

WHAT PATIENTS WITH DISABILITIES TEACH US ABOUT THE EVERYDAY ETHICS OF HEALTH CARE

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INTRODUCTION

In *Healers: Extraordinary Clinicians at Work*,¹ by David Schenck and Dr. Larry Churchill, and in *What Patients Teach: The Everyday Ethics of Health Care*,² their follow-up with Joseph Fanning, the authors look at the everyday experience of health care and the relationships that shape it. They call attention to the ethical dimensions of the clinical encounter and the hope for, and desirability of, a genuine human engagement between the clinician and the patient. In their view, *healers* are clinicians who cultivate a therapeutic relationship with their patients. They identify a set of skills that accomplish this, including welcoming patients to the clinical space, attentive listening, and feeling and showing a deep respect for the patient as a person.³

The authors distill the skills or lessons of patient-centered care from in-depth conversations with patients about their experience of health care, rather than from abstract ethical principles or clinician-centered codes. The central inquiry of *What Patients Teach* is “[w]hat new possibilities for being human can we discover if we listen carefully and deeply enough to what patients have to teach us?”⁴ Here, I expand upon that inquiry by exploring the experiences and challenges of patients with disabilities and by exploring what patients with disabilities can teach us about the everyday ethics of health care.

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1. DAVID SCHENCK & LARRY CHURCHILL, *HEALERS: EXTRAORDINARY CLINICIANS AT WORK* (2012).

2. LARRY CHURCHILL, JOSEPH FANNING & DAVID SCHENCK, *WHAT PATIENTS TEACH: THE EVERYDAY ETHICS OF HEALTH CARE* (2013).

3. SCHENCK & CHURCHILL, *supra* note 1, at 23–24.

4. CHURCHILL, FANNING & SCHENCK, *supra* note 2, at 2.

Churchill, Fanning, and Schenck state that the experience of being a patient is emblematic of human experience and challenge the notion of independent, vigorous health as a norm.⁵ This fundamental insight resonates with the everyday experience of disability, which also challenges the socially constructed norms of health, function, and independence. In fact, one in five Americans lives with a disability, and many, if not most of us, will experience a disability over our lifespan. Recent U.S. Census data reveal that 56.7 million Americans reported some level of disability in 2010, encompassing a range of impairments, activity limitations, and participation restrictions in physical, mental, or communication domains.⁶ Given these numbers, all clinicians can expect to see many patients with many different disabilities.⁷

Patients with disabilities are vulnerable. They carry a high risk for poor health and poor health outcomes.⁸ As a group, they experience social disadvantages such as poverty, underemployment and unemployment, isolation, and discrimination at a higher rate than the general population.⁹ They also face multiple barriers to quality health care and report poorer health statuses than people without disabilities. A body of literature has found that people with disabilities use fewer preventive services, have poorer overall health outcomes, experience more preventable emergency room visits, and report more unmet needs and dissatisfaction with the services they do receive.¹⁰ A 2009 report by the National Council on Disability confirmed these findings, adding that people with disabilities use health care at a significantly higher rate than people who do not have disabilities, experience a higher prevalence of secondary

5. *Id.*

6. MATTHEW W. BRAULT, U.S. CENSUS BUREAU, AMERICANS WITH DISABILITIES: 2010: CURRENT POPULATION REPORTS 4 (2012), *available at* <http://www.census.gov/prod/2012pubs/p70-131.pdf>.

7. Clinicians can also expect to work with colleagues with disabilities. *See* Alicia Ouellette, *Patients to Peers: Barriers and Opportunities for Doctors with Disabilities*, 13 NEV. L.J. 645, 646 (2013).

8. Valerie A. Lewis et al., *The Promise and Peril of Accountable Care for Vulnerable Populations: A Framework for Overcoming Obstacles*, 31 HEALTH AFF. 1777, 1778 (2012).

9. *See, e.g.*, U.S. DEP'T OF LABOR, ECONOMIC PICTURE OF THE DISABILITY COMMUNITY PROJECT; KEY POINTS ON DISABILITY AND OCCUPATIONAL PROJECTIONS TABLES (2014), *available at* <http://www.dol.gov/odep/pdf/20141022-KeyPoints.pdf>; U.S. SENATE COMM. ON HEALTH, EDUC., LABOR & PENSIONS, FULFILLING THE PROMISE: OVERCOMING PERSISTENT BARRIERS TO ECONOMIC SELF-SUFFICIENCY FOR PEOPLE WITH DISABILITIES 2 (2014).

10. Karen Hwang et al., *Access and Coordination of Health Care Service for People with Disabilities*, 20 J. DISABILITY POL'Y STUD. 28, 29–30 (2009) (collecting results of population-based surveys).

conditions, and experience more problems accessing health care than other groups.¹¹

Despite the number and vulnerability of patients with disabilities, their everyday experience receives little attention in scholarship. Scholars of disability studies have called attention to the ways in which disability impacts health care interactions, and they have challenged bioethics scholars to address issues of disability and the disability rights perspective throughout the health care ethics agenda.¹² However, those studies that exist often focus on medical ethics related to the very beginning or very end of life and in circumstances in which the patient is (or is thought to be) unable to express his or her own wishes. As a result, the everyday lived experience of disability is often left unexamined or relegated to the status of special circumstances.¹³

The ethical dimensions of the health care experiences of people with disabilities reveals the critical role of architecture and attitudes in shaping successful clinical encounters. Patients with disabilities experience fundamental physical barriers in health care offices and facilities, including a lack of accessible medical and diagnostic equipment, and a lack of policies or procedures designed to accommodate special needs and promote access. Underlying attitudinal barriers—such as clinician assumptions, biases or lack of knowledge about living with disability, and a lack of awareness of the federal laws that protect and promote accessible health care—accompany these physical barriers.

Churchill, Fanning, and Schenck implicitly address these attitudinal barriers when they say that clinicians can learn the skills critical to the formation of therapeutic relationships. Clinician exposure, attitudes, and cognitive biases present obstacles in the development of these skills with respect to patients with disabilities. While medical institutions should foster these skills for medical students and clinicians to the benefit of all patient care, I

11. NAT'L COUNCIL ON DISABILITY, *THE CURRENT STATE OF HEALTH CARE FOR PEOPLE WITH DISABILITIES* 10 (2009).

12. Classic works on stigma and disability in the health care context include Adrienne Asch, *Distracted by Disability*, 7 *CAMBRIDGE Q. HEALTHCARE ETHICS* 77 (1998) and Paul K. Longmore, *Medical Decision Making and People with Disabilities: A Clash of Cultures*, 23 *J.L. MED. & ETHICS* 82 (1995). Other works on disability include ALICIA OUELLETTE, *BIOETHICS AND DISABILITY: TOWARD A DISABILITY-CONSCIOUS BIOETHICS* (Cambridge 2011); ANITA SILVERS ET AL., *DISABILITY, DIFFERENCE, DISCRIMINATION: PERSPECTIVES ON JUSTICE IN BIOETHICS AND PUBLIC POLICY* (1998); Ron Amundson & Shari Tresky, *On a Bioethics Challenge to Disability Rights*, 32 *J. MED. & PHIL.* 541 (2007); and Gregor Wolbring, *Disability Rights Approach Toward Bioethics?*, 14 *J. DISABILITY POL'Y STUD.* 174 (2003).

13. Anita Silvers, *Reconciling Equality to Difference: Caring (F)or Justice for with Disabilities*, 10 *HYPATIA* 30, 36 (1995).

argue here that all medical students and clinicians should receive disability-specific education. Such education should include the requirements of the Americans with Disabilities Act of 1990 (“ADA”)¹⁴ in the clinical context.

I. PHYSICAL ACCESS TO THE CLINICAL SPACE

What Patients Teach describes the physical aspects of clinical space, as well as the relational environment in which a clinician practices, as an “interesting and understudied facet of healing.”¹⁵ The passage goes on to quote a patient who ended a relationship with an internist because her office space was “wheelchair unfriendly” and the staff was unwelcoming.¹⁶ Research suggests that redesigned spaces can foster healing.¹⁷ As the experience of the patient quoted in *What Patients Teach* suggests, inaccessible spaces reflect and reinforce negative attitudes toward people with disabilities. My research on inaccessible medical and diagnostic equipment—such as exam tables, chairs, scales, and imaging equipment—reveals that the physical and the attitudinal barriers are deeply connected.¹⁸

The experiences of patients with disabilities bring into focus the physical architecture of the clinical space and the nature and extent of the physical barriers that continue to exclude them. Numerous studies have found that patients with disabilities experience a variety of physical barriers to care.¹⁹ Barriers can include inaccessible entry doors, hallways, restrooms, examination rooms, examination tables and chairs, weight scales, and X-ray and imaging equipment.²⁰ Two recent studies showed that less than ten percent of outpatient facilities have examination tables that adjust

14. Americans with Disabilities Act of 1990, Pub. L. No. 101-336, 104 Stat. 327 (codified as amended at 42 U.S.C. §§ 12101–12213 (2012)).

15. CHURCHILL, FANNING & SCHENCK, *supra* note 2, at 54.

16. *Id.*

17. Michael Kimmelman, *In Redesigned Room, Hospital Patients May Feel Better Already*, N.Y. TIMES, Aug. 21, 2014, at A1.

18. See Elizabeth Pendo, *Disability, Equipment Barriers and Women’s Health: Using the ADA to Provide Meaningful Access*, 2 ST. LOUIS U. J. HEALTH L. & POL’Y 15, 16–17 (2008) [hereinafter Pendo, *Disability*]; Elizabeth Pendo, *Reducing Disparities Through Health Care Reform: Disability and Accessible Medical Equipment*, 2010 UTAH L. REV. 1057, 1057. My research on the barrier of inaccessible medical and diagnostic equipment focuses on patients with mobility impairments, but there are many other types of disabilities that can impact the patient experience of health care.

19. Pendo, *Disability*, *supra* note 18, at 19–26.

20. Nancy R. Mudrick et al., *Physical Accessibility in Primary Health Care Settings: Results from California On-Site Reviews*, 5 DISABILITY & HEALTH J. 159, 160–65 (2012).

to allow for a safe transfer, be it assisted or on one's own, from a wheelchair.²¹

For patients with mobility impairments, the lack of accessible medical and diagnostic equipment is a significant barrier, but not the only barrier. A 2013 study published in the *Annals of Internal Medicine* documented the difficulty of simply making an appointment for patients with disabilities.²² In that study, the surveyors employed the use of a “secret shopper” method, similar to the investigatory testing model used to document civil rights violations in other arenas, such as public accommodations, lending, housing, and employment.²³ Posing as patients, the surveyors attempted to make appointments, some of which required the use of an examination table, with a variety of specialists in four large cities.²⁴ They sought to determine whether the patient could make an appointment and whether the patient could be safely transferred to an examination table.²⁵ Each surveyor related the chief symptoms relevant to the practice and medical history, including obesity, use of a wheelchair, and the need for assistance to transfer to the examination table.²⁶

The researchers found that men and women who report mobility disabilities have difficulty making appointments for care with specialists, and they may receive less or lesser care as a result.²⁷ Of the 256 specialty practices surveyed, fifty-six practices (twenty-two percent) reported that they could not accommodate a patient in a wheelchair, typically because they could not transfer a patient to an examination table.²⁸ A few inaccessible practices reported a willingness to use potentially risky methods to transfer the patient to the table, such as manually transferring the patient from the wheelchair to a table that was not height-adjustable.²⁹ Only twenty-two practices (nine percent) reported the use of accessible equipment such as height-adjustable tables or lifts.³⁰

21. Tara Lagu et al., *Access to Subspecialty Care for Patients with Mobility Impairments*, 158 ANNALS INTERNAL MED. 441, 443–44 (2013); Mudrick et al., *supra* note 20, at 163–64.

22. Lagu et al., *supra* note 21; Elizabeth Pendo, *New Study Quantifying Lack of Access for People with Disabilities*, HEALTHLAWPROF BLOG (Feb. 11, 2014), http://lawprofessors.typepad.com/healthlawprof_blog/2014/02/guest-blogger-associate-dean-elizabeth-pendo-new-study-quantifying-lack-of-access-for-people-with-disabilities.html (discussing the study).

23. Lagu et al., *supra* note 21, at 441–45; Pendo, *supra* note 22.

24. See Lagu et al., *supra* note 21, at 442; Pendo, *supra* note 22.

25. Lagu et al., *supra* note 21, at 442.

26. *Id.*; Pendo, *supra* note 22.

27. Lagu et al., *supra* note 21, at 442.

28. *Id.* at 441, 443.

29. See *id.* at 443–44.

30. *Id.* at 441.

Almost all inaccessible practices provided reasons for refusing to see a patient who used a wheelchair, most of them providing reasons that violated the ADA requirement that health care programs and facilities be accessible to patients with disabilities.³¹ In another troubling finding, a few such practices reported a willingness to provide a less-than-full examination of the patient from his or her wheelchair, instead of from the examination table.³²

II. CLINICIAN ATTITUDES AND BIASES

In its 2007 report, *The Future of Disability in America*,³³ the Institute of Medicine stated that the lack of provider education and disability awareness is one of the most significant barriers to care and that providing more education to providers is critical to counter lack of knowledge about disability, disability stereotypes, and disability misconceptions.³⁴ A body of research on the role of cognitive bias and emotion in interactions with people with disabilities, including in the clinical setting, suggests the significance of the barriers. People with disabilities often report negative encounters with clinicians, ranging from overt discrimination to subtle expressions of paternalism, exclusion, or diminishment.³⁵

The authors of *Healers* describe Kay Jamison's story about a consult for treatment of her own bipolar disorder, which appears in one of her several books on the subject.³⁶ Her psychiatrist asked her if she planned to have children and if she knew that manic-depression was a genetic disease.³⁷ Ms. Jamison responded that she knew that bipolar disorder was a genetic disease and that she very much wanted children.³⁸ Ms. Jamison then recounted:

At that point, in an icy and imperious voice that I can hear to this day he stated—as though it were God's truth, which he no doubt felt that it was—"You shouldn't have children. You have

31. *Id.* at 445. See generally Pendo, *Disability*, *supra* note 18 (containing a detailed discussion of the application of the ADA to barriers in health care settings).

32. See Lagu et al., *supra* note 21, at 443–44.

33. INST. OF MED., *THE FUTURE OF DISABILITY IN AMERICA* (Marilyn J. Field & Alan M. Jette eds., 2007).

34. See *id.* at 5–9.

35. See Pendo, *Disability*, *supra* note 18, at 40–47; Silvia Yee & Mary Lou Breslin, *Achieving Accessible Health Care for People with Disabilities: Why the ADA is Only Part of the Solution*, 3 *DISABILITY & HEALTH J.* 253, 255 (2010).

36. SCHENCK & CHURCHILL, *supra* note 1, at 145.

37. *Id.*

38. *Id.*

manic-depressive illness.” I felt sick, unbelievably and utterly sick, and deeply humiliated.³⁹

The impact of clinician attitudes, assumptions, and biases can also be more subtle, as evidenced by a robust body of research on the role of cognitive bias in interactions with people with disabilities, including in the clinical setting.⁴⁰ Considerable evidence suggests that many people without a disability cannot identify with people with a disability and, in fact, significantly and unreasonably devalue the lives of people with disabilities.⁴¹ In an example of this disconnect, people with disabilities consistently report a good or excellent quality of life despite the negative assessments of others, a phenomenon known as the *disability paradox*.⁴² Studies have consistently demonstrated that clinicians also hold negative views of people with disabilities.⁴³ Carol J. Gill’s examination of these views found that “health professionals significantly underestimate the quality of life of persons with disabilities compared with the actual assessments made by people with disabilities themselves. In fact, the gap between health professionals and people with disabilities in evaluating life with disability is consistent and stunning.”⁴⁴ Other studies have examined the attitudes of students in the health care professions with similar results.⁴⁵

Inaccurate and negative assessments about the lives of people with disabilities may prevent a clinician from seeing a patient as a complete person. Irving Kenneth Zola describes a “spoiling process,” in which the physical impairment “obscure[s] all other characteristics behind that one and swallow[s] up the social identity

39. *Id.*

40. See generally J.D. Trout, *Paternalism and Cognitive Bias*, 24 L. & PHIL. 393 (2005) (reviewing the robust literature on cognitive bias).

41. Elizabeth Pendo, *Substantially Limited Justice?: The Possibilities and Limits of a New Rawlsian Analysis of Disability-Based Discrimination*, 77 ST. JOHN’S L. REV. 225, 226–67 (2003).

42. See Gary L. Albrecht & Patrick J. Devlieger, *The Disability Paradox: High Quality of Life Against All Odds*, 48 SOC. SCI. & MED. 977, 978–79 (1999).

43. Carol J. Gill, *Health Professionals, Disability, and Assisted Suicide: An Examination of Relevant Empirical Evidence and Reply to Batavia (2000)*, 6 PSYCHOL. PUB. POL’Y & L. 526, 530 (2000).

44. *Id.*

45. Raymond C. Tervo et al., *Health Professional Student Attitudes Towards People with Disability*, 18 CLINICAL REHABILITATION 908, 908 (2004) (finding nursing, medicine, and allied health students held less positive attitudes than the norm, as measured on the Scale of Attitudes Toward Disabled Persons (“SADP”)); Raymond C. Tervo et al., *Medical Students’ Attitudes Toward Persons with Disability: A Comparative Study*, 83 ARCHIVES PHYSICAL MED. & REHABILITATION 1537, 1541 (2002) (finding first-year medical students held less positive attitudes than SADP norms).

of the individual.”⁴⁶ In the clinical context, seeing the disability rather than the person speaks to that which *What Patients Teach* describes as a way of “[n]ot-seeing people.”⁴⁷

The social science literature discusses disability as a stigmatizing “‘master status’ that prevents seeing the entire person, or a source of ‘spread,’ whereby a person who is disabled in one way is seen as disabled in all other ways.”⁴⁸ Patients with disabilities often report that clinicians do not address them directly, such as when a clinician speaks to a family member rather than to a visually-impaired patient.⁴⁹ A recent *Health Affairs* commentary describes a doctor who spoke slowly as if his patient might not understand him, merely because the patient had a stutter.⁵⁰

Patients with disabilities report that both clinician attitudes and clinician competence about disability issues can compromise their care.⁵¹ Clinicians also report discomfort, reluctance, and limited experience in caring for patients with disabilities, and they attribute these reactions to limited training.⁵² Bias or negative assumptions, real or perceived, can impact communication within the clinician-patient relationship⁵³ and can diminish the essential element of trust.⁵⁴ Lack of knowledge or awareness can also diminish quality of care. As bioethicist Adrienne Asch observed in *Distracted by Disability*:

46. Irving Kenneth Zola, *Self, Identity, and the Naming Question: Reflections on the Language of Disability*, 36 SOC. SCI. MED. 167, 169 (1993).

47. CHURCHILL, FANNING & SCHENCK, *supra* note 2, at 4.

48. Pendo, *Disability*, *supra* note 18, at 43.

49. See CHURCHILL, FANNING & SCHENCK, *supra* note 2, at 18.

50. Leana S. Wen, *A Simple Case of Chest Pain: Sensitizing Doctors to Patients with Disabilities*, 33 HEALTH AFF. 1868, 1868 (2014).

51. See Pendo, *Disability*, *supra* note 18, at 42–43.

52. Ashley Duggan et al., *What Can I Learn from This Interaction? A Qualitative Analysis of Medical Student Self-Reflection and Learning in a Standardized Patient Exercise About Disability*, 14 J. HEALTH COMM. 797, 799 (2009) (citing Marielle Aulagnier et al., *General Practitioners’ Attitudes Towards Patients with Disabilities: The Need for Training and Support*, 27 DISABILITY & REHABILITATION 1343, 1346 (2005)); Sweetie Jain, *Care of Patients with Disabilities: An Important and Often Ignored Aspect of Family Medicine Teaching*, 38 FAM. MED. 13, 13 (2006) (describing proper etiquette and the connection to patient-centered care) (“Family medicine residents and medical students are often uncomfortable when treating patients with disabilities. One reason for this discomfort is the lack of training they receive about this important aspect of medicine.”).

53. See, e.g., Mary Catherine Beach et al., *Are Physicians’ Attitudes of Respect Accurately Perceived by Patients and Associated with More Positive Communication Behaviors?*, 62 PATIENT EDUC. & COUNSELING 347, 352 (2006).

54. Mary Crossley, *Infected Judgment: Legal Responses to Physician Bias*, 48 VILL. L. REV. 195, 196 (2003). See generally Mark Hall et al., *Trust in the Medical Profession: Conceptual and Measurement Issues*, 37 HEALTH SERVICES RES. 1419 (2002) (discussing the effects of trust on clinician-patient relationships).

Doctors and bioethicists shape decisions of individual patients and families, and they cannot help others make genuinely informed decisions about how to handle life with a disability if they themselves continue to be disbelieving or astonished that people with a variety of impairments can pursue life plans they find satisfying.⁵⁵

Disability can also be a distraction from the patient's needs, which may or may not be related to his or her disability. As Asch writes:

Disability . . . interacts differently from [ethnicity, language and social class] . . . ; patients, families, and bioethics and medical professionals struggle to understand in what ways disability is a biological characteristic that warrants attention in medical decisions, and in what ways it is best seen as a background social variable not pertinent to decisions about any particular medical situation.⁵⁶

The first story in *Healers* illustrates this point. The physician sees a patient with no legs and immediately assumes that the patient needs help for whatever medical condition caused the loss of his legs.⁵⁷ However, the patient explains, "I make shoes and can't support my family with failing eyes."⁵⁸ By listening rather than relying on initial assumptions, the clinician was able to address the patient's complaint, restoring the patient to his role as a provider for his seven children.⁵⁹

An example from my prior research on inaccessible medical and diagnostic equipment illustrates the significance of biases and assumptions. I found that many health care providers believe that women with mobility disabilities are not sexually active and are not, or should not be, mothers.⁶⁰ They therefore may assume that patients with mobility disabilities do not need services such as screening for sexually transmitted infections or discussing birth control or fertility.

The work on cognitive biases discussed earlier could explain why a clinician might make incorrect assumptions about the sexual and family life of a woman with a mobility disability, or why a clinician might see the wheelchair but not the woman using it. Cognitive bias might also explain why a clinician would be less likely to recommend mammography within established guidelines for a woman with a disability. In my review of the literature, I

55. Asch, *supra* note 12, at 80.

56. *Id.* at 77.

57. SCHENCK & CHURCHILL, *supra* note 1, at xiii.

58. *Id.*

59. *Id.*

60. Pendo, *Disability*, *supra* note 18, at 44–45.

found that women with disabilities are less likely to have had a mammogram within suggested guidelines—fifty-four percent of women with disabilities had a mammogram within suggested guidelines as opposed to sixty-eight percent of women over forty without a disability.⁶¹ Women with disabilities experience later diagnoses, higher breast cancer mortality rates, and are less likely to undergo standard therapy after breast-conserving surgery than are other women.⁶²

Research identifies several barriers to regular mammography among women without disabilities, including lack of an explicit recommendation from a health care provider.⁶³ A study in the *American Journal of Public Health* sought to examine the reasons for the disparity in mammography rates by comparing the experiences of women with and without disabilities.⁶⁴ The researchers surveyed women in a state mammography registry and sent a letter to any patient who had not returned for a mammography screening within the generally recommended time period after the initial appointment.⁶⁵ The study found that women with disabilities report barriers similar to those reported by women without disabilities, but they report them at a higher rate.⁶⁶ The study also found that women with disabilities are less likely to receive a physician recommendation for a screening mammogram.⁶⁷ This is particularly the case among women over the age of sixty-five and women with multiple disabilities.⁶⁸

The literature clearly suggests that disability matters in clinical relationships, treatment recommendations, and outcomes, often in ways that raise ethical concerns. The literature on cognitive bias also suggests that perceptions of disability may inappropriately influence clinicians' medical judgments regarding appropriate diagnostic intervention or treatment.⁶⁹

61. *Id.* at 19–20; Bonnie C. Yankaskas et al., *Barriers to Adherence to Screening Mammography Among Women with Disabilities*, 100 AM. J. PUB. HEALTH 947, 947 (2010).

62. Pendo, *Disability*, *supra* note 18, at 19–20; Yankaskas et al., *supra* note 61.

63. Yankaskas et al., *supra* note 61, at 952.

64. *Id.* at 947–53.

65. *Id.* at 947. Twenty-three percent of women surveyed reported a disability, consistent with estimates from the U.S. Census. *Id.* at 951.

66. *Id.* at 951.

67. *Id.* at 947.

68. Lack of physician recommendation (16%), facility access problems (5.6%), and transportation (7.9%) were cited as barriers at least twice as often by women with multiple disabilities than any other group. *Id.* at 950.

69. Crossley, *supra* note 54, at 234–35.

III. DISABILITY-INCLUSIVE EDUCATION

The authors of *What Patients Teach* identify the education of medical students as a critical opportunity to develop skilled, patient-centered healers.⁷⁰ In their view, “[e]ducation begins with the attitudes, skills, and demeanors, the habits of mind and heart that students bring with them to their training.”⁷¹ Only twenty-five percent of medical schools include caring for patients with disabilities in their program of study.⁷² ADA compliance is not a core requirement for licensure, accreditation, or federal funding for medical schools and hospitals.⁷³ Many health care providers, including primary-care providers, therefore lack basic training in disability issues.⁷⁴

Clinicians and medical educators have called for increased education and training on disability issues.⁷⁵ Familiarity with disability issues is a key element of cultural competence for health care providers⁷⁶ and is a cornerstone of patient-centered care.⁷⁷ There are models for disability education, such as the six core competencies for medical trainees proposed by Kristie Kirschner and Raymond Curry in a 2009 article in the *Journal of the American Medical Association*.⁷⁸ There is also a growing body of disability and medical literature on communicating with patients with disabilities.⁷⁹ These models and literature might supply a foundation for disability education for health care providers.

70. CHURCHILL, FANNING & SCHENCK, *supra* note 2, at 153.

71. *Id.* at 154.

72. Wen, *supra* note 50, at 1869.

73. *Id.*

74. See COMM. ON DISABILITY IN AM., INST. OF MED., *THE FUTURE OF DISABILITY IN AMERICA* 153 (Marilyn J. Field & Alan M. Jette eds., 2007); NAT’L COUNCIL ON DISABILITY, *supra* note 11; U.S. DEP’T OF HEALTH & HUMAN SERVS., *THE SURGEON GENERAL’S CALL TO ACTION TO IMPROVE THE HEALTH AND WELLNESS OF PERSONS WITH DISABILITIES* (2005).

75. See generally Paula M. Minihan et al., *Teaching About Disability: Involving Patients with Disabilities as Medical Educators*, 24 *DISABILITY STUD. Q.* (2004) (calling for educating medical students about disability).

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

77. Duggan et al., *supra* note 52, at 799.

78. Kristi L. Kirschner & Raymond H. Curry, *Educating Health Care Professionals to Care for Patients with Disabilities*, 302 *JAMA* 1334, 1334 (2009); see also Lisa I. Iezzoni, *Toward Universal Design in Assessing Health Care Experiences*, 40 *MED. CARE* 725, 725–27 (2002); Tara Lagu et al., *The Axes of Access—Improving Care for Patients with Disabilities*, 370 *NEW ENG. J. MED.* 1847, 1847–50 (2014).

79. See Lisa I. Iezzoni et al., *Communicating About Health Care: Observations from Persons Who Are Deaf or Hard of Hearing*, 140 *ANNALS INTERNAL MED.* 356, 356–61 (2004); Lisa I. Iezzoni et al., *Teaching Medical Students About Communicating with Patients Who Have Sensory or Physical Disabilities*, 25 *DISABILITY STUD. Q.* (2005), available at

Providing education is critical to counter disability stereotypes, misconceptions, and biases. Education can help clinicians see the person, rather than just the disability, and focus on commonalities, rather than on differences. Inclusion of people with disabilities in the educational process might have additional benefits as there is evidence that positive, direct, and structured contact between people with and people without disabilities can decrease disability-based cognitive biases.⁸⁰ Under the right circumstances, interaction and education may create room for a clinician to reinterpret illness, or a different or changed body, as a part of the human experience that is not simply negative. The words of one clinician in *Healers* illustrates such a reinterpretation:

I have one patient who is really amazing. She has vascular disease and I've basically amputated both of her legs—not even any thighs But she would tell you that she wouldn't even want her legs back now, because of how it's changed her life, how it's made her a different person If you know that person and you saw her, you might not know how real a person she is And about her handicap or disability . . . the whole language of that. What enables all of us? What disables all of us? How can we call people disabled? Because she's a hell of a lot more enabled than most people I know, and she has no legs. But she is more of what makes a human being than most of us can aspire to.⁸¹

Education should include the basic requirements of the ADA, a landmark law establishing the rights of individuals with disabilities, in the clinical context. For example, the ADA requires that health care institutions and offices be accessible.⁸² Together with the Rehabilitation Act, the ADA applies to all public entities, including state and local public health care programs, such as Medicare and Medicaid,⁸³ and private health care offices.⁸⁴ These laws prohibit discrimination and require the removal of physical and other barriers to equal access.⁸⁵ In addition, in 2010, the Department of Justice published a technical-assistance manual that provides

sds.org/article/view/527/704; Lisa I. Iezzoni et al., *Teaching Medical Students About Communicating with Patients with Major Mental Illness*, 21 J. GEN. INTERNAL MED. 1112, 1112–15 (2006).

80. Pendo, *supra* note 41, at 272 & n.174 (citing literature on the effects of contact).

81. SCHENCK & CHURCHILL, *supra* note 1, at 213.

82. Pendo, *Disability*, *supra* note 18, at 18.

83. *Id.* at 49–51.

84. *Id.* at 33; see 42 U.S.C. § 12181(7)(F) (2012) (listing professional health care offices as certain private entities that are considered public accommodations under the ADA); *id.* § 12182(a) (prohibiting discrimination by public accommodations).

85. Pendo, *Disability*, *supra* note 18, at 33; see §§ 12181(7)(F), 12182(a).

guidance for health care providers on the requirements of the ADA in health care settings with respect to people with mobility disabilities.⁸⁶ Every medical school and nursing school should require its students to be familiar with this manual.

The education health care providers should receive to understand their legal obligations would create awareness of the nature and extent of barriers to care for patients with disabilities and raise awareness as to the importance of legal guarantees of equal treatment. Such education might help clinicians acknowledge the continuing lack of accessibility for patients with disabilities as an issue of professional ethics and quality of care. An individual clinician may or may not have control or influence over the physical space of the clinical encounter or the policies and procedures of the office or institution, but clinicians need to be aware that the physical aspects of the clinical space can positively or negatively influence relationships and quality of care.

Clinicians and patients alike should see the requirements of the ADA in health care settings as a floor, rather than as a ceiling, of high-quality, patient-centered practice. Consider the impact that a *disability friendly* clinical space free of physical barriers might make for patients with disabilities, as well as for patients with small children, elderly or frail patients, injured patients, patients of short stature, or bariatric patients. This means, among other things, that: parking is accessible; every patient can enter the building; the elevator is functional; doors and hallways are clear and navigable; bathrooms have accessible toilets, sinks, and grab bars; examination tables, chairs, and scales are adjustable and accessible; and accessible diagnostic and other specialized equipment is available.⁸⁷ As Dr. Lisa Iezzoni asked, “If barbers found simple ways to lift and lower their customers eons ago, why haven’t physicians done the same with patients and examination tables?”⁸⁸ A *disability friendly* clinical space would also have policies and procedures that promote access, addressing topics such as scheduling appointments, reserving equipment, and providing education and training on disability issues for the office.⁸⁹

The Patient Protection and Affordable Care Act (“ACA”), as amended,⁹⁰ offers some additional support for education. It

86. U.S. DEP’T OF JUSTICE & U.S. DEP’T OF HEALTH & HUMAN SERVS., ACCESS TO MEDICAL CARE FOR INDIVIDUALS WITH MOBILITY DISABILITIES 1 (2010), available at http://www.ada.gov/medcare_mobility_ta/medcare_ta.pdf.

87. Lagu et al., *supra* note 78, at 1847–48.

88. Lisa I. Iezzoni, *Ups and Downs of Improving Physical Examination Access for Patients and Physicians*, 158 ANNALS INTERNAL MED. 491, 491 (2013).

89. Lagu et al., *supra* note 78, at 1848.

90. Patient Protection and Affordable Care Act, Pub. L. No. 111-148, 124 Stat. 119 (2010) (codified as amended in scattered sections of 26 and 42 U.S.C.).

provides support for grants and incentives to institutions for additional training in caring for “vulnerable populations” and in cultural competency, which could include people with disabilities.⁹¹ The ACA also calls for identification of locations where people with disabilities are seeking care as well as the physical, equipment, and attitudinal barriers they may face there,⁹² which could also inform the development of training and education programs for providers. With appropriate funding, these provisions could support the development of patient-centered and disability-inclusive education of clinicians and other health care providers.

CONCLUSION

The authors of *What Patients Teach* provide a framework in which to focus on the everyday experience of health care from the perspective of patients. Their effort to promote the cultivation of the skills essential to relational and patient-centered care should be supported to improve care for all patients, including patients with disabilities. Attention to the ethical dimensions of the experiences of patients with disabilities in particular yields valuable lessons for clinicians about the architecture and attitudes that impact patient care. It suggests that, in addition to the skills of relationship-building, medical students and clinicians should receive disability-specific education, including education on the requirements of the ADA in clinical settings. Finally, consideration of the health and health care experiences of patients with disabilities presents an opportunity to develop an ethic of care grounded in the reality of disability shared by both patients and clinicians.

91. See 42 U.S.C. §§ 293k(b)(3)(I), 293k-2(c)(5), 299b-36(d)(2)(D) (2012).

92. See *id.* § 300kk(a)(2)(D)(i)–(iii).