding disability).

81. *See generally* Eddey & Robey, *supra* note 12 (advocating early on for disability cultural competence training in medical education).

82. *Id.* at 706.

83. *See* Paula M. Minihan et al., *Desired Educational Outcomes of Disability-Related Training for the Generalist Physician: Knowledge, Attitudes, and Skills*, 86 ACAD. MED. 1171, 1173-75 (2011); Kenneth L. Robey et al., *Teaching Health Care Students About Disability Within a Cultural Competency Context*, 6 DISABILITY & HEALTH J. 271, 273-74 (2013).

84. *See* Woodard et al., *supra* note 25, at 540.

85. *See* Smith et al., *supra* note 20, at 6 (noting that among the growing body of health professions literature on disability education, only a few addressed disability as an element of cultural competency training); *see also* Eddey & Robey, *supra* note 12, at 711 (arguing for a cultural competence approach); *cf.* Elizabeth Pendo, *What Patients with Disabilities Teach Us about the Everyday Ethics of Health Care*, 50 WAKE FOREST L. REV. 287 (2015) (arguing that medical education should include instruction on how the ADA applies in clinical settings).

86. Shakespeare et al., *supra* note 33, at 1815 (relying on the rights articulated in the United Nations Convention of the Rights of Persons with Disabilities).

87. *See* Vertrees, *supra* note 49, at 265; *see also* K.L. Kirshner & R.H. Curry, *Educating Health Care Professionals to Care for Patients with Disabilities*, 302 [J] AMA 1334, 1334 (2009) (stating that health care professional education should include "the use of pictorial boards, assistive communications technologies, Braille or large print, and TTY machines or telephone relay operators" to effectively communicate with persons with various disabilities).

a medicalized, rather than humanistic, view of disability. And one physician, writing poignantly about how she became aware of her own negative perceptions of disabled patients, argues for “a robust exposure to medical ethics and humanities.”<sup>88</sup>

I think, though, that using a cultural competence lens to consider how to train medical students (and practicing physicians) to care for people with disabilities may go further in remediating the disparities that group experiences than other rationales. A cultural competence approach to disability treats disability as one among many important aspects of a person’s cultural identity and as a natural part of human diversity.<sup>89</sup> It does not treat disability as a problem to be fixed, any more than it would race, sex, or religion. Nor does it set a disabled person apart as somehow “special” or inferior.<sup>90</sup> In addition, it calls on individual physicians to recognize how their own professional culture affects their attitudes toward and treatment of people with disabilities.<sup>91</sup>

This essay need not exhaustively list all possible disability cultural competencies,<sup>92</sup> but highlighting a few may be helpful. A core competency in providing health care to persons with disabilities is being able to engage in open and effective communication.<sup>93</sup> The most salient aspect of this competency relates to effectiveness: Can the physician communicate in a way that permits the physician and patient to understand one another’s language? The physician’s mode of communication should accommodate whatever visual, auditory, or cognitive impairment the patient might have.<sup>94</sup> A culturally competent physician will inquire of the patient what mode of communication she prefers.<sup>95</sup> Beyond simple effectiveness of communication (meaning here that each party is able to convey meaning to the other),<sup>96</sup> open communication

88. Vertrees, *supra* note 49, at 265.

89. Cf. Kirshner & Curry, *supra* note 87, at 1334 (suggesting as a core competency, “a conceptual framework of disability in the context of human diversity, illness, the life span, and the constructed social and cultural environments”).

90. Cf. Shakespeare et al., *supra* note 33, at 1815 (noting that medical students may display concern for patients with disabilities “but have negative views about the experience of living with a disability”).

91. Robey et al., *supra* note 83, at 274.

92. See generally Eddey & Robey, *supra* note 12 (expanding fuller discussions of the competencies needed to provide culturally competent care for people with disabilities).

93. *Id.* at 707 (“[T]he physician must be willing and able to explore means of communicating with persons who might be fully nonverbal or have other verbal communication impairments.”).

94. Shakespeare et al., *supra* note 33, at 1816.

95. *Id.* (“[F]ailure to communicate effectively . . . not only wastes time and human resources, but potentially causes delays in diagnoses and treatment.”).

96. Cf. Eddey & Robbey, *supra* note 12, at 707 (suggesting that a doctor examining a nonverbal patient may need to abandon “the traditional open-ended questioning style . . . in favor of yes/no questions”).



is also essential to culturally competent care. Physicians need to learn how to avoid medicalizing a patient's disability or making assumptions about the intelligence,<sup>97</sup> values, or lifestyles of their disabled patients.<sup>98</sup>

Along with skills, disability cultural competencies also encompass knowledge and attitudes. Knowledge competencies include, for example, being familiar with common medical sequelae of disabling conditions and understanding how social factors contribute to disability.<sup>99</sup> Attitudinal components could include an acceptance that some persons with disabilities may not trust doctors because of previous negative experiences, and a willingness to support any caregivers that a patient may have.<sup>100</sup> Of course, while some competencies may be called for in treating most people with disabilities, specific disabilities or types of disabilities may require a more tailored competency.<sup>101</sup>

As described, these competencies reflect a cultural competency approach, asking health care providers to realize how their own cultures affect how they view patients and also to recognize and validate how a disabled patient values her functioning, health, and lifestyle. Fundamentally, these competencies also reflect the patient-centered approach to care—with its respect for patients' values and preferences—that is central to the Institute of Medicine's recommendations for improving the quality of care more broadly.<sup>102</sup> As Dr. Lisa Iezzoni writes, persons whose medical conditions limit their physical or mental abilities are likely to seek "information [from their doctors] about options that permit educated choices for conducting daily activities and maximizing the quality of life. A lack of open, productive, informative dialogue with physicians can impede, delay, or derail these choices."<sup>103</sup> By contrast, a doctor who has some appreciation for the lived experience of disability can be a valued partner.<sup>104</sup>

Medical educators have begun to take note. In 2012, an expert panel commissioned by the AAMC and the American Schools of Public Health issued recommendations that include disability as an element of cultural

97. See *id.* at 708 (noting a common assumption that a patient's inability to speak is associated with cognitive impairment).

98. See Iezzoni, *supra* note 50, at 978.

99. Minihan et al., *supra* note 83, at 1173.

100. *Id.* at 1174.

101. See Smith et al., *supra* note 20, at 7-8.

102. Cf. Iezzoni & Long-Bellil, *supra* note 41.

103. Iezzoni, *supra* note 50, at 976.

104. Cf. Shakespeare et al., *supra* note 33, at 1816 ("Disabled people have great insight into their own condition and this can ideally make their relationships with health professionals more of a partnership, where each can learn from the other and where disabled people and their health-care choices are respected.").

diversity of which students should have knowledge.<sup>105</sup> The recommendations are aimed at faculty and administrators in medical and public health schools who are responsible for curriculum decisions.<sup>106</sup> The panel's anticipated payoffs for improved cultural competency training include both improved outcomes overall and a reduction in health disparities.<sup>107</sup>

### C. *Emerging Curricular Initiatives*

Of course, knowing which competencies will permit physicians to treat people with disabilities in a manner informed by understanding of and respect for the lived experience of disability and its cultural components is just the first step toward ensuring that physicians exhibit those competencies. Medical schools and other educational organizations<sup>108</sup> must devise ways to help medical students and practicing physicians develop those competencies. In recent years, some medical schools have undertaken curricular initiatives to exactly that end—fostering students' ability to care effectively for people with disabilities.<sup>109</sup>

These innovations take a variety of forms and include both classroom and clinical experiences.<sup>110</sup> A common theme is to give medical students a chance to interact with people with disabilities in ways that do not focus exclusively on a discrete medical issue or the patient's disability, but that give students an opportunity to hear patients' perspectives on health and functioning, to appreciate the fullness of patients' lives, and to realize the kinds of barriers

105. ASS'N OF AM. MED. COLLS. & ASS'N OF SCHS. OF PUB. HEALTH, EXPERT PANEL ON CULTURAL COMPETENCE EDUCATION FOR STUDENTS IN MEDICINE AND PUBLIC HEALTH: REPORT OF AN EXPERT PANEL 8 (2012).

106. *Id.* at 3.

107. *Id.*

108. A non-profit organization, the Alliance for Disability in Health Care Education, now exists and promotes the development of disability-related curricula across the range of health care education. See ALLIANCE FOR DISABILITY IN HEALTH CARE EDUC., <http://www.adhce.org/> (last visited Nov. 2, 2015).

109. See Iezzoni, *supra* note 50, at 976 (listing "Selected Medical School Activities Related to Patients with Disabilities" from six medical schools).

110. See, e.g., Woodard et al., *supra* note 25, at 538 (describing a disability module within a mandatory third-year rotation that involves classroom sessions, model patients with disabilities, community-based activities, community site visits, home visits, and inter-professional experiences); A.B. Symons et al., *A Curriculum to Teach Medical Students to Care for People with Disability: Development and Initial Implementation*, 9 BMC MED. EDUC. 78, 78 (2009) (describing a longitudinal program throughout the four years of medical school that integrates disability-oriented activities); Iezzoni, *supra* note 50, at 976 (listing "Selected Medical School Activities Related to Patients with Disabilities" from six medical schools); Eddey & Robey, *supra* note 12, at 711.

people with disabilities regularly encounter when seeking health care.<sup>111</sup> For example, some authors highlight the value of students' visiting a patient with a disability in his own home, so that students can better understand the person's capabilities.<sup>112</sup> In some instances, the planning and presentation of trainings have included persons with disabilities, a step that better ensures that trainings capture the perspectives and concerns of disabled patients.<sup>113</sup> The essential points are to humanize people with disabilities in the fullness of their experiences and to help medical students understand their values and what it means to live in the world with a disability.

#### V. CONNECTING DISABILITY CULTURAL COMPETENCE TO MEDICAL WORKFORCE DIVERSITY

Purely from the perspective of providing high-quality care to patients with disabilities and reducing the health and health care disparities that the group experiences, promoting disability cultural competence training for health care professionals offers value. I would like to close by suggesting, though, that increasing disability cultural competence also may indirectly help increase the opportunities available to people with disabilities in the medical workforce.

A common refrain in discussions of racial and ethnic health care disparities is that one important avenue for addressing disparities lies in increasing the diversity of the health care workforce, and of physicians in particular.<sup>114</sup> These discussions typically cite data regarding the differential between representation of a racial or ethnic group in the general population and its representation within the medical profession. For example, although African Americans, Hispanics, and Native Americans make up more than twenty-five percent of the population in the United States, they represent only about six percent of the physician workforce.<sup>115</sup> In light of minority physicians' disproportionate tendency to practice in underserved areas and higher satisfaction levels for minority patients who receive care from a doctor in their own racial or ethnic group,<sup>116</sup> minority under-representation in the medical profession contributes

111. See generally Woodard et al., *supra* note 25; Symons et al., *supra* note 110; Iezzoni, *supra* note 50; Eddey & Robey, *supra* note 12.

112. See Shakespeare et al., *supra* note 33, at 1816.

113. Cf. Iezzoni & Long-Bellil, *supra* note 41 (applying the exhortation "Nothing about us without us!" to designing disability-related medical training).

114. See, e.g., *America Needs a More Diverse Physician Workforce*, ASS'N AM. MED. COLLEGES, <https://www.aamc.org/download/87306/data/physiciandiversityfacts.pdf> (last visited Dec. 18, 2015); see also Thomas A. LaVeist & Geraldine Pierre, *Integrating the 3Ds—Social Determinants, Health Disparities, and Health-Care Workforce Diversity*, 129 PUB. HEALTH REP. 9, 9 (2014).

115. ASS'N AM. MED. COLLEGES, *supra* note 114.

116. Cf. Damon Tweedy, *The Case for Black Doctors*, N.Y. TIMES (May 15, 2015), <http://www.nytimes.com/2015/05/17/opinion/sunday/the-case-for-black-doctors.html>.

to health disparities for minority groups. Increasing the number of racial and ethnic minority physicians does more than simply grow the supply of providers for patients, though. As the AAMC explains:

Exposure to racial and ethnic diversity in medical school contributes importantly to the cultural competence of all of tomorrow's doctors. A diverse student body brings an array of ideas to the learning environment; helps students challenge their assumptions; and broadens their perspectives regarding racial, ethnic, and cultural differences.<sup>117</sup>

This line of reasoning applies equally to the connectedness of disparities, cultural competence, and physician workforce under-representation for people with disabilities. While constituting about nineteen percent of the U.S. population, people with disabilities make up a significantly smaller share of the medical profession.<sup>118</sup> Good data regarding the number of practicing physicians with physical or mental disabilities have been lacking. As recently as 2010, an AAMC report titled *Diversity in the Physician Workforce*, while asserting that disability is an aspect of diversity, failed to report on the number of physicians with disabilities for lack of data.<sup>119</sup> Information regarding physician disability status simply has not been collected.<sup>120</sup> It is generally agreed, though, that people with disabilities are under-represented in medicine, with a 2005 article reporting estimates ranging from two to ten percent.<sup>121</sup>

Estimates of the percentage of medical students with disabilities are even lower, suggested at fewer than one percent having physical disabilities.<sup>122</sup> The higher rate of representation among practicing doctors likely reflects that many of those doctors acquired their disability, whether through injury, illness, or

117. ASS'N AM. MED. COLLEGES, *supra* note 114.

118. *Id.*

119. ASS'N OF AM. MED. COLLS., *DIVERSITY IN THE PHYSICIAN WORKFORCE: FACTS & FIGURES 2010 11-13* (2010), <https://www.aamc.org/download/432976/data/factsandfigures2010.pdf>.

120. *Id.* at 13.

121. DeLisa & Thomas, *supra* note 3, at 6.

122. Alicia F. Ouellette, *Patients to Peers: Barriers and Opportunities for Doctors with Disabilities*, 13 NEV. L. REV. 645, 649, 655 nn.20, 655 nn.44 (citing estimates). Worth remembering, however, is that the comparison pool of younger adults from which medical students typically are drawn is also lower than the nineteen percent figure for the U.S. population as a whole. The rate of medical students with mental health impairments rising to the level of disabilities may be higher, in part due to the stresses of medical school, but these "invisible" disabilities are even harder to count. *See generally* James T.R. Jones, "High Functioning": *Successful Professionals with Severe Mental Illness*, 7 DUKE F. L. & SOC. CHANGE 1, 3, 4-5 (2015).

aging, once already in practice.<sup>123</sup> As late as 2015, the AAMC could not report how many medical students had some kind of disability.<sup>124</sup>

Several reasons explain the paucity of medical students with disabilities. Professor Alicia Ouellette has written about medical schools' adoption of technical standards demanding, as admissions criteria, that applicants have certain physical and sensory abilities, and courts' reluctance to second-guess schools' judgments in imposing those standards as barriers to entry to medical school.<sup>125</sup> And even if a disabled student is admitted, some medical schools may be unwilling to make the accommodations needed to permit those students to successfully complete the program.<sup>126</sup> That said, in recent years the AAMC has espoused a more welcoming attitude toward students with disabilities,<sup>127</sup> and the pipeline of academically successful college graduates with disabilities has grown.<sup>128</sup> Thus, the representation of people with disabilities in medical schools may be growing.

Whatever the reasons for the relatively small number of doctors and medical students with disabilities, the point that increasing the diversity of the medical workforce can contribute to its development of cultural competence applies here.<sup>129</sup> Increasing the number of medical students and doctors with disabilities would help raise providers' consciousness in ways that should improve the care received by people with disabilities. As Shakespeare, Iezzoni, and Groce point out:

Perhaps the most dramatic learning can come when it is a peer who is disabled, rather than a patient. Learning alongside a student who is a wheelchair user or has restricted growth or is deaf can challenge negative assumptions directly, as well as broaden the pool of qualified people entering the health professions.<sup>130</sup>

123. See Myrle Croasdale, *Able to practice: Physicians with disabilities do what it takes to thrive*, AM. MED. NEWS (Jan. 17, 2005), <http://www.amednews.com/article/20050117/profession/301179956/4/>.

124. Email from AAMC Data Request Staff to Gabrielle Nicole Morella, Research Assistant to Mary Crossley (July 13, 2015, 6:15 EST) (on file with author).

125. See Ouellette, *supra* note 122, at 655-56.

126. Cf. ASS'N OF AM. MED. COLLS., MEDICAL STUDENTS WITH DISABILITIES: A GENERATION OF PRACTICE 20-28 (2005) (discussing case law).

127. See, e.g., ASS'N OF AM. MED. COLLS., MEDICAL STUDENTS WITH DISABILITIES: RESOURCES TO ENHANCE ACCESSIBILITY (2010) (providing information to medical schools considering whether and how to accommodate students with disabilities).

128. See Linda Villarosa, *Barriers Toppling for Disabled Medical Students*, N.Y. TIMES, Nov. 25, 2003, at F5 (describing "a growing number of students with disabilities who are thriving in medical school" but acknowledging that "no statistics document" that number).

129. Accord DeLisa & Thomas, *supra* note 3, at 5.

130. Shakespeare et al., *supra* note 33, at 1816; cf. Woodard et al., *supra* note 25, at 540 (noting the value of having a faculty member with a physical disability teaching a disability-focused clerkship module); Eddey & Robey, *supra* note 12, at 711 ("Beyond exposure to patients

I suggest, however, that the direction of influence might also operate in reverse. In other words, including more disability cultural competency education in medical schools and continuing medical education (as long as it is not marginalized within the curriculum)<sup>131</sup> may also enrich the perspective of medical school administrators and faculty and increase their willingness to admit more students with disabilities to programs and to accommodate them effectively once matriculated. Similarly, it may encourage health care organizations to think more flexibly about how to accommodate health care professionals who become disabled.<sup>132</sup> Ultimately, while cultural competency education is typically understood as enhancing medical communication and care for the benefit of patients, broadly incorporating disability cultural competence education into medical training may also produce significant benefits flowing to the profession, to would-be members of the profession with disabilities, and to the broader group of people with disabilities in our society.

## VI. CONCLUSION

Long devalued and misunderstood by members of the medical profession, persons with disabilities experience health and health care disparities. Improving medical education by incorporating disability into cultural competence curricula should help reduce those disparities by increasing physicians' ability to care effectively for people with disabilities. Including disability cultural competence as part of medical students' training offers another benefit as well. By giving medical educators and physicians a richer understanding of the lived experience of disability and the barriers that still impede access to disabled persons' full inclusion in society, embracing disability cultural competence training may pave the way for greater acceptance by the medical academy and profession of medical students and doctors with disabilities. Addressing the under-representation of people with disabilities in the medical profession promises in turn to improve the care received by patients who are disabled. Thus, a commitment to disability cultural competence may help erode remaining barriers to workforce access and equitable health care for Americans with disabilities.

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who have disabilities, exposure to faculty and other medical students who have disability may be helpful.”).

131. *Cf.* Lubet, *supra* note 40.

132. *See, e.g.,* Laura Rothstein, *Impaired Physicians and the ADA*, 313 [J] AMA 2219, 2220 (2015) (offering a recent discussion of how disability law's protections apply to impaired physicians).

