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## Health Law as Disability Rights Law

Jessica L. Roberts

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**Article**

**Health Law as Disability Rights Law**

**Jessica L. Roberts**<sup>†</sup>

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INTRODUCTION

In 2014, the Patient Protection and Affordable Care Act (ACA) will take full effect.<sup>1</sup> With its intimidating length and complex provisions, the ACA means many things to many people. On the one hand, it is a health-insurance statute, designed to extend coverage to the un- and under-insured. On the other, it is public health legislation, geared toward improving the overall health and wellness of Americans. It contains provisions dealing with prescription drug regulation, funding for health education, and fraud and abuse.<sup>2</sup> However, this Article argues that the ACA functions as yet another kind of law: civil rights law. Specifically, the statute may be understood as a disability rights law. Although not yet widely recognized as such, the ACA constitutes one of the most significant civil rights victories for the disability community in recent history.

Legislation bearing on disability has traditionally been divided into two distinct substantive areas of protection: (1) legislation regulating health-care access and promoting public health and welfare (“health law”) and (2) legislation furthering equality, access, and integration (“civil rights law”). “Health law” encompasses statutes and regulations that provide public health insurance and benefits, govern the private health-insurance industry, and promote public health. Examples include Medicare and Medicaid, the Health Insurance Portability and Accountability Act, and statutes requiring federally funded entities to collect and report health-related data. Alternatively, “civil rights law” is designed to promote equality, access, and integration. Disability rights statutes serve these goals by prohibiting discrimination on the basis of disability. The primary disability antidiscrimination statutes are the Rehabilitation Act of 1973 and the Americans with Disabilities Act (ADA).

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1. See Patient Protection and Affordable Care Act (ACA) of 2010, Pub. L. No. 111-148, 124 Stat. 119 (to be codified in scattered sections of 42 U.S.C.).

2. See TIMOTHY STOLTZFUS JOST, 1 HEALTH CARE REFORM SPECIAL ALERT § 1.01 (2010) (providing an overview of history and provisions of the ACA).

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Until the disability rights movement of the last forty years, disability legislation consisted almost exclusively of social welfare protections, some of which fall under the broad umbrella of health law. However, when disability rights advocates mobilized in the 1970s, they reframed the disadvantages faced by people with disabilities from personal, medical problems to the consequences of pervasive, society-wide stigma and discrimination. In promoting independence for individuals with disabilities, advocates renounced the charity-driven paternalism of the existing social-benefits system, resulting in a move toward antidiscrimination protections as the preferred means for accomplishing their goals.

Yet despite the groundswell of support within the disability rights movement, civil rights laws have failed to address the serious health disparities that the disability community faces. People with disabilities encounter numerous barriers to accessing health care. For instance, Medicaid and Medicare often fail to cover needed health services and medical equipment. Moreover, for individuals with disabilities who do not qualify for public programs, the risk assessment and cost-sharing practices of the private health-insurance industry frequently render them un- or under-insured. Finally, public health authorities have historically failed to compile information related to disability, making the extent of these disparities difficult to assess. Although both the Rehabilitation Act and the ADA facially apply in health-care settings, those statutes have been ineffective at targeting these inequities because of their civil rights structure. The statutes' vulnerability to restrictive court interpretations, coupled with their focus on individual instances of discrimination, make civil rights law an inappropriate tool for challenging health disparities.

Quite intuitively, the solution to the inequities experienced by individuals with disabilities in health care appears to rest—not in civil rights law—but in health law. Both scholars and activists alike have proposed that the future of disability rights lies in protections traditionally associated with health legislation. The ACA makes that proposal a reality. The statute includes multiple provisions that both explicitly and implicitly benefit people with disabilities, including its attempted expansion of Medicaid and public health-insurance coverage for ongoing care, its elimination of preexisting condition exclusions and limitations on health status-based rating, and its recognition of people with disabilities as a health disparities group.

By promoting the interests of people with disabilities, the ACA demonstrates that a health law can *function* as a civil rights law. That is to say, legislation written with health law objectives and content may have a civil rights impact, such as furthering equality, access, and integration. More broadly, the ACA exemplifies how advocates can harness law outside the traditional civil rights paradigm to achieve their goals.

This Article, therefore, asserts that laws may have meaningful effects outside their substantive paradigms. In so doing, it makes a novel distinction between a law's articulated purpose and that law's practical impact. It is an article about the effectiveness of statutes, not their superficial substantive classification. Moreover, this Article provides the first broad, in-depth reading of recent health-care reform in terms of disability rights. Specifically, it argues that, although not explicitly framed as disability rights legislation, the ACA still functions as such. Thus, this Article establishes that non-civil rights statutes can affect civil rights outcomes, a useful insight in this context and beyond.

The Article proceeds in three parts. Part I limns the historical division between the health and civil rights paradigms within disability law and proposes the potential reasons for that divide. Part II explores the disparities in health-care access experienced by people with disabilities and the failure of traditional civil rights legislation to address these inequities adequately. Finally, Part III reads the ACA as a piece of disability rights legislation, examining the role of disability rights organizations in its passage and the statute's impact on individuals with disabilities. The ACA therefore demonstrates that health legislation may act as a vehicle for civil rights. The Article concludes that to achieve holistic equality for people with disabilities, disability rights advocates must move beyond the civil rights paradigm by integrating other kinds of legal protections into their agendas for change. This valuable lesson applies both beyond the realm of health law and beyond the needs of the disability community.

#### I. "HEALTH" AND "CIVIL RIGHTS": COMPETING PARADIGMS

This Article proposes that portions of the ACA function as disability rights law. Disability legislation has traditionally fallen into two separate, substantive categories: one intended to provide health care and resources to people with disabilities

and one intended to promote their equality, access, and integration. Thus, insofar as the ACA represents a health law that furthers the rights of people with disabilities, it constitutes a departure from this conventional division. Part I explores the concept of disability as it pertains to both health and civil rights laws, traces the historical schism between those frameworks, and provides some explanations for that divide.

#### A. TRADITIONAL SCHISM

Disability is conceptually complex, incorporating social, legal, and medical aspects.<sup>3</sup> Not surprisingly, the law has struggled regarding what qualifies as a disability and how to protect individuals within this large and diverse category.<sup>4</sup> Given the increased need for health care faced by many individuals with disabilities, the law has at times framed “disability” as a medical designation. However, people with disabilities also face significant social barriers, which stem not from medical need but from stigma and stereotype. Consequently, the law has also defined “disability” in terms of the social experiences of exclusion, disadvantage, and discrimination. The result has been a substantive split between the health and civil rights protections for individuals with disabilities.<sup>5</sup>

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3. Defining “disability” has been an on-going source of debate. At various points in time, disability has held differing connotations: social, medical, and even moral. See generally Deborah Kaplan, *The Definition of Disability: Perspective of the Disability Community*, 3 J. HEALTH CARE L. & POL’Y 352 (2000) (examining the historically complex task of defining a person with a disability, as well as the Supreme Court’s recent interpretation of disability under the ADA); Simi Linton, *Reassigning Meaning, in THE DISABILITY STUDIES READER* 223, 223–36 (Lennard J. Davis ed., 3d ed. 2010).

4. See, e.g., Samuel R. Bagenstos, “Rational Discrimination,” *Accommodation, and the Politics of (Disability) Civil Rights*, 89 VA. L. REV. 825 (2003); see also Michael Ashley Stein, *Same Struggle, Different Difference: ADA Accommodations as Antidiscrimination*, 153 U. PENN. L. REV. 579 (2004).

5. I am not the first disability legal scholar to identify this distinction. Most famously, Samuel Bagenstos differentiated between types of legal protections for people with disabilities in his groundbreaking article, *The Future of Disability Law*, describing them as the “antidiscrimination” and “social welfare” paradigms. Samuel R. Bagenstos, *The Future of Disability Law*, 114 YALE L.J. 1 (2004). Similarly, Ani Satz has explored the limits of antidiscrimination law and the “targeted legal approach” in her scholarship on fragmentation. See Ani B. Satz, *Disability, Vulnerability, and the Limits of Antidiscrimination*, 83 WASH. L. REV. 513 (2008) [hereinafter Satz, *Disability, Vulnerability, and the Limits of Antidiscrimination*]; Ani B. Satz, *Fragmented Lives: Disability Discrimination and the Role of “Environment-Framing,”* 68 WASH. & LEE L. REV. 187 (2011) [hereinafter Satz, *Fragmented Lives*]; Ani B. Satz, *Overcoming Fragmentation in Disability and Health Law*, 60 EMORY L.J.

## 1. Health Law and Disability

Health law encompasses several kinds of legal protections.<sup>6</sup> For the purposes of this Article, “health law” connotes laws that govern access to health services and health insurance coverage, as well as those intended to restore or promote health and wellness.<sup>7</sup> It, therefore, focuses on three kinds of substantive health law protections: (1) public health insurance and government benefits; (2) laws governing private health insurance; and (3) public health initiatives and regulation. All three kinds of health law protections relate to people with disabilities.

### a. *Public Benefits and Disability*

Before the advent of the disability rights movement of the 1970s and 1980s, “disability law” consisted almost exclusively of social welfare statutes.<sup>8</sup> In the United States, people with disabilities tend to seek health insurance in the public sector—frequently from Medicare and Medicaid—due to the various risk-assessment and cost-reducing mechanisms common in the private insurance industry.<sup>9</sup>

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277 (2010) [hereinafter Satz, *Overcoming Fragmentation*].

Notably, Bagenstos and Satz focus primarily on social welfare as a legal category. Alternatively, while the health law model I describe includes social welfare protections, it also incorporates private insurance and public health law, making it a broader designation.

6. Practicing health law may concurrently incorporate aspects of administrative law, contracts, corporate law, torts, and even criminal law. Jennifer A. Stiller, *What is Health Law?*, in HEALTH LAW PRACTICE GUIDE § 1:1 (2011). Thus, health law practitioners must integrate multiple fields of legal expertise, including professional licensure and regulation, tax, fraud and abuse, antitrust, medical malpractice (and other torts), insurance law, and various other specialties—pharmaceuticals, biotechnology, and intellectual property to name a few—depending on the scope of their practice. *Id.*

7. Samuel Bagenstos defines his “social welfare approach” as “sustained and direct government intervention through such means as public funding and provision of services.” See Bagenstos, *supra* note 5, at 55. Thus, the “health law paradigm” as used in this Article describes the substance and purpose of the legislation, i.e., its goal of promoting and sustaining health, whereas Bagenstos’s “social welfare approach” describes how the programs created by that legislation are provided, i.e., through government intervention. Thus, while public health initiatives are part of the “health law paradigm,” insofar as they don’t confer some kind of a tangible benefit, they may not fall within the “social welfare approach.”

8. Bagenstos, *supra* note 5, at 10 (describing pre-1970s “disability law” as “effectively nothing more than a subcategory of social welfare law”). Many of these benefits provision policies date back as far as the Civil War era. *Id.*

9. *Id.* at 32 (explaining that “limitations on private insurance coverage have driven people with disabilities into the public health care system, primarily Medicare and Medicaid”). These mechanisms include preexisting condi-

People with disabilities may qualify for public health insurance. Often, that eligibility is linked to government wage benefits. Individuals with disabilities can apply for two different programs pursuant to the Social Security Act: Social Security Disability Insurance (SSDI) under Title II and Supplemental Security Income (SSI) under Title XVI. SSDI pays benefits to recipients based on their previous wage contributions.<sup>10</sup> Thus, only individuals with disabilities who have worked may apply.<sup>11</sup> After two years of SSDI enrollment, beneficiaries become eligible for federally provided health insurance under Medicare.<sup>12</sup> Alternatively, SSI is a means-tested program: eligibility is based only on the applicant's current income.<sup>13</sup> SSI, therefore, provides wage support—regardless of work history—to certain enumerated groups.<sup>14</sup> SSI recipients are eligible for public health insurance under Medicaid.<sup>15</sup> Individuals with disabilities may receive benefits simultaneously from both programs; however a recipient's SSDI benefits are included when calculating her SSI eligibility.<sup>16</sup> Thus, four social welfare programs apply to individuals with disabilities—two providing cash benefits and two providing public health-insurance coverage.<sup>17</sup>

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tion exclusions and lifetime and annual caps. For a discussion of the negative impact of traditional private, for-profit health insurance practices on individuals with disabilities, see discussion, *infra* notes 21–35 and accompanying text and *infra* notes 143–48 and accompanying text.

10. SOC. SEC. ADMIN., 2012 RED BOOK: A SUMMARY GUIDE TO EMPLOYMENT SUPPORTS FOR PERSONS WITH DISABILITIES UNDER THE SOCIAL SECURITY DISABILITY INSURANCE AND SUPPLEMENTAL SECURITY INCOME PROGRAMS, available at <http://www.ssa.gov/redbook/eng/main.htm> [hereinafter SOC. SEC. ADMIN., RED BOOK]. Thus, Samuel Bagenstos characterizes SSDI as “early retirement pay.” Bagenstos, *supra* note 5, at 11.

11. Bagenstos, *supra* note 5, at 11 (explaining that SSDI applies to workers who have contributed to the Social Security trust fund).

12. SOC. SEC. ADMIN., DISABILITY BENEFITS 14 (June 2012).

13. SOC. SEC. ADMIN., RED BOOK, *supra* note 10, at 7 (stating that “[t]he SSI program makes cash assistance payments to aged, blind, and disabled persons (including children) who have limited income and resources”).

14. *See id.*

15. SOC. SEC. ADMIN., SUPPLEMENTAL SECURITY INCOME (SSI) 10 (2012) (directing SSI recipients to their local welfare or medical assistance office for information about Medicaid).

16. SOC. SEC. ADMIN., RED BOOK, *supra* note 10, at 7 (describing receiving both SSDI and SSI benefits as “concurrent benefits”).

17. Bagenstos, *supra* note 5, at 11 (discussing disability benefits programs).



b. *Private Health Insurance and Disability*

Laws governing private health insurers also constitute part of the health law universe. Yet in this context, one can perhaps learn more about the effect of health law on people with disabilities from where regulation is absent, rather than where it is present. Private health insurers have historically engaged in a variety of practices that, although not explicitly dealing with disability, have systematically disadvantaged the chronically ill and disabled.<sup>18</sup> With some notable exceptions, such as the Employee Retirement Income Security Act (ERISA) and the Health Insurance Portability and Accountability Act (HIPAA), health insurance law is by and large an area of regulation left to the states. It typically deals with setting standards for insurers (including access to coverage, required benefits, and premium rates), regulating market conduct, and fielding complaints.<sup>19</sup> Yet, until recently, the law of health insurance did not intervene to mitigate many of the industry practices that disadvantage people with disabilities.<sup>20</sup>

In the private sector, health insurers obtain their profits by accurately assessing the risks of their insureds.<sup>21</sup> One historically common mechanism for differentiating between good and bad health risks impacts many individuals with disabilities: the preexisting condition exclusion. Health insurers have used preexisting conditions to deny or to limit coverage. Prior to health-care reform, insurers cited preexisting conditions to justify denying coverage to one in seven applicants.<sup>22</sup> In addition

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18. See Jessica L. Roberts, "Healthism": A Critique of the Antidiscrimination Approach to Health Insurance and Health-Care Reform, 2012 U. ILL. L. REV. 1159, 1166 ("In private, for-profit health-insurance, both individual and group health insurers have historically engaged in risk-assessment and other profit-maximizing strategies that systematically disadvantage people with histories of illness and chronic health conditions."); see also Mary Crossley, *Discrimination Against the Unhealthy in Health Insurance*, 54 U. KAN. L. REV. 73 (2005) [hereinafter Crossley, *Discrimination Against the Unhealthy*]; Elizabeth Pendo, *Working Sick: Lessons of Chronic Illness for Health Care Reform*, 9 YALE J. HEALTH POL'Y L. & ETHICS 453 (2009) [hereinafter Pendo, *Working Sick*].

19. KAISER FAMILY FOUND., HOW PRIVATE HEALTH INSURANCE WORKS: A PRIMER 2008 UPDATE 813 (2008), available at <http://www.kff.org/insurance/upload/7766.pdf>.

20. The ACA addresses many of the provisions that adversely affect people with disabilities. See discussion *infra* Part III.B.1.

21. See Roberts, *supra* note 18, at 1162.

22. Memorandum from Henry A. Waxman & Bart Stupak to Members of the Comm. on Energy & Commerce, Coverage Denials for Pre-Existing Conditions in the Individual Health Insurance Market (Oct. 12, 2010) (finding that

to denying an individual outright,<sup>23</sup> a private health insurer may offer the applicant a policy that excludes coverage for a particular condition if that condition pre-dates the individual's application for health insurance.<sup>24</sup> Preexisting conditions may include any number of conditions, ranging from life-threatening to purely cosmetic.<sup>25</sup> Consequently, impairments that rise to the level of disability almost always represent the kind of preexisting condition that would impede one's access to health insurance.

Pricing premiums based on health status may also disparately affect people with disabilities who apply for private health insurance. When setting rates and premiums, health insurers traditionally evaluate their potential insureds' health histories.<sup>26</sup> Individuals who have required more health services in the past are thus more likely to require health services in the future, thereby increasing the likelihood that the insurance company will at some point pay out for a claim. As a result,

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"[f]rom 2007 through 2009, the four largest for-profit health insurance companies, Aetna, Humana, UnitedHealth Group, and WellPoint, refused to issue health insurance coverage to more than 651,000 people based on their prior medical history" and that "[o]n average, the four companies denied coverage to one out of every seven applicants based on a pre-existing condition").

23. *Id.*

24. DICTIONARY OF HEALTH INSURANCE AND MANAGED CARE 226 (David Edward Marcinko ed., 2006) (defining "preexisting condition" as "[i]n health insurance, an injury, sickness, or physical condition that existed before the policy effective date. Most individual policies will not cover a preexisting condition; most group policies will."); *see also* Deborah A. Stone, *The Struggle for the Soul of Health Insurance*, 18 J. HEALTH POL. POL'Y & L. 287, 304 (1993) ("Pre-existing condition clauses exclude payment for any condition the applicant had prior to the insurance contract."). Importantly, the Health Insurance Portability and Accountability Act (HIPAA) placed some limits on group insurers' ability to impose preexisting condition exclusions. *See* 29 U.S.C. § 1181(a)(1) (2006) (stating that insurers may only impose a preexisting condition exclusion when "(1) such exclusion relates to a condition (whether physical or mental), regardless of the cause of the condition, for which medical advice, diagnosis, care, or treatment was recommended or received within the 6-month period ending on the enrollment date; (2) such exclusion extends for a period of not more than 12 months (or 18 months in the case of a late enrollee) after the enrollment date; and (3) the period of any such preexisting condition exclusion is reduced by the aggregate of the periods of creditable coverage").

25. Anything from AIDS to acne may be considered a preexisting condition. *See* KAREN POLLITZ ET AL., KAISER FAMILY FOUND., HOW ACCESSIBLE IS INDIVIDUAL HEALTH INSURANCE FOR CONSUMERS IN LESS-THAN-PERFECT HEALTH? 1 (2001), *available at* <http://www.kff.org/insurance/20010620a-index.cfm>.

26. Roberts, *supra* note 18, at 1165.

health insurers charge more to insure “high-risk” applicants.<sup>27</sup> People with disabilities—who as a group use health services more frequently—therefore often pay higher rates for private health insurance.<sup>28</sup>

Although preexisting condition exclusions and health-status based rating have been characteristic of the individual insurance market, people with disabilities may likewise experience disadvantages in group health insurance. Group health insurers also engage in several cost-sharing practices—such as deductibles, co-insurance, and co-payments—that result in insureds with higher health-care costs paying more out-of-pocket.<sup>29</sup> Finally, both annual and lifetime caps on coverage force individuals in need of on-going care to cover significant portions of their treatment costs.<sup>30</sup> All of these practices have a disproportionate impact on people with disabilities, who as a group tend to consume more health services.

Ironically, having an increased need for health services often makes attaining those services more challenging for people with disabilities, either because private health insurers are less likely to cover them or because the available policies contain cost- or coverage-limiting provisions.<sup>31</sup> Even prior to the ACA,

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27. Stone, *supra* note 24, at 306 (explaining that health insurers may increase premiums and limit coverage for high-risk individuals).

28. NAT'L COUNCIL ON DISABILITY, THE CURRENT STATE OF HEALTH CARE FOR PEOPLE WITH DISABILITIES 46 (2009) (stating that “purchasers [with disabilities] are often charged premiums that are higher than those charged to individuals without disabilities”).

29. *Id.*; see also Pendo, *Working Sick*, *supra* note 18, at 466–67.

30. Bagenstos, *supra* note 5, at 27–28 (describing the effect of preexisting condition exclusions and annual and lifetime caps on people with disabilities).

31. See Mary Crossley, *Becoming Visible: The ADA's Impact on Health Care for Persons with Disabilities*, 52 ALA. L. REV. 51, 83 (2000) [hereinafter Crossley, *Becoming Visible*] (“[I]n many cases . . . high-risk enrollees whom insurers try to avoid are individuals who have a chronic medical condition or some other disabling condition. A situation results in which the profit motive drives insurers in many cases to actively avoid persons with disabilities as customers . . . .”); see also Bagenstos, *supra* note 5, at 27–29 (explaining the effect of preexisting condition exclusions and annual and lifetime caps on private insurance coverage for people with disabilities). This irony is central to many of Deborah Stone's critiques of the American health-insurance system. See, e.g., Stone, *supra* note 24, at 308 (“The logic and methods of actuarial fairness mean denying insurance to those who most need medical care. The principle actually distributes medical care in *inverse* relation to need, and to the large extent that commercial insurers operate on this principle, the American reliance on the private sector as its main provider of health insurance establishes a system that is perfectly and perversely designed to keep sick people away from doctors.”); see also Deborah Stone, *Protect the Sick: Health Insurance Reform in One Easy Lesson*, 36 J.L. MED. & ETHICS 652 (2008).

both state and the federal legislators attempted to limit some of these exclusionary practices by restricting pre-existing condition exclusions<sup>32</sup> or through guaranteed issue laws.<sup>33</sup> Yet despite these efforts, many individuals with disabilities continued to be ineligible for private insurance and those that did qualify paid substantial premiums for their policies.<sup>34</sup> Thus, individuals with disabilities not covered by Medicare or Medicaid frequently found themselves uninsured.<sup>35</sup>

*c. Public Health and Disability*

Finally, laws designed to promote public health also deal with issues related to disability. Public health is “what we as a society, do collectively to assure the conditions in which people can be healthy.”<sup>36</sup> In the United States, public health has re-

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32. KAISER FAMILY FOUND., FOCUS ON HEALTH REFORM, HEALTH INSURANCE MARKET REFORMS: PRE-EXISTING CONDITION EXCLUSIONS (Sept. 2012) (describing the pre-ACA regulation of pre-existing condition exclusions by state and federal laws and the impact of health-care reform on that regulation).

33. KAISER FAMILY FOUND., FOCUS ON HEALTH REFORM, HEALTH INSURANCE MARKET REFORMS: GUARANTEED ISSUE (June 2012) (“In most states, insurers are not required to guarantee issue policies to individuals. However, under the federal Health Insurance Portability and Accountability Act (HIPAA) of 1996, some insurance companies are required to guarantee issue policies to certain individuals, referred to as HIPAA-eligible individuals, regardless of their health status and disability.”). As of June 2012, only six states guaranteed issue of all products to all of their residents. *Id.*

34. *See supra* notes 21–33 and accompanying text.

35. RHODA OLKIN, WHAT PSYCHOTHERAPISTS SHOULD KNOW ABOUT DISABILITY 18 (1999) (“Disability status is associated with certain patterns of health insurance. Persons with disabilities are less likely to be covered by private health insurance than the nondisabled. Those with severe disabilities are more likely to be covered by government (vs. private) insurance than are people with no or mild disabilities, and persons with mild disabilities are the most likely to be uninsured (36%). This latter group might be analogous to those referred to as the working poor—too much income to qualify for aid and too little income to be sufficient for needs, particularly given increased costs of living with a disability.”). While the above summary describes the historical practices of the private, for-profit health-insurance industry, several of the conventions described above will soon become a thing of the past. Many of the provisions of the ACA discussed in Part III attempt to dismantle this historically disadvantageous system. *See infra* Part III.B. Moreover, although Congress clearly intended to eliminate some of the disadvantages produced by the existing insurance structure when crafting the ACA, I have my reservations regarding the effectiveness of those provisions. *See generally* Roberts, *supra* note 18 (contending that the ACA protections will ultimately fail to eliminate the disparities).

36. Barry S. Levy, *Twenty-First Century Challenges for Law and Public Health*, 32 IND. L. REV. 1149, 1150 (1999) (quoting a 1988 report from the In-

sulted in significant increases in overall life expectancy for Americans.<sup>37</sup> Public health law has many branches, such as environmental law, disease tracking and reporting standards, and statutes mandating involuntary testing and treatment.<sup>38</sup> Public health law, therefore, seeks to promote health at the community level, usually by preventing members of a population from getting sick or injured in the first place.

Consequently, people with disabilities occupy a rather unique role with respect to public health, a role that might explain why they have been markedly absent from most health disparities research.<sup>39</sup> As mentioned, reducing the incidence of disease and injury in a given population constitutes a central objective of the public health project. Individuals with disabilities often acquire their impairments through disease and injury.<sup>40</sup> Hence, the goal of public health—as it relates to individuals with disabilities—has historically been to prevent them from existing in the first place.<sup>41</sup> Instead of construing people with disabilities as members of the served population, public health law has instead treated them as the very problems public health policies seek to solve.

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stitute of Medicine).

37. *Id.*

38. *Id.* at 1150–52 (explaining the eight areas of public health law outlined in F. DOUGLAS SCUTCHFIELD & C. WILLIAM KECK, PRINCIPLES OF PUBLIC HEALTH PRACTICE (1997)). Those areas are: (1) environmental health laws; (2) laws and regulations on reporting disease and injury; (3) laws pertaining to vital statistics; (4) disease and injury control; (5) involuntary testing; (6) contact tracing; (7) immunization and mandatory treatment; and (8) personal restrictions. *Id.*

39. See NAT'L COUNCIL ON DISABILITY, *supra* note 28, at 12 (describing the “dissonance” between “the longstanding public health goal of eliminating disability and disease and the emerging view . . . defin[ing] disability as a demographic characteristic”).

40. Harlan Hahn has quipped, “Violence is how people with disabilities reproduce.” Professor Harlan Hahn, Univ. of S. Cal., Lecture to Stigma in Society Class (Fall 2001).

41. In fact, a 1991 report from the Institute of Medicine’s Committee on a National Agenda for the Prevention of Disabilities (perhaps the committee name already says it all), makes its primary goal preventing potentially disabling conditions from developing into disabilities and explains that “[d]espite an officially stated national goal of independence and equality of opportunity for people with disabilities, current approaches to preventing disability and improving the lives of people with disabling conditions lack conceptual clarity and unity of purpose.” INST. OF MEDICINE, DISABILITY IN AMERICA: TOWARD A NATIONAL AGENDA FOR PREVENTION 4 (Andrew M. Pope & Alvin R. Tarlov eds., 1991).

People with disabilities have a complex relationship with health law. While programs such as Medicaid and Medicare provide them with access to government benefits, the laws and regulations governing private insurance and public health classify them as at-risk individuals who represent either high potential payouts that may be too costly to insure, or as an undesirable population demographic that should be eliminated. Thus, several kinds of “health law” directly affect individuals with disabilities.

## 2. Civil Rights Law and Disability

In the context of this Article, “civil rights law” means laws designed to elevate the social standing of a historically disadvantaged group.<sup>42</sup> Therefore, the underlying purpose of civil rights legislation is to eradicate group subordination. Civil rights statutes prohibit covered entities from discriminating on the basis of a protected trait.<sup>43</sup> As part of their antidiscrimination mandate, they may also require positive differential treatment, such as the ADA’s reasonable accommodation provision.<sup>44</sup> The two most prominent civil rights laws for people with disabilities are the Rehabilitation Act and the ADA.

The Rehabilitation Act, passed in 1973, requires that entities receiving federal funds provide equal access to their programs and services for people with disabilities.<sup>45</sup> Its most famous provision, Section 504, states that

No otherwise qualified individual with a disability in the United States . . . shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal fi-

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42. This definition of civil rights law undeniably embraces antisubordination. However, given the common understanding of a “civil rights movement” as an effort to promote the equal social standing of a historically disadvantaged group, I find linking the concept to group subordination here sensible.

43. I have in the past described an “antidiscrimination paradigm” to connote framing an issue as a matter of untenable discrimination, see Roberts, *supra* note 18, at 1163, or to describe particular kinds of legal protections, mainly antisubordination or anticlassification, see Jessica L. Roberts, *The Genetic Information Nondiscrimination Act as an Antidiscrimination Law*, 86 NOTRE DAME L. REV. 597, 630–34 (2011).

44. Significantly, the ADA definition of to “discriminate” includes “not making reasonable accommodations to the known physical or mental limitations of an otherwise qualified individual with a disability.” 42 U.S.C. § 12112(b)(5)(A) (2006).

45. Rehabilitation Act of 1973, 29 U.S.C. §§ 701–796 (1998).

nancial assistance or under any program or activity conducted by any Executive agency or by the United States Postal Service.<sup>46</sup>

The Rehabilitation Act constituted landmark legislation at the time because it—perhaps accidentally—framed the disadvantages and exclusion faced by people with disabilities as “discrimination” and therefore a matter of civil rights.<sup>47</sup> By adopting an antidiscrimination frame, the law provided a catalyst for the American disability rights movement.<sup>48</sup>

Almost twenty years later, President George H.W. Bush signed the ADA into law. The ADA contains four substantive titles,<sup>49</sup> which prohibit discrimination on the basis of disability in employment,<sup>50</sup> local and state government services,<sup>51</sup> public accommodations,<sup>52</sup> and telecommunications.<sup>53</sup> People with disabilities, along with their family members and friends, mobilized to push Congress to pass the ADA, forming what one scholar famously called a “hidden army” for civil rights.<sup>54</sup> However, the story does not end there. Following a series of restrictive court interpretations of the ADA, Congress passed the Americans with Disabilities Amendments Act (ADAAA) in 2008, in an attempt to restore the statute to its original state.<sup>55</sup>

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46. *Id.* § 794(a).

47. See RUTH O'BRIEN, CRIPPLED JUSTICE: THE HISTORY OF MODERN DISABILITY POLICY IN THE WORKPLACE 123 (2001) (stating that “few foresaw . . . that Section 504 [of the Rehabilitation Act] . . . would provide the basis for the disability rights revolution”).

48. *Id.*

49. Title V of the ADA includes miscellaneous technical provisions. See 42 U.S.C. §§ 12201–12213.

50. *Id.* §§ 12111–12117.

51. *Id.* §§ 12131–12165.

52. *Id.* §§ 12181–12189.

53. 47 U.S.C. § 225 (amending the Communications Act of 1934).

54. JOSEPH P. SHAPIRO, NO PITY: PEOPLE WITH DISABILITIES FORGING A NEW CIVIL RIGHTS MOVEMENT 117 (1993).

55. Americans with Disabilities Amendments Act of 2008, Pub. L. No. 110-325, 122 Stat. 3553. The ADAAA expressly rejected the Supreme Court's limited interpretation of disability under the ADA in *Sutton* and *Toyota Motor Manufacturing*. Congress found that “the holdings of the Supreme Court in *Sutton v. United Air Lines, Inc.*, 527 U.S. 471 (1999) and its companion cases have narrowed the broad scope of protection intended to be afforded by the ADA, thus eliminating protection for many individuals whom Congress intended to protect,” *id.* § 2(a)(4), and that “the holding of the Supreme Court in *Toyota Motor Manufacturing, Kentucky, Inc. v. Williams*, 534 U.S. 184 (2002) further narrowed the broad scope of protection intended to be afforded by the ADA,” *id.* § 2(a)(5).

As mentioned, the health law paradigm predates the civil rights paradigm.<sup>56</sup> Disability rights activists, therefore, made a strategic choice to adopt an alternate legislative paradigm.<sup>57</sup> Their decision to move away from health law toward civil rights law had its roots in the goals of the disability rights movement.<sup>58</sup> Thus, following the disability rights movement of the 1970s and 1980s, two concurrent, yet mutually exclusive<sup>59</sup> kinds of legislation applied to people with disabilities: (1) health laws governing issues related to health-care access and wellness and (2) civil rights laws prohibiting covered entities from discriminating on the basis of disability.

## B. EXPLANATIONS FOR THE SCHISM

Explanations for the schism between the health and civil rights paradigms in disability law exist on both sides of the divide. Perhaps, health law- and policy-makers believed that these two concepts existed in tension, adopting the perspective that “disability” constitutes the absence—or juxtapositional opposite—of “health.” Simultaneously, the disability rights movement actively adopted the social model of disability, leading advocates to demedicalize disability and to reject the paternalism of the social welfare system.

### 1. Health Law Explanations

Health law (specifically social benefits, insurance, and public health law) tends to define disability in largely medical terms. Consequently, those laws do not characterize people with disabilities as a social group entitled to civil rights.

The concepts of “health” and “disability” have a complicated, long-standing relationship. Health is an elusive concept with no single universally accepted definition. As a result, bioethical philosophers have written extensively on the meaning of “health.” The two dominant theories in this area, naturalism and normativism, illuminate why health and disability may appear to be mutually exclusive categories, thereby explaining

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56. See *supra* note 8 and accompanying text.

57. See Bagenstos, *supra* note 5, at 5 (explaining that advocates of disability rights viewed antidiscrimination laws as an alternative to civil rights laws).

58. See *infra* Part I.B.2.

59. See Bagenstos, *supra* note 5, at 19 (explaining that the ADA made no changes to the existing social benefits program).



the frequently complicated relationship between these categories within the law.

Naturalism, the most widely accepted philosophical approach, grounds itself in scientific theory.<sup>60</sup> Naturalists maintain that health exists when an organism is functioning at a normal, biologically natural level.<sup>61</sup> Christopher Boorse, author of one of the most popular naturalist definitions, presents his construction of health as a four-part syllogism, which relies both on the concept of normalcy and the idea of disease as a departure from that state:

1. The *reference class* is a natural class of organisms of uniform functional design; specifically, an age group or a sex of a species.
2. A *normal function* of a part or process within members of the reference class is a statistically typical contribution by it to their individual survival and reproduction . . . .
3. A *disease* is a type of internal state which is either an impairment of normal functional ability, i.e., a reduction of one or more functional abilities below typical efficiency, or a limitation on functional ability caused by the environment.
4. *Health* is the absence of disease.<sup>62</sup>

Boorse, therefore, defines health in the negative. Health occurs where disease is absent. Boorse uses the term “disease” to signify “an impairment of normal functional ability,” a definition that parallels many of the accepted definitions of “disability.”<sup>63</sup> Without the concept of a “normal” or healthy body, there is no such thing as an “abnormal” or disabled body.<sup>64</sup> In fact, the very thing that unites individuals with varying types and degrees of impairment as members of the group “people with disabilities” is their shared departure from the accepted norm. In making “normal” functioning its touchstone, the naturalist approach puts health and disability in opposition with each other, making them incompatible categories.

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60. Marc Ereshefsky, *Defining ‘Health’ and ‘Disease,’* 40 *STUD. HIST. & PHIL. BIOLOGICAL & BIOMEDICAL SCI.* 221, 221 (2009).

61. *Id.*

62. *Id.* at 222 (quoting Christopher Boorse, *A Rebuttal on Health,* in *WHAT IS DISEASE?* 1, 7–8 (James M. Humber & Robert F. Almeder eds., 1997)).

63. All three legal definitions of disability discussed in Part I.C. include some reference to an impairment that limits functioning.

64. See Lennard J. Davis, *Constructing Normalcy,* in *THE DISABILITY STUDIES READER,* *supra* note 3, at 3 (“To understand the disabled body, one must return to the concept of the norm, the normal body . . . I do this because the ‘problem’ is not the person with disabilities; the problem is the way that normalcy is constructed to create the ‘problem’ of the disabled person.”).

Normativism presents an alternative to naturalism. The normativist approach defines health as a socially valued state, while disease represents a socially undesirable state.<sup>65</sup> This definition may likewise position disability at odds with health. Society has historically devalued people with disabilities. Having a disability has—in the past—led to the denial of several basic civil liberties, including the right to vote, the right to marry, and the right to procreate, among others.<sup>66</sup> Society has not treated people with disabilities as full persons. Moreover, because disability is considered an undesirable state, governments and institutions devote significant resources to the treating, preventing, or curing of potentially disabling conditions.<sup>67</sup> Therefore, like in naturalism, the concepts of “health” and “disability” may also exist in tension within normativism, depending on how society values certain traits.<sup>68</sup>

Even if health and disability are not characterized as perfectly opposed to one another, they still maintain some degree of inverse relation. As the seriousness of an individual’s disability increases, she can expect her level of health to decrease; likewise, as an individual’s health declines, her likelihood of manifesting a disabling impairment increases.<sup>69</sup> Thus, while “health” and “disability” are not always understood as juxtapositional opposites they are nonetheless related conceptually, making it challenging to define one without at least some reference to the other.<sup>70</sup>

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65. Ereshefsky, *supra* note 60, at 221.

66. Robert Funk, *Disability Rights: From Caste to Class in the Context of Civil Rights*, in *IMAGES OF THE DISABLED, DISABLING IMAGES* 7, 7–8 (Alan Gartner & Tom Joe eds., 1987) (explaining that people with disabilities constitute “a minority group who [has] been denied basic civil liberties such as the right to vote, to marry and bear children, to attend school, and to obtain employment”).

67. Contrary to this sentiment, many individuals with disabilities would not seek a cure of their underlying conditions were it available. See Harlan D. Hahn & Todd L. Belt, *Disability Identity and Attitudes Toward Cure in a Sample of Disabled Activists*, 45 *J. HEALTH & SOC. BEHAV.* 453 (2004).

68. It is important to note that in some cultural and historical contexts, people with disabilities are revered. See CAROLYN L. VASH & NANCY M. CREWE, *PSYCHOLOGY OF DISABILITY* 31 (2d ed. 2003).

69. One disability scholar has explained the relationship between health and disability as follows: “[T]hink of two continua, one denoting health and the other disability. The two continua are not parallel but get closer as severity increases on each one; that is, the two concepts of health and disability are related, but they are neither completely coincidental nor orthogonal.” OLKIN, *supra* note 35, at 9–10.

70. *Id.* (“It is possible to have a disability—for example, [cerebral palsy]—

Given the frequently oppositional relationship between health and disability, it stands to reason that legislation intended to promote "health" would likewise seek to cabin "disability," as in the context of public health.<sup>71</sup> Further, social benefits law provides resources to those in need. Thus—as a variety of health law—social welfare legislation construes people with disabilities as objects of charity or members of the deserving poor.<sup>72</sup> With the seeming conflict between "health" and "disability" it is not surprising that health and civil rights protections have remained discrete areas of disability law.

Finally, as discussed, the law of health insurance deals primarily with industry regulation. For-profit health insurers generate revenue by investing in "good risks" with limited expenses, making accurate risk assessment essential to this system. Hence, the historically predominant approach to American private health insurance has been one of actuarial fairness.<sup>73</sup> The central tenet of actuarial fairness is that individuals should be responsible for their own needs, thereby making widespread risk pooling in health insurance undesirable as the healthy will inevitably bear the costs of the sick. Conversely, the solidarity principle maintains that risk-pooling is desirable to ensure that those who are in need of care can receive it.

Whereas actuarial fairness promotes a norm of personal responsibility, the solidarity principle advocates mutual aid.<sup>74</sup> Although public benefits programs like Medicare and Medicaid may intervene to help those deemed deserving, for most of American history the health insurance industry and its governing laws have preferred an individualized account of fairness that favors "healthy" people over those with ongoing health-

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and also to be in excellent health. However, more serious disabilities often compromise an individual's health. . . . [T]he overlap between disability and illness becomes increasingly important as the conditions on either or both increase in severity. It is probably not possible to come up with a definition of disability that includes only disability and not illness, and vice versa."); see also NAT'L COUNCIL ON DISABILITY, *supra* note 28, at 127 (explaining that "a disability is often incorrectly assumed to determine a person's general health status").

71. See *supra* note 41 and accompanying text.

72. The disability rights movement would reject these constructions of disability as unduly paternalistic. See *infra* notes 84–86 and accompanying text.

73. See Stone, *supra* note 24, at 290 (arguing that actuarial fairness is "deeply embedded in the structure of competitive markets in insurance").

74. See *id.* at 290–94.

care needs.<sup>75</sup> With the health insurance industry's desire to assess risk accurately and the relevance of disability to those inquiries, separating health law from civil rights law keeps the actuarial fairness model intact.<sup>76</sup>

To sum up, the relevant areas of health-law regulation do not construct "disability" as a civil rights issue. While social-benefits law treats people with disabilities as objects of charity, public health law views them as problems to be solved. Although not explicitly dealing with disability, health insurance regulation has traditionally permitted insurers to differentiate between good and bad health risks. Thus, all three areas of health law frame disability in more or less medical terms. Because civil rights law protects individuals based on their social standing, the construction of disability as a medical issue within health law has contributed to the schism in the protections available to people with disabilities.

## 2. Civil Rights Law Explanations

Health laws dealing with disability came well before the civil rights legislation of the 1970s and beyond. Consequently, in promoting a civil rights model, members of the disability rights movement actively chose to move away from the existing legal paradigm. This choice of legislative framework was essen-

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75. See *id.* at 308 ("The logic and methods of actuarial fairness mean denying insurance to those who most need medical care. The principle actually distributes medical care in *inverse* relation to need, and to the large extent that commercial insurers operate on this principle, the American reliance on the private sector as its main provider of health insurance establishes a system that is perfectly and perversely designed to keep sick people away from doctors.").

76. As discussed below, the ADA contains a "safe harbor" provision for insurance. See *infra* notes 93–96 and accompanying text. Whether such an exemption is desirable, however, depends upon the model of health insurance one adopts: actuarial fairness or solidarity. See Lawrence O. Gostin, *Impact of the ADA on the Health Care System*, in IMPLEMENTING THE AMERICANS WITH DISABILITIES ACT: RIGHTS AND RESPONSIBILITIES OF ALL AMERICANS 175, 182 (Lawrence O. Gostin & Henry A. Beyer eds., 1993) ("The ADA's exemption of underwriting is reasonable if the industry is regarded strictly as a business. It is difficult to question the right of the insurance industry to discriminate on the basis of sound actuarial data. The very essence of underwriting is to classify people according to risk, treating those with higher risks differently. However, if health insurers are viewed as an integral part of health care policy, the ADA's exemption of underwriting becomes worrisome. The social purpose of health insurance is to spread risk across groups, enabling wider access to health care services. If health benefits become unavailable or unaffordable to those who are most likely to become ill, the social purpose of health coverage is thwarted.").

tial to their cause. As Justin Dart, a prominent activist popularly known as the father of the ADA, explained: "Around 1980 it became clear to me that we would never overcome the barriers to mainstream participation until the message of our full humanity was communicated in the consciousness and political process of America by a strong, highly visible, comprehensive *civil rights law*."<sup>77</sup>

Moreover, for many of the disability rights advocates of the late twentieth century, adopting the civil rights law paradigm meant simultaneously renouncing the health law paradigm.<sup>78</sup> This "either-or" mentality resulted from a number of characteristics associated with health law.

As explained, health law construes disability as a medical category. The disability rights movement, however, adopted a different position, known as the "social model" of disability. The social model recasts "disability" from a functional limitation to a limitation imposed by the interaction between a person's impairment and her physical and social environment.<sup>79</sup> Once disability is understood as a social problem, the focus shifts from the individual body of the person with a disability to the structural shortcomings of the society at large.<sup>80</sup> The social model gives way to the civil rights model: construing disability as a social category lays the foundation for understanding people with disabilities as a minority group that has experienced discrimination and oppression.<sup>81</sup> By advocating the social model of

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77. JACQUELINE VAUGHN SWITZER, *DISABLED RIGHTS: AMERICAN DISABILITY POLICY AND THE FIGHT FOR EQUALITY* 91 (2003) (emphasis added) (quoting Justin W. Dart, Jr., *Introduction: The ADA: A Promise to Be Kept*, in *IMPLEMENTING THE AMERICANS WITH DISABILITIES ACT: RIGHTS AND RESPONSIBILITIES OF ALL AMERICANS* xxii (Lawrence O. Gostin & Henry A. Beyer eds., 1993)).

78. See Bagenstos, *supra* note 5, at 18 ("[I]n the campaign to enact the ADA, disability rights activists frequently posed a stark choice between welfare and civil rights approaches.").

79. Michael Ashley Stein, *Disability Human Rights*, 95 CALIF. L. REV. 75, 85 (2007) ("The social model of disability asserts that contingent social conditions rather than inherent biological limitations constrain individuals' abilities and create a disability category."). See generally Tom Shakespeare, *The Social Model of Disability*, in *THE DISABILITY STUDIES READER*, *supra* note 3, at 266–72 (explaining the application of the social model theory in Britain).

80. See Shakespeare, *supra* note 79, at 268 ("Impairment is distinguished from disability. The former is individual and private, the latter is structural and public.").

81. Harlan Hahn equates people with disabilities to "other oppressed groups" distinguished from the majority by a particular trait, citing such common experiences as segregation and severe poverty. Harlan Hahn, *Adver-*

disability, those activists reframed the historical exclusion of people with disabilities from the result of functional limitations to an issue of civil rights.

Part of demedicalizing disability involves rejecting the traditional connotations of normalcy that are so essential to the naturalist understanding of health.<sup>82</sup> Proponents of disability rights, therefore, used the language of equality to attack what it means to be normal. As one disability scholar and advocate opined:

There is nothing a health care provider can do that will make us 'normal.' The problem is not the use of a wheelchair, but the concept of what is normal. People who use wheelchairs are quite normal. We are different, but normal. We have a right to be different and a right to be treated equally.<sup>83</sup>

By rejecting the medical model of disability and the underlying notion of statistical normalcy as desirable, disability rights activists moved away from the traditional goals of treatment and cure. Under the social framework, the solution to their historical oppression and exclusion lay not in medical science but in civil rights.

Another related ideological move within the disability rights movement was the rejection of paternalistic attitudes toward people with disabilities.<sup>84</sup> The medical model construed

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*tising the Acceptably Employable Image: Disability and Capitalism*, 15 POLY STUD. J. 551, 553 (1987); see also OLKIN, *supra* note 35, at 36 (explaining the "disability experience" as one that involves the "prejudice, stigma, and discrimination which is common to all minority groups"). But see SHAPIRO, *supra* note 54, at 126 ("The disability rights movement spanned a splintered universe. There are hundreds of different disabilities, and each group tended to see its issues in relation to its specific disability."); SWITZER, *supra* note 77, at 70 ("There is some disagreement about whether disabled persons fit into the social movement typology because they do not represent a minority group in the traditional sense of the word and therefore should not be regarded in the sense of a class of individuals. Nor are they sufficiently united in their discrimination."). More recently, some disability scholars have challenged the framing of people with disabilities as an oppressed minority as inconsistent with the other goals of the disability rights movement. See Andrew I. Batavia, *The New Paternalism: Portraying People with Disabilities as an Oppressed Minority*, 12 J. DISABILITY POLY STUD. 107, 112 (2001) ("Characterizing the population of people with disabilities as an oppressed minority . . . is a strategy destined to sustain people with disabilities in a state of subsistence.").

82. See generally Davis, *supra* note 64 (explaining the relatively new origins of the current meaning of the word "normal" and the framing of the "average" as the "ideal" in medical science).

83. SWITZER, *supra* note 77, at 7–8 (quoting David Pfeiffer).

84. Batavia, *supra* note 81, at 112 (explaining that the disability rights movement "specifically rejected the paternalism of the medical model of disability, which characterized people with disabilities as dependent patients who

people with disabilities as dependents in need of assistance and care. Frequently, individuals with disabilities were not active participants in the decisions regarding their own treatment, medical and otherwise.<sup>85</sup> Thus, the disability rights movement sought to free people with disabilities from the oppressive (yet arguably well-meaning) hold of family, friends, and social institutions.<sup>86</sup>

At the time of the early disability rights movement, its staunch rejection of both the medical model and the historically paternalistic attitudes toward people with disabilities made health law a wholly undesirable tool for pursuing the goals of access, independence, and integration.

To start, both health insurance regulation and public health law contain strong medical components. Health insurance law governs a market that provides insureds with access to medical care. However, the removal of structural barriers—both physical and attitudinal—was at the heart of the disability rights movement. Thus, not only was insurance law ill-equipped to achieve the movement's primary objectives, but even attempting to reform the health insurance system to improve coverage for people with disabilities could reify the construction of disability as a medical state.

Similarly, public health law frames its goals in medical terms. As noted, the historical position of public health has been that disability is something to be reduced and eventually eliminated. Employing a legislative paradigm that seeks to eradicate the very existence of people with disabilities seems counterintuitive to a movement designed to promote their equality and full citizenship. Further, it would not be surprising if members of the disability rights movement had significant reticence with respect to public health legislation. One of the most shameful public health initiatives in American history—the eugenics movement of the nineteenth and twentieth centuries—targeted people with disabilities.<sup>87</sup>

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must be cared for by the medical establishment and who were often cared for in a manner that did not satisfy their interests").

85. *See id.*

86. Bagenstos, *supra* note 5, at 7 ("One overarching goal is a negative one: freedom from the control of paternalistic parents, professionals, institutions, and welfare bureaucracies.").

87. During this time states enacted laws to sterilize the "feeble-minded." *See* SWITZER, *supra* note 77, at 36–38. Probably the most famous state-sanctioned sterilization was that of Carrie Buck, the subject of the still-infamous holding in *Buck v. Bell*, 274 U.S. 200 (1927). These forced steriliza-

Moreover, social benefits law was a similarly unappealing tool. The disability rights movement by and large rejected the social welfare system as unduly oppressive and paternalistic.<sup>88</sup> Advocates critiqued the programs on at least three different, yet related, grounds. Some believed that the benefits themselves represented an effort to pay off a potentially bothersome group.<sup>89</sup> Others maintained that disability-specific benefits promoted a culture of dependence and a “welfare mentality” that ran counter to the goal of independent living.<sup>90</sup> Finally, certain members of the disability rights movement believed that the beneficence of the social welfare programs simply masked a deep-seated discomfort regarding people with disabilities.<sup>91</sup> Civil rights law, therefore, presented an attractive alternative: people with disabilities could achieve independence through civil rights and no longer need the paternalistic benefits provided by social welfare.<sup>92</sup>

Thus, the conceptual dissonance between traditional connotations of “health” and “disability,” the reframing of disability as a social—not medical—category, and the rejection of paternalism led advocates of disability rights initially to keep health and civil rights protections distinct.

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tions carried on well into the latter half of the twentieth century, with individuals sterilized against their wills continuing to come forward today. *See, e.g.*, Kim Severson, *Thousands Sterilized, a State Weighs Restitution*, N.Y. TIMES, Dec. 9, 2011, at A1.

88. Bagenstos, *supra* note 5, at 5 (“Much of the thinking of the disability rights movement in this country developed as a reaction to the perceived paternalism and oppression that attended a welfare-based response to disability.”). Samuel Bagenstos has written prolifically on this topic.

89. *Id.* at 15.

90. *Id.* at 15–16.

91. *Id.* at 16–17; *see also* Harlan Hahn, *Antidiscrimination Laws and Social Research on Disability: The Minority Group Perspective*, 14 BEHAV. SCI. & L. 41, 43 (1996) (arguing that superficial sympathy and pity “has perpetuated the segregation and inequality of [disabled persons] segment in society”).

92. *See* Bagenstos, *supra* note 5, at 5 (“By the 1970s, many disability rights advocates were presenting antidiscrimination laws as an alternative to social welfare provision for people with disabilities—a tool that would obviate welfare programs by giving people with disabilities opportunities to make a living on their own.”); *id.* at 10 (“[M]any disability rights activists sought to change the social welfare orientation of disability law. Those activists argued that welfare is oppressive and stifling and that antidiscrimination and accommodation requirements would enable people with disabilities to leave the benefits rolls and enter the workforce.”).



## C. IMPLICATIONS

Separating the health and civil rights models affects the kind of legal protections available to people with disabilities. The way in which the ADA—a civil rights statute—deals with employer-provided health insurance—an area governed by health law—exemplifies how “health law” and “civil rights” law operate separately in the context of disability. The ADA includes a so-called “safe harbor” provision, which provides that health insurance providers may engage in risk assessment practices for underwriting and rating purposes,<sup>93</sup> so long as those practices do not constitute “subterfuge” to evade the statute’s purpose.<sup>94</sup> While Congress’s intent in drafting this provision is not entirely clear,<sup>95</sup> including a health-insurance safe harbor at a minimum indicates a desire to leave traditional insurance practices intact.<sup>96</sup> Arguably, Congress did not want a federal civil rights statute intruding into the area of primarily state-governed health law regulation.

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93. 42 U.S.C. § 12201(c)(1) (2006) (“Subchapters I through III of this chapter and title IV of this Act shall not be construed to prohibit or restrict—(1) an insurer, hospital or medical service company, health maintenance organization, or any agent, or entity that administers benefit plans, or similar organizations from underwriting risks, classifying risks, or administering such risks that are based on or not inconsistent with State law; or (2) a person or organization covered by this chapter from establishing, sponsoring, or observing or administering the terms of a bona fide benefit plan that are based on underwriting risks, classifying risks, or administering such risks that are based on or not inconsistent with State law; or (3) a person or organization covered by this chapter from establishing, sponsoring, or observing or administering the terms of a bona fide benefit plan that is not subject to State laws that regulate insurance.”).

94. *Id.* (“Paragraphs (1), (2), and (3) shall not be used as a subterfuge to evade the purposes of subchapter I and III of this chapter.”).

95. See Crossley, *Becoming Visible*, *supra* note 31, at 78 (noting that “[t]he meaning and application of Section 501(c) have been the source of much confusion and the subject of much litigation”); see also Bagenstos, *supra* note 5, at 38 (describing the provision as “nearly inscrutable”).

96. See Crossley, *Becoming Visible*, *supra* note 31, at 85 (“[T]he legislative history of the ADA contains some indication that Congress did indeed include the safe harbor in order to make perfectly clear that the ADA would not require insurance companies to change how they conducted their underwriting or risk classification practices.”); Crossley, *Discrimination Against the Unhealthy*, *supra* note 18, at 95 (“Congress’s inclusion of the insurance safe harbor reflected a conscious decision not to disrupt traditional underwriting practices by insurers.”); see also Wendy E. Parmet, *Discrimination and Disability: The Challenges of the ADA*, 18 LAW MED. & HEALTH CARE 331, 340 (1990) (stating that, because of the safe harbor provision, the ADA “cannot be read as a mandated insurance law”).

Further, quite tellingly, the law cannot decide on a unified way of defining disability. Both the ADA and the Rehabilitation Act employ a definition of disability that includes social elements. They define “disability” as “(A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (B) a record of such an impairment; or (C) being regarded as having such an impairment.”<sup>97</sup> Although impairment-based, this definition—especially the “regarded as” provision—still communicates an understanding of disability as social category. To begin, the definition separates the “disability” (social condition) from the “impairment” (medical condition).

Part of the social model’s contribution to disability theory was distinguishing the shared social experience of disability from a given individual’s functional ability.<sup>98</sup> For example, a person who uses a wheelchair may have a mobility impairment, such as difficulty walking. However, she may not experience that condition as disabling until she attempts to enter a building with a stairwell or a narrow doorway. Thus, the *impairment*—difficulty walking—is distinct from the *disability*—a lack of access.

The civil rights law definition of disability, found in the Rehabilitation Act and the ADA, reflects this distinction. It separates “impairment” from “disability,”<sup>99</sup> indicating they are not one and the same. Pursuant to the definition, an impairment only becomes disabling when it leads to some kind of tangible restriction on a person’s ability to function in her environment, in the form of a substantial limitation on a major life activity.<sup>100</sup> Furthermore, including individuals “regarded as” disabled indicates that a person may *experience* disability—such as exclusion, disadvantage, or a lack of access—even absent a substantially limiting impairment.<sup>101</sup> The “regarded as” prong eliminates the need to establish an underlying medical

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97. 42 U.S.C. § 12102(1) (Supp. V 2011). The Rehabilitation Act defines disability almost identically. See 29 U.S.C. § 705(9) (2006).

98. See MICHAEL OLIVER, *THE POLITICS OF DISABLEMENT: A SOCIOLOGICAL APPROACH* 12–24 (1990) (arguing that both impairment and disability are socially constructed).

99. 42 U.S.C. § 12201(c)(1).

100. *Id.*

101. Similarly, the “record of” provision indicates that a person may continue to experience disability, even after the impairment no longer substantially limits her.

condition.<sup>102</sup> That is not to say the civil rights law definition is completely social in nature. While containing aspects of the social model, scholars have criticized both the disability/impairment binary generally and the ADA definition specifically for ultimately relying too heavily on a medicalized understanding of disability.<sup>103</sup>

On the contrary, the social welfare definition of disability relies more heavily on functional limitation, as well as an inability to perform wage work.<sup>104</sup> The Social Security Act defines disability as an “inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months.”<sup>105</sup> The definition has a strong diagnostic feel: the impairment must be “medically determinable” and carrying a poor prognosis—at least a year of duration or resulting in death. Moreover, predicating benefits on a medicalized understanding of disability means that, improvements in functioning may lead to an individual’s benefits being terminated.<sup>106</sup> Thus, individuals with temporary or episodic conditions who qualify for support may choose not to reenter

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102. Perhaps because the “regarded as” definition of disability does not require the existence of an underlying impairment, Congress eliminated the availability of reasonable accommodation for claims brought under solely under that prong. See 42 U.S.C. § 12201(h).

103. Brad Areheart takes on the binary both conceptually and as applied. Bradley A. Areheart, *Disability Trouble*, 29 YALE L. & POL’Y REV. 347 (2011); see also Ramona L. Paetzold, *Why Incorporate Disability Studies into Teaching Discrimination Law?*, 27 J. LEGAL STUD. EDUC. 61, 74–76 (2010) (explaining the philosophical shortcomings of both the social model, with its distinction between impairment and disability, and the ADA).

104. Social welfare and civil rights law defined disability differently. Possibly because of the redistributive aim of the benefits programs, the civil rights definition of disability is more expansive than its social welfare counterpart. See Satz, *Overcoming Fragmentation*, *supra* note 5, at 295 (“Unlike civil rights approaches, benefits statutes seek to provide material resources to address disability discrimination. They are social welfare statutes and are intended to be redistributive in nature. Social welfare statutes restrict disability status to limit expenditures rather than to limit protected class status to those with a history of oppression. Perhaps as a result, the definition of *disability* is more restrictive under benefits statutes than under civil rights statutes.”).

105. 42 U.S.C. § 423(d)(1)(A) (2006).

106. Samuel Bagenstos has noted the fear of losing benefits to be of substantial concern for people with disabilities. Consequently, even in light of medical improvement, beneficiaries may remain out of the labor force. Bagenstos, *supra* note 5, at 32–34 (describing how the current structure of the public health insurance system creates a psychological investment in unemployment).

the workforce out of the fear that should their condition return they would no longer be eligible.<sup>107</sup>

Public health and insurance law also adopt medical, functional definitions of disability. For example, the *Dictionary of Public Health* defines disability as the “[r]educed capacity of a person to perform usual functions, usually the consequence of an impairment, such as impaired mobility or intellectual impairment.”<sup>108</sup> Likewise, the *Dictionary of Health Insurance and Managed Care* adopts a definition very similar to the social welfare iteration, explaining that a disability is “[a] physical or mental impairment caused by accident or illness that partially or totally limits one’s ability to perform duties of his or her own occupation or any occupation for which the individual is reasonably suited by education, training, or experience.”<sup>109</sup> (Importantly, the definition of disability may also vary pursuant to individual policies and programs.<sup>110</sup>) Thus, while sometimes distinguishing disability from impairment, health law definitions are more medical in nature and place greater weight on the existence and effect of the underlying impairment than the civil rights definitions.

The differing legislative paradigms associated with disability law have led to confusion regarding the legal meaning of “disability,” as well as who qualifies as “a person with a disability.”<sup>111</sup> As demonstrated in the following Part, the separation between health and civil rights law has led to shortcomings in the legal protections available to people with disabilities, particularly with respect to gaining meaningful access to health care.

Summing up, protections for people with disabilities have historically been split between two substantive legal paradigms: health law and civil rights law. That rift stems at least in part from how we understand disability: a predominantly medical conceptualization favors the health law paradigm,

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107. *See id.*

108. A DICTIONARY OF PUBLIC HEALTH 94 (John M. Last ed., 2007). *But see* J.E. SCHMIDT, 2 ATTORNEY’S DICTIONARY OF MEDICINE & WORD FINDER D-157 (2011) (adopting the first prong of the ADA’s definition of “disability”).

109. DICTIONARY OF HEALTH INSURANCE AND MANAGED CARE 88 (David Edward Marcinko ed., 2006).

110. *Id.* (“In life and health insurance policies or government benefit programs, definitions of disability may vary.”).

111. *See, e.g.,* *Cleveland v. Policy Mgmt. Sys. Corp.*, 526 U.S. 795, 797 (1999) (holding that the “pursuit, and receipt, of SSDI benefits does not automatically estop the recipient from pursuing an ADA claim”).

whereas a predominantly social conceptualization favors the civil rights paradigm. While the civil rights statutes described above facially apply to various kinds of health-care providers, the Rehabilitation Act and the ADA have failed to facilitate equality, access, and integration for people with disabilities in the context of health care.

## II. HEALTH-CARE ACCESS FOR PEOPLE WITH DISABILITIES

While advocates of disability rights construe discrimination based on disability as a social—not medical—problem, health-care access presents unique challenges for individuals with disabilities. This Part examines the pervasive inequalities experienced by people with disabilities with respect to health care and the failure of the civil rights laws, specifically the ADA and the Rehabilitation Act, to address these notable shortcomings.

### A. HEALTH DISPARITIES FOR PEOPLE WITH DISABILITIES

Although some disability scholars maintain that “illness” is not in and of itself a disability rights issue,<sup>112</sup> people with disa-

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112. See Satz, *Overcoming Fragmentation*, *supra* note 5, at 300 (citing Satz, *Disability, Vulnerability, and the Limits of Antidiscrimination*, *supra* note 5, at 561–67). Satz makes this distinction because while “disability” and “illness” may overlap, they are not identical categories. *Id.* at 300–01 (“Individuals who are sick may not be disabled, and vice-versa. Further, access to adequate health care, in terms of both coverage and the range of medical services available, is a problem for individuals with and without disabilities. While disability may seem to raise some complicating factors—including a possible higher consumption of health care resources than most individuals, health care rationing schemes that disfavor those with medical impairments, and difficulty moving between public assistance programs that include health care and the workforce—these are problems that individuals without disabilities face as well.”); see also Satz, *Disability, Vulnerability, and the Limits of Antidiscrimination*, *supra* note 5, at 561 (“First and foremost, disability does not equate with illness. The population of individuals who are ill or medically fragile exceeds the disability class. Illness may give rise to disability, but it does not presuppose it.”). Instead, she views illness as universalizing principle that demonstrates our shared vulnerability. *Id.* at 552 (“Illness is perhaps the prime example of a universal and constant vulnerability. When manifest, it significantly heightens other vulnerabilities for disabled and nondisabled people alike; it is not a disability issue.”). In my previous scholarship, I myself have distinguished between the concepts of “healthism” (discrimination on the basis of health status) and “ableism” (discrimination on the basis of (dis)ability). See Roberts, *supra* note 18, at 1171 n.68 (differentiating healthism and ableism). However, simply because some of the challenges faced by people with disabilities also affect individuals outside the disability com-

bilities have on-going health-care needs related to their impairments. Obtaining health services is, therefore, of particular importance to members of the disability community.<sup>113</sup> However, individuals with disabilities experience significant barriers with regard to their ability to access care, resulting in substantial health disparities.<sup>114</sup>

Research reveals that people with disabilities endure numerous types of inequities with respect to their health. Despite using health services at a greater rate than people without disabilities, individuals with disabilities report lower levels of overall health,<sup>115</sup> including a higher incidence of secondary conditions.<sup>116</sup> Further, although people with disabilities consume health care more frequently, they enjoy less access to preventive measures.<sup>117</sup> Barriers to accessing care—like antiquated medical equipment or insufficient training—disproportionately impact the disability community.<sup>118</sup> Thus, while disability rights advocates champion understanding disability as primarily a social issue,<sup>119</sup> on a purely practical level certain impairments may result in the need for various health services. An

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munity does not diminish their importance, severity, or pervasiveness as issues of health-care access specifically for people with disabilities.

113. Crossley, *Becoming Visible*, *supra* note 31, at 53 (noting that “because many persons with disabilities have ongoing and sometimes extensive health care needs as a result of their disabilities, legal protection against discrimination in accessing health care services can be of critical importance”); *see also* NAT’L COUNCIL ON DISABILITY, *supra* note 28, at 9–10 (explaining that “[p]eople with disabilities comprise the largest and most important health care consumer group in the United States”).

114. NAT’L COUNCIL ON DISABILITY, *supra* note 28, at 1 (finding that “[p]eople with disabilities experience significant health disparities and barriers to health care, as compared with people who do not have disabilities”); *see also* Karen Hwang et al., *Access and Coordination of Health Care Service for People with Disabilities*, 20 J. DISABILITY POL’Y STUD. 28, 28 (2009) (stating that for people with disabilities the risk of suboptimal care is “especially problematic because individuals with disabilities face multiple barriers to receiving quality health care services, ranging from structural barriers (e.g., physical access to doctors’ offices) to procedural barriers (e.g., difficulty scheduling appointments, problems obtaining insurance coverage”).

115. NAT’L COUNCIL ON DISABILITY, *supra* note 28, at 9, 23; *see also id.* at 34–35 (“About half of people with complex limitations and one-third of people with basic actions difficulties assessed their health status as fair or poor, compared with the three-fourths of adults who did not have a disability who assessed their health as excellent or very good.”).

116. *Id.* at 23.

117. *Id.* at 9, 23.

118. *Id.*

119. *See supra* notes 77–81 and accompanying text.

inability to access those necessary services lowers the overall level of health for many individuals with disabilities.

In analyzing the reasons behind these disparities, an additional discussion of health insurance provides a logical point of departure. People with disabilities frequently find themselves either un- or under-insured.<sup>120</sup> Not only do barriers to obtaining health insurance limit access to coverage, but—because of the cost of health services—access to health insurance also serves as a proxy for access to health care generally.<sup>121</sup> Significantly, people with disabilities encounter numerous obstacles to accessing care within both the private and the public health-insurance systems.

### 1. Public Benefits and Health Disparities

As discussed, most people with disabilities who have health insurance are insured through government-run programs, such as Medicaid and Medicare.<sup>122</sup> In fact, Medicaid has been described as the “largest single source of health insurance and long-term care and the largest source of public financial support for people with disabilities.”<sup>123</sup> Although public health insurance serves as an important resource for individuals with

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120. NAT'L COUNCIL ON DISABILITY, *supra* note 28, at 1 (finding that “[p]eople with disabilities frequently lack either health insurance or coverage for necessary services, such as specialty care, long-term services, prescription medications, durable medical equipment, and assistive technologies”); *id.* at 11–12 (noting that “[t]he health care system in the United States is complex, highly fragmented, and sometimes overly restrictive in terms of program eligibility . . . leav[ing] some people with disabilities with no health care coverage and others with cost-sharing obligations and limits on benefits that prevent them from obtaining health-preserving prescription medications, medical equipment, specialty care, dental and vision care, long-term care, and care coordination”).

121. See Katherine Unger Davis, *Racial Disparities in Childhood Obesity: Causes, Consequences, and Solutions*, 14 U. PA. J.L. & SOC. CHANGE 313, 314 n.5 (2011) (“Because ‘health insurance facilitates entry into the health care system,’ levels of insurance coverage have been used as a proxy to analyze access to healthcare more generally.” (quoting AGENCY FOR HEALTHCARE RESEARCH & QUALITY, NATIONAL HEALTHCARE DISPARITIES REPORT 113 (2007), available at <http://www.ahrq.gov/qual/nhdr07/nhdr07.pdf>)); see also NAT'L COUNCIL ON DISABILITY, *supra* note 28, at 38 (explaining that “[i]nsurance coverage tends to determine whether people with disabilities visit a doctor regularly or have access to a usual source of medical care”).

122. See *supra* note 9 and accompanying text.

123. NAT'L COUNCIL ON DISABILITY, *supra* note 28, at 110 (quoting *Helping Families with Needed Care: Medicaid's Role for People with Disabilities: Testimony Before the H. Comm. on Energy and Commerce Subcomm. on Health* 110th Cong. 22 (2008) (testimony of Diane Rowland)).

disabilities in need of health care, those programs are not without their limitations. For instance, the Centers for Medicare and Medicaid Services (CMS), the federal funding agencies responsible for those programs, collect data related to the public health insurance system but do not assess the compliance of those programs with the ADA.<sup>124</sup>

Despite being the primary source of health insurance for people with disabilities, Medicaid has several shortcomings that contribute to the health disparities experienced by the disability community. First, beneficiaries have trouble locating health-care providers who will accept Medicaid payments.<sup>125</sup> Thus, low-income people with disabilities encounter programmatic barriers even before the treatment relationship begins. Furthermore, structural problems persist after a Medicaid recipient finds a physician willing to accept her. Health-care professionals who serve Medicaid recipients with disabilities report impediments to providing care resulting from improper referrals and accessibility issues.<sup>126</sup> Medicaid managed care programs suffer from poor coordination of care, reduced consumer choice, and a limited ability to access specialists, thereby negatively impacting health care for people with disabilities.<sup>127</sup> Additionally, Medicaid only provides limited coverage. It fails to cover many essential services, such as dental, vision, and personal assistance, as well as durable medical equipment.<sup>128</sup>

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124. *Id.* at 21 (“Federal health care funding agencies such as the Centers for Medicare and Medicaid Services (CMS) do not conduct oversight of Americans with Disabilities Act (ADA) architectural and programmatic accessibility compliance by states, health plans, and medical providers or assess health providers’ disability cultural competence.”).

125. NAT’L COUNCIL ON DISABILITY, *supra* note 28, at 45.

126. Hwang et al., *supra* note 114, at 29 (“A Texas survey of 62 general practitioners, family practitioners, internists, and obstetrician-gynecologists serving Medicaid recipients revealed that despite the requirements of the Americans with Disabilities Act, a substantial portion of primary care physicians are unable to serve people with disabilities, owing to inappropriate referrals and structural inaccessibility.”).

127. NAT’L COUNCIL ON DISABILITY, *supra* note 28, at 88 (“In some cases, Medicaid managed care programs are poorly equipped to meet the needs of people with disabilities . . . . Problem areas include inadequate care coordination, limited access to specialists, limited consumer choice, and inadequate risk adjustment for capitation rates.”).

128. *Id.* at 45 (“For many of these low-income beneficiaries, however, essential health care services—including dental and vision care, medical supplies, and durable medical equipment—may be out of reach financially, even with low cost-sharing under Medicaid.”); *see also* Hwang et al., *supra* note 114, at 29 (“Among a sample of 502 Missouri residents with disabilities who were receiving Medicaid services in central Missouri, nearly two thirds reported dif-



Lastly, while Medicaid includes a home health benefit, states can limit coverage based on factors like “medical necessity.”<sup>129</sup> Many “optional” services may actually be *necessary* for people with certain kinds of disabilities to function.<sup>130</sup> Taken as a whole, these structural and programmatic barriers lead to health disparities for individuals with disabilities insured through Medicaid.<sup>131</sup> It is, therefore, not surprising that Medicaid recipients have expressed dissatisfaction with the program and its benefits.<sup>132</sup>

Medicare also has its limits. Medicare recipients pay more out-of-pocket than their Medicaid counterparts.<sup>133</sup> These increased costs may lead Medicare beneficiaries to choose to forgo necessary care or equipment.<sup>134</sup> Like Medicaid, Medicare does not cover a variety of important health services, including vision, dental, or long-term care.<sup>135</sup> Moreover, people under sixty-five who wish to qualify for Medicare through SSDI must wait

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difficulties in obtaining needed health care services—particularly dental, optometric, and personal assistance services.”).

129. NAT’L COUNCIL ON DISABILITY, *supra* note 28, at 110 (“The category of ‘medical supplies, equipment and appliances suitable for use in the home’ is a mandatory home health service benefit, but a state can establish reasonable standards under the Medicaid statute and set limits on coverage based on such factors as ‘medical necessity’ or ‘utilization control.’”).

130. *Id.* (“The distinction between mandatory and optional services can be particularly important for people with disabilities, because many optional services can be critical to maintaining health and the ability to function in the community.”).

131. *Id.* at 111 (“A state’s tolerance of structural and programmatic barriers in the multiple levels of its health care system is an ongoing violation of the Medicaid program and greatly contributes to the health care disparities endured by people with disabilities.”).

132. Hwang et al., *supra* note 114, at 29 (“In a 1999–2000 national survey, Medicaid beneficiaries with disabilities reported dissatisfaction in key areas of access and care.”).

133. NAT’L COUNCIL ON DISABILITY, *supra* note 28, at 45.

134. *Id.* (“Both Medicare and Medicaid beneficiaries . . . have reported difficulties obtaining the care and services they require. With higher copayments, Medicare beneficiaries with disabilities report significant cost-related problems including forgoing needed equipment, postponing care, and paying for long-term care.”).

135. *Id.* at 113 (“[T]he program contains significant gaps in coverage benefits for items or services that can be both expensive and particularly important for maintaining function and independence. For instance, Medicare does not pay for long-term care services at home or in an institution, routine dental care or dentures, routine vision care or eyeglasses, or hearing exams hearing aids.”).

two years to obtain coverage.<sup>136</sup> During that period, many of them go uninsured.<sup>137</sup>

Given these limitations, disability rights advocates have recommended that CMS update their definitions of “medical equipment” and “medical necessity” and pay for interpreters, rehabilitative services, and assistive technologies for people with disabilities to address these health disparities.<sup>138</sup>

## 2. Private Health Insurance and Health Disparities

Characteristics of the private insurance market likewise contribute to the health disparities faced by people with disabilities. As discussed, insurers may exclude them outright or may impose limitations or caps on what the policy covers.<sup>139</sup> Further, health-status based rating has compounded the problem.<sup>140</sup> Traditionally when insurers have offered policies to individuals with disabilities, those policies came with heightened premiums.<sup>141</sup> Even in the group health-insurance system, people with disabilities are likely to pay more out-of-pocket because of cost-sharing mechanisms, like deductibles and co-payments, combined with their increased need for medical services.<sup>142</sup> Yet, beyond the difficulties discussed in the preceding part, people with disabilities also experience substantial barriers to obtaining equipment and services that are essential to their health-care needs.

Similar to the structural impediments people with disabilities encounter in public health insurance, certain aspects of private health insurance may thwart their access to needed

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136. *Id.* at 45 (“Medicare imposes a 2-year waiting period for coverage for individuals who are under age 65 who become eligible for the program when they receive Social Security Disability Insurance (SSDI).”).

137. *Id.* at 113 (“Another serious gap involves people who become disabled before age 65. They must wait 2 years after they establish eligibility for SSDI before they can receive Medicare coverage, a period during which many do not have any insurance coverage.”).

138. *Id.* at 95 (recommending that “the Centers for Medicare & Medicaid Services (CMS) should update their current definitions of durable medical equipment and medical necessity, which are outdated and give little consideration to increasing an individual’s functional status”); *id.* at 94–95 (recommending that the Centers for Medicare & Medicaid Services pay for interpreters, rehabilitative services, and assistive technologies for people with disabilities).

139. *See supra* notes 22–25 and accompanying text.

140. *See supra* notes 26–28 and accompanying text.

141. *See* NAT’L COUNCIL ON DISABILITY, *supra* note 28.

142. *See supra* note 29.

care, thereby leading to health disparities. Samuel Bagenstos identifies two characteristics of the private health-insurance industry that substantially restrict the care available to people with disabilities: (1) emphasizing acute care and (2) limiting coverage to “medically necessary” treatments.<sup>143</sup>

Health care generally focuses on addressing acute—not on-going—needs.<sup>144</sup> Perhaps the centrality of acute care stems from the notion that “health” is the default state, making disease or disability exceptional events.<sup>145</sup> Under such a model, the goal of medical care is not to provide chronic treatment but rather to restore health following isolated incidents of disease or injury. Because people with disabilities often have on-going health-care needs, the focus on acute care means that private health insurance will not cover those required services over the long-term.<sup>146</sup> The resulting gaps in coverage impede the ability of individuals with disabilities to obtain needed health services, thus leading to health disparities.

Moreover, like their government-funded counterparts, many private health insurers have not traditionally provided adequate coverage for assistive technologies or durable medical equipment.<sup>147</sup> Policies that limit their coverage to “medically necessary” treatments have invoked those clauses to deny payment for any number of assistive devices, including hearing aids, prostheses, and even wheelchairs.<sup>148</sup> Further exacerbating the problem, private health insurers have chosen to limit their annual payments for durable medical equipment irrespective of its medical necessity.<sup>149</sup> Not having access to needed equipment

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143. Bagenstos, *supra* note 5, at 30 (“Two aspects of private insurance largely account for this effect: (1) the tilt of insurance policies toward acute, as opposed to chronic care; and (2) the typical requirement that covered treatments be ‘medically necessary.’”).

144. Hwang et al., *supra* note 114, at 31 (noting that “[t]raditional models of health care delivery have generally been designed for acute rather than chronic care”).

145. See Satz, *Overcoming Fragmentation*, *supra* note 5, at 306 (explaining that “[w]ithin social contract theory, disability and illness are not viewed as part of the human experience, but rather as exceptional”).

146. Bagenstos, *supra* note 5, at 31 (noting that for private health insurers will cover a treatment “when it is a short-term response to an acute condition, but not when it is a continuing response to a chronic condition”).

147. *Id.*

148. See *id.* at 31–32.

149. NAT’L COUNCIL ON DISABILITY, *supra* note 28, at 46 (“[P]rivate insurance plans increasingly limit annual payments for durable medical equipment such as wheelchairs, crutches, braces, and ventilators, regardless of medical necessity and at a level that makes the individual’s out-of-pocket costs for

and services negatively impacts the health of individuals with disabilities.

Inaccessible medical equipment also contributes to the health disparities experienced by people with disabilities.<sup>150</sup> As a result, people with disabilities may be unable to obtain basic preventive care services because of inaccessible exam tables and screening equipment, thereby leading to later detection and treatment of serious health conditions such as breast, cervical, and prostate cancers.<sup>151</sup> These factors contribute to both a lower level of overall health and higher incidence of late detection and secondary conditions.<sup>152</sup> In a particularly chilling example, a woman who used a wheelchair approached her doctor regarding a lump in her breast.<sup>153</sup> In lieu of performing a mammogram, her physician concluded that she had overdeveloped her pectoral muscle from using her wheelchair.<sup>154</sup> Later, she was diagnosed with breast cancer.<sup>155</sup> By that time, the cancer was terminal. She died within three years.<sup>156</sup>

### 3. Public Health and Health Disparities

Although people with disabilities face substantial health disparities, public health research has historically failed to recognize people with disabilities as a health disparities population with its own unique health-care needs.<sup>157</sup>

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higher priced items such as motorized wheelchairs prohibitively expensive.”).

150. Elizabeth Pendo has written extensively on the topic of inaccessible medical equipment as an impediment to health care access for people with disabilities. See, e.g., 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, 17 (2008); Elizabeth Pendo, *Reducing Disparities Through Health Care Reform: Disability and Accessible Medical Equipment*, 4 UTAH L. REV. 1057, 1057 (2010) [hereinafter Pendo, *Reducing Disparities*].

151. See Pendo, *Reducing Disparities*, *supra* note 150, at 1060–65 (describing the affect of inaccessible examination tables, examination chairs, weight scales, and X-ray and other imaging equipment on access to preventative services and screenings for people with disabilities); see also NAT'L COUNCIL ON DISABILITY, *supra* note 28, at 49 (explaining that health-care providers “frequently conduct examinations or diagnostic tests while patients are seated in their wheelchairs, which can generate inaccurate test results or conceal physician evidence required for appropriate diagnosis and treatment”).

152. NAT'L COUNCIL ON DISABILITY, *supra* note 28, at 56.

153. *Id.* at 58.

154. *Id.*

155. *Id.*

156. *Id.*

157. The term “health disparity” holds multiple meanings. NAT'L COUNCIL ON DISABILITY, *supra* note 28, at 29 (“The phrase ‘health disparity’ is widely used in the articulation of health care research, funding, and service delivery

Prior to 2010, the majority of federally funded research programs did not recognize people with disabilities as a health disparities population.<sup>158</sup> The Department of Health and Human Services first recognized “disability” as a relevant population for public health purposes in 2010, when the Surgeon General issued the report *Call to Action to Improve the Health and Wellness of Persons with Disabilities* and when *Healthy People 2010* defined disability as a demographic trait.<sup>159</sup> Yet despite this limited inclusion, major federal public health entities—most notably the National Center on Minority Health and Health Disparities—still do not include people with disabilities in their health disparities research.<sup>160</sup> Moreover, because no single federal agency acts as a clearinghouse for disability-related public health information, any research related to people with disabilities and health-care access occurs piecemeal.<sup>161</sup> It is, therefore, difficult to ascertain the true extent of public health initiatives impacting individuals with disabilities.<sup>162</sup> These shortcomings have resulted in a lack of comprehensive data documenting the experiences of individuals with disabilities in obtaining health care. This absence ultimately hinders the development of coherent, coordinated public health efforts targeting the disability community.<sup>163</sup>

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priorities by both public and private organizations. The exact definition of health disparity varies. In some cases, it includes many population subgroups and indicators; in other cases, it is narrowly restricted to specific populations and health conditions. In broad terms, ‘health disparity’ can be defined as ‘differences in health outcomes and health care access that occur between specific populations and the general population’ . . . . In most instances in the United States, when the phrase ‘health disparity’ is used, it is understood to describe circumstances in which differences are interpreted to indicate bias or unacceptable disproportion in health outcomes, aspects of health care system access, or differences in health treatment for one group compared with the general population.”).

158. NAT’L COUNCIL ON DISABILITY, *supra* note 28, at 1.

159. *Id.* at 12.

160. *Id.* at 12.

161. *Id.* at 12–13.

162. *Id.* at 12.

163. *Id.* at 13 (“Specific structural problems evident Federal agency disability research functionally impede the development of a unified, coherent plan for disability and health research and program development. Specifically, (1) the level of funding and research is wholly inadequate to spur a coherent investigative strategy that will inform policy and planning for the growing number of people who will acquire disabilities with age and for the overall future impact of disability on society; and (2) within the Federal research community, commitment to disability health disparities and health promotion research is weak, and coordination mechanisms are lacking.”).

Given the lack of good, reliable data on disability and health-care access, perhaps it comes as no surprise that medical professionals lack adequate training regarding disability competency. The treatment needs of people with disabilities are not traditionally part of core medical curriculum,<sup>164</sup> leaving many health-care professionals uneducated in meeting the needs of the disability community. This ignorance ranks among the most significant obstacles to adequate health care that people with disabilities face.<sup>165</sup> Consequently, disability rights advocates have pushed for additional research into the barriers to health-care access faced by people with disabilities.<sup>166</sup>

Thus, the ubiquitous physical and structural barriers people with disabilities regularly encounter permeate all aspects of their lives, including their ability to access health care. Significantly, an inability to obtain needed health services adversely affects other areas of people's lives, such as employment.<sup>167</sup> While civil rights law may facially cover various areas of health-care delivery, those statutes have by and large been ineffective in ensuring adequate access to care for the disability community.

#### B. FAILURE OF THE CIVIL RIGHTS PARADIGM

People with disabilities experience serious health disparities. Although designed to improve access and integration for

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164. *Id.* at 13 (“Disability competency is not a core curriculum requirement for (1) accreditation or receipt of Federal funding for most medical and dental schools and other professional health care training institutions; or (2) for hospitals to participate in federally funded medical student internship and residency programs. In addition, applicants who seek either a medical or other professional health care license are generally not required to demonstrate disability competency.”).

165. *Id.*; *see also id.* at 49 (explaining that “health care providers hold incorrect assumptions and stereotypes about people with disabilities, which can affect every aspect of care and can result in inadequate and inappropriate care”).

166. *See, e.g., id.* at 125 (suggesting that if the Agency for Healthcare Research and Quality “promoted research that clearly identified the various barriers encountered by people with disabilities as a priority population when seeking health care, it could help advocates document a statistically accurate record of, for example, the extent to which health care technologies, facilities, and equipment remain inaccessible to people with disabilities and bolster efforts to effect change”).

167. *See Bagenstos, supra* note 5, at 22–23 (noting the failure of the ADA to improve the level of employment for people with disabilities); *id.* at 26–27 (attributing that failure in part to the structure of the pre-ACA health-insurance system and its resulting barriers to access).

the disability community, the Rehabilitation Act and the ADA have failed to have a lasting impact in the area of health care. This failure can in part be attributed to the statutes' civil rights structure.<sup>168</sup>

The failure of the civil rights paradigm, however, does not stem from an explicit lack of coverage. Both the Rehabilitation Act and the ADA extend to health-care settings. As noted, the Rehabilitation Act requires federally funded entities to ensure equal access to their programs and services for people with disabilities.<sup>169</sup> The statute, therefore, applies to clinics, hospitals, and other health-care providers that accept federal monies, such as Medicare or Medicaid.<sup>170</sup> Further, the relevant regulations prohibit covered entities from providing any benefit or service that denies people with disabilities the opportunity to participate in or benefit from Medicaid, affords people with disabilities an opportunity to participate in or benefit from health care services that are not equal to that afforded others, or provides people with disabilities an aid, benefit or service that is not as effective as that provided to others.<sup>171</sup> Despite its applicability, the courts have been reluctant to interpret the Rehabilitation Act's protections aggressively with respect to issues of health care.<sup>172</sup>

Similarly, certain provisions of the ADA also apply—at least facially—to health-care providers. The ADA's legislative history indicates that people with disabilities encountered numerous barriers to accessing health care,<sup>173</sup> and the findings of the original statute stated that “discrimination against individuals with disabilities persists in such critical areas

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168. See Crossley, *Becoming Visible*, *supra* note 31, at 88–89 (proposing that part of the ADA's failure to improve health-care access for people with disabilities is attributable to the fact that “the ADA is a civil rights statute, not a health care reform statute”).

169. See *supra* note 45 and accompanying text.

170. NAT'L COUNCIL ON DISABILITY, *supra* note 28, at 99 (“Section 504 prohibits discrimination against otherwise qualified people with disabilities under any program or activity that receives Federal financial assistance; it directly applies to state Medicaid agencies and the many corporate health care entities and providers that receive Federal monies through Medicaid, Medicare, or Federal block grants.”).

171. 34 C.F.R. § 104.52(a) (2013).

172. Crossley, *Becoming Visible*, *supra* note 31, at 53 (explaining that courts took a “hands-off approach to health care issues” with respect to Section 504).

173. *Id.* at 51 (“[T]he voluminous legislative history that underpins the ADA includes ample testimony regarding the barriers that people with disabilities faced in obtaining health care.”).

as . . . health services.”<sup>174</sup> Thus, barriers to health-care access were among the impediments Congress sought to dismantle when passing the ADA.

As written, the ADA applies to both public and private health care providers. Title II covers state and local entities,<sup>175</sup> including public health programs and providers that accept state funding like Medicaid.<sup>176</sup> It provides that government institutions cannot exclude, deny benefits to, or discriminate against qualified individuals with disabilities.<sup>177</sup> Likewise, Title III, which governs privately owned “public accommodations,” applies to physicians’ offices and hospitals,<sup>178</sup> regardless of whether the provider is operating out of a private residence.<sup>179</sup> That provision prevents commercial entities from denying people with disabilities the full and equal enjoyment of their goods and services.<sup>180</sup> The law requires the programs, vendors, and service-providers covered by Titles II and III to make reasonable modifications to facilitate the equitable participation of individuals with disabilities.<sup>181</sup> Thus, the ADA arguably man-

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174. 42 U.S.C. § 12101(a)(3) (2006).

175. *See id.* § 12131(1).

176. *See* NAT’L COUNCIL ON DISABILITY, *supra* note 28, at 99 (stating that “State Medicaid agencies . . . fall under Title II of the ADA”).

177. 42 U.S.C. § 12132 (“Subject to the provisions of this subchapter, no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity.”).

178. *Id.* §§ 12181(7)(F), 12182(a). In fact, the definition of a “public accommodation” explicitly includes an “insurance office, professional office of a health care provider, hospital, or other service establishment.” *Id.* § 12181(7)(F).

179. *See* 28 C.F.R. § 36.207 (2013).

180. 42 U.S.C. § 12182 (“No individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation by any person who owns, leases (or leases to), or operates a place of public accommodation.”).

181. *See id.* § 12131 (defining a “qualified individual” for Title II purposes as “[a]n individual with a disability who, with or without reasonable modifications to rules, policies, or practices, the removal of architectural, communication, or transportation barriers, or the provision of auxiliary aids and services, meets the essential eligibility requirements for the receipt of services or the participation in programs or activities provided by a public entity”); *see also* NAT’L COUNCIL ON DISABILITY, *supra* note 28, at 99 (“In the health care context, this means that a health care entity must modify its policies, practices, and procedures when necessary to enable people with disabilities to gain full and equal access to its services, unless a requested modification constitutes a fundamental alteration of the health care service itself.”).



dates that people with disabilities enjoy equal access to health care.<sup>182</sup> However, much like the Rehabilitation Act, the ADA has not had a meaningful impact on access to health care for people with disabilities.<sup>183</sup> The civil rights structure of those laws offers an explanation as to why.

Civil rights statutes share certain characteristics with respect to their purpose, as well as the content of their protections. As discussed, antidiscrimination laws seek to eliminate group subordination.<sup>184</sup> Consequently, their protections forbid covered entities from discriminating on the basis of a particular trait.<sup>185</sup> However, whether specific conduct rises to the level of actionable discrimination is a question frequently left to judicial interpretation.<sup>186</sup> Because civil rights statutes prohibit discriminatory conduct—opposed to providing explicit substantive entitlements—courts have been free to interpret the Rehabilitation Act and the ADA very narrowly in the context of health care. Further, civil rights statutes' emphasis on individualized instances of discrimination and private enforcement renders those laws ill-equipped for addressing health disparities occurring at the population level.<sup>187</sup>

Because of its inherent limitations, the civil rights paradigm has failed to achieve meaningful access to health services in the three areas of health law discussed: (1) public health in-

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182. See Pendo, *Reducing Disparities*, *supra* note 150, at 1071 (“The ADA requires equal access to health care.”).

183. *Id.* at 1065 (“Although the ADA establishes the necessary foundation for ensuring equal and accessible care for people with disabilities, people with disabilities continue to experience significant barriers to care, including basic preventive health services.”); see also Crossley, *Becoming Visible*, *supra* note 31, at 86–87 (“A frank assessment shows that, aside from its impact on the individual encounters between patient and provider, the ADA’s application has [as of 2000] been neither forceful nor sweeping.”).

184. See *supra* note 42 for a discussion of an antisubordination orientation for antidiscrimination law.

185. Protections framed as blanket prohibitions on the consideration of a particular trait are arguably anticlassification, not antisubordination, in nature. However, even those protections may be in response to group subordination. See generally Jack M. Balkin & Reva B. Siegel, *The American Civil Rights Tradition: Anticlassification or Antisubordination?*, 58 U. MIAMI L. REV. 9 (2003).

186. For example, in the instances described below, the Supreme Court was deciding whether policies and practices that had a tangible negative impact on people with disabilities constituted “discrimination” for the purposes of the Rehabilitation Act and the ADA. See discussion *infra* notes 188–205 and accompanying text.

187. See *infra* note 214 and accompanying text.

surance and government benefits; (2) private insurance; and (3) public health. I will discuss each in turn.

First, with regard to social-welfare programs, the courts have been reluctant to apply civil rights legislation in a manner that ensures health-care access for people with disabilities. Even before the passage of the ADA, the Supreme Court severely limited the applicability of antidiscrimination-style legislation to public health-insurance programs, like Medicaid. In the 1985 landmark case, *Alexander v. Choate*, the Supreme Court held that the Rehabilitation Act did not apply to a state's Medicaid rationing decision, regardless of its potentially disparate impact.<sup>188</sup> As of 1980, Tennessee's Medicaid program cost more than the state legislature chose to fund.<sup>189</sup> Faced with this budgeting dilemma, the state proposed limiting Medicaid recipients to fourteen days of in-patient hospital care per year.<sup>190</sup> While neutral on its face, that restriction would likely have impacted individuals with disabilities more severely, as they tend to consume more health services.<sup>191</sup> Consequently, Tennessee Medicaid beneficiaries filed a class action lawsuit, alleging the decision violated the Rehabilitation Act.<sup>192</sup> The Supreme Court unanimously upheld the state's decision, holding that limiting the number of covered hospital days did not eliminate "meaningful access" to the Medicaid program for people with disabilities.<sup>193</sup> The Court reasoned that because both recipients with and without disabilities received an identical benefit (in this case fourteen days of in-patient care), each group enjoyed the *same* access.<sup>194</sup> Perhaps most importantly, the Court construed the benefit at stake as a "package of health care services," not adequate, equitable, or accessible health care.<sup>195</sup> Thus, under *Choate*, public health-insurance providers do not *discriminate* on the basis of disability, even when their deci-

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188. 469 U.S. 287 (1985).

189. *Id.* at 289.

190. The state had previously covered twenty days. *Id.*

191. *Id.* at 290. According to the evidence, 27.4% of people with disabilities who received Medicaid used over fourteen days of in-patient hospital care, compared with only 7.8% of recipients without disabilities. *Id.*

192. *Id.*

193. *Id.* at 306–09. Bagenstos identifies *Choate* as the advent of the "access/content" distinction he explores in much of his work on disability rights law. See Bagenstos, *supra* note 5, at 46–49.

194. *Choate*, 469 U.S. at 302.

195. *Id.* at 303.

sions negatively impact people with disabilities, so long as they provide identical benefits.<sup>196</sup>

Further, courts have been likewise reluctant to enforce civil rights legislation with respect to private insurance. With its focus on facilitating independence for people with disabilities, the ADA can be understood as an effort to shift the provision of care for the disability community from the public to the private sector.<sup>197</sup> However, as discussed, the legislation includes a safe-harbor provision that allows insurers, health-care providers, and other benefit administrators to engage in traditional risk assessment and underwriting activities, as long as those activities have a sound actuarial basis.<sup>198</sup> The ADA, therefore, does not outlaw any of the traditional insurance practices that disadvantage people with disabilities, such as preexisting condition exclusions, caps on coverage, and health status-based rating.<sup>199</sup> Interestingly, however, courts have not relied on the safe-harbor provision when rejecting challenges to insurance practices that disadvantage people with disabilities. For instance, in *Doe v. Mutual of Omaha Insurance Co.*, two HIV-positive plaintiffs challenged their private insurer's caps on HIV-related coverage as a violation of Title III of the ADA.<sup>200</sup> In lieu of invoking the safe-harbor, the Seventh Circuit instead upheld the caps as nondiscriminatory because the insurer offered the *same* products to all of its insureds, regardless of HIV status.<sup>201</sup> Thus, courts have relied on the content of the policy or

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196. Scholars have challenged whether the access granted under *Choate* is truly "meaningful" with respect to the varying needs of the disabled and non-disabled. See, e.g., Leslie Pickering Francis & Anita Silvers, *Debilitating Alexander v. Choate: "Meaningful Access" to Health Care for People with Disabilities*, 35 *FORDHAM URB. L.J.* 447, 451–52 (2008) ("A fourteen-day hospital stay is 'meaningful' for those whose conditions can be adequately treated within a fourteen-day period. For those whose conditions require more, such as patients requiring high-dose chemotherapy plus stem cell rescue, fourteen days of hospitalization might as well be no benefit at all.")

197. Parmet, *supra* note 96, at 340 ("The ADA can be seen not as the public recognition of the needs of the disabled, but as a way of supporting the privatization of the disabled's health care needs").

198. See *supra* notes 93–94 and accompanying text.

199. Gostin, *supra* note 76, at 182 ("The ADA, therefore, does not restrict an insurer, health care provider, or any entity that administers benefit plans from carrying on its normal underwriting activities. This includes the use of preexisting condition clauses in health insurance contracts, the placing of caps or other limits on coverage for certain procedures or treatments, or the charging of a premium to persons with higher risks.")

200. 179 F.3d 557 (7th Cir. 1999).

201. *Id.* at 558–62.

benefit offered—not the relative utility of that policy or benefit to the individual policy-holders or beneficiaries—when deciding whether discrimination occurred.<sup>202</sup>

Importantly, the courts have interpreted the Rehabilitation Act and ADA to leave the patient-professional relationship largely intact. In the leading case on the subject, the Second Circuit held that the Rehabilitation Act does not apply to treatment decisions.<sup>203</sup> Likewise, the ADA preserves a physician's ability to make treatment and other decisions, such as accepting or rejecting a patient, so long as she does not base her decision on the patient's disability.<sup>204</sup> Justice Ginsburg, writing for the majority, further reiterated this point in a footnote in the 1999 Title II case, *Olmstead v. L.C. ex rel. Zimring*. She opined:

We do not in this opinion hold that the ADA imposes on the States a 'standard of care' for whatever medical services they render, or that the ADA requires States to 'provide a certain level of benefits to individuals with disabilities.' We do hold, however, that States must adhere to the ADA's nondiscrimination requirement with regard to the services they in fact provide.<sup>205</sup>

It has, therefore, been the position of the courts that civil rights laws, like the Rehabilitation Act and the ADA, do not ensure a basic level of medical care or benefits for people with disabilities, but rather protect individuals with disabilities from being treated *differently* than patients and beneficiaries without disabilities.

The ADA also has its limits in ensuring accessible medical equipment. In the over two decades since Congress passed the ADA, only a handful of lawsuits have challenged inaccessible

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202. Bagenstos, *supra* note 5, at 40–41 (explaining that “[w]ith only a few exceptions, [courts] have not found it necessary to rely on the safe harbor provision” and have instead employed the “access/content” distinction “[s]o long as the insurer offers people with disabilities the opportunity to purchase policies on the same terms as everyone else, it has not denied them access to the benefit received by the nondisabled” even if the caps and exclusions are for specific disabling conditions).

203. See *United States v. Univ. Hosp.*, 729 F.2d 144, 157–61 (2d Cir. 1984).

204. See Gostin, *supra* note 76, at 179 (“The ADA does not guarantee access to health care but merely requires that the refusal to provide equal access cannot be based on a person's disability. A provider's health care decision may be based, in part, on cost. Providing health services of inferior quality or not providing services at all because of a person's inability to pay may be unethical, but it is not necessarily unlawful.”).

205. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 603 n.14 (1999) (citation omitted).

medical equipment as violations of the legislation.<sup>206</sup> Of the four private actions filed against health-care providers lacking accessible medical equipment, all four settled.<sup>207</sup> Additionally, the Department of Justice took part in several actions against health-care providers for architectural barriers and inaccessible medical equipment from 1994 to 2009.<sup>208</sup> Despite this flurry of activity, both private and public ADA litigation have failed to increase the availability of accessible medical equipment to a meaningful extent.<sup>209</sup>

Thus, while the ADA indicates a strong ideological opposition to discriminating against individuals with disabilities in health care, its practical effect on the health disparities experienced by people with disabilities has been limited.<sup>210</sup> The National Council on Disability has criticized the Department of Justice and the Department of Health and Human Services for failing to enforce both the Rehabilitation Act and the ADA aggressively in the context of health care.<sup>211</sup> Because of this limited enforcement, civil rights laws are an ineffective means to

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206. Pendo, *Reducing Disparities*, *supra* note 150, at 1067 tbl.1; *see also id.* at 1067–69 (summarizing the private ADA actions against facilities with inaccessible medical equipment).

207. *Id.* at 1069.

208. *Id.* (“Between 1994 and September 2009, the Department was involved in fifty-five actions involving architectural barriers in a health care setting, and twelve actions involving inaccessible medical equipment . . . .”); *see also id.* at 1070 tbl.2; *id.* at 1070–71 (describing the Department of Justice actions).

209. *Id.* at 1071. Elizabeth Pendo has attributed this result in part to a lack of sufficiently detailed accessibility requirements for medical equipment. *Id.* at 1065, 1071.

210. NAT’L COUNCIL ON DISABILITY, *supra* note 28, at 1, 14 (“The Americans with Disabilities Act (ADA) has had limited impact on how health care is delivered for people with disabilities. Significant architectural and programmatic accessibility barriers still remain, and health care providers continue to lack awareness about steps they are required to take to ensure that patients with disabilities have access to appropriate, culturally competent care.”). These limitations have arguably been apparent since the law’s passing. *See Gostin, supra* note 76, at 180 (“The ADA, then, in only a limited sense tears down barriers to access to health services. It steadfastly refuses to allow a person to be turned away because of the provider’s fears and biases toward the disability. However, it remains uncertain as to what extent the act will help to ensure access to health care for those who arguably need it most.”).

211. *See* NAT’L COUNCIL ON DISABILITY, *supra* note 28, at 14 (“The U.S. Department of Justice and the Office for Civil Rights of the U.S. Department of Health and Human Services are charged with responsibility for enforcing the ADA and Section 504 in health care settings, yet they have taken on only a relatively small number of cases involving disability discrimination in health care, particularly when offices of health providers are involved.”).

address the health disparities people with disabilities so often face.<sup>212</sup>

Finally, civil rights legislation provides an improper tool to address disability-related inequities within public health. To start, much of the disadvantage experienced by people with disabilities in that context results not from overt discrimination, but rather from the failure to include the disability community as a relevant public health population.<sup>213</sup> The Rehabilitation Act and the ADA, with their primary reliance on private enforcement mechanisms, are geared more toward combating *individual* instances of discrimination rather than systematic exclusion at the population level.<sup>214</sup> Moreover, courts have valued public health concerns over those of individuals with disabilities, even in the face of civil rights challenges.<sup>215</sup> This practice evolved into the doctrine known as the “direct threat” defense, which allows covered entities (including employers and commercial entities) to differentiate on the basis of disability in the face of “significant risk to the health or safety of others that cannot be eliminated by reasonable accommodation.”<sup>216</sup> Thus, covered entities are allowed to make decisions based on an individual’s disability when that decision implicates issues of public health, such as the spread of communicable disease.<sup>217</sup> Importantly, the determination of what constitutes a “significant risk” is influenced by public health officials.<sup>218</sup> Direct

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212. *Id.* at 14–15 (“Without robust enforcement, the disability rights laws are ineffective tools for challenging discriminatory conduct or care that people with disabilities often report experiencing.”); *see also id.* at 18 (“Limited implementation of key disability rights laws by health care systems, managed care organizations, and health care providers directly affects the quality of care available to people with disabilities.”).

213. *See supra* notes 36–41 and accompanying text.

214. Michael Waterstone has discussed the limits of public and private enforcement mechanisms of Titles II and III of the ADA. *See* Michael Waterstone, *The Untold Story of the Rest of the Americans with Disabilities Act*, 58 VAND. L. REV. 1807 (2005).

215. *See, e.g.*, *Leckelt v. Bd. of Comm’rs*, 909 F.2d 820, 833 (5th Cir. 1990) (holding that a hospital request to test an employee for HIV did not violate the Rehabilitation Act).

216. 42 U.S.C. § 12111(3) (2006). While the statute explicitly protects decisions made to avoid or mitigate “significant risk to the health or safety of others,” judicial interpretation has extended the direct threat defense to apply to significant risks to the disabled individual herself. *See Chevron U.S.A. Inc. v. Echazabal*, 536 U.S. 73, 85–86 (2002).

217. 42 U.S.C. § 12111(3).

218. *See* SAMUEL R. BAGENSTOS, *LAW AND THE CONTRADICTIONS OF THE DISABILITY RIGHTS MOVEMENT* 79–86 (2009) [hereinafter BAGENSTOS, *LAW AND CONTRADICTIONS*] (discussing the creation of the “direct threat” doctrine

threat doctrine is justifiable on public health and safety grounds, as long as the discriminatory behavior eliminates or mitigates a potential public health concern.<sup>219</sup>

While the Rehabilitation Act and the ADA sought to improve health-care access for people with disabilities, those statutes have not had a lasting impact. They have failed to address the underlying structural barriers impeding access to health care for people with disabilities, which are at the root of those disparities. As discussed, this failure stems in significant part from the structure of civil rights statutes.

### C. THE NEED FOR ALTERNATE PARADIGMS

The health disparities discussed above affect not only an individual's wellness but also her ability to participate in other aspects of daily living. When someone experiences poor health, it impacts her independence, her ability to work, and her overall quality of life. As a result, health disparities are not restricted to issues of medical care: they may adversely touch myriad facets of an individual's existence.

Academics writing in the area of disability legal studies have explored the limitations of civil rights legislation as a tool for promoting equality, access, and integration for people with disabilities. Samuel Bagenstos and Ani Satz have provided nuanced criticisms of the ADA and the Rehabilitation Act, both generally and with respect to health care. In so doing, they have urged disability rights advocates to move beyond the confines of the civil rights approach.

Bagenstos critiques the shortcomings of civil rights law in the workplace. Since passing in 1990, the ADA has not substantially increased employment for people with disabilities.<sup>220</sup> Bagenstos attributes this failure, at least in part, to the unilateral preference for the antidiscrimination paradigm during the first half of the disability rights movement.<sup>221</sup> As he explains,

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and the role of public health entities in determining "significant risk"); *see also* Gostin, *supra* note 76, at 183 (noting the potential applicability of the ADA to public health determinations of "significant risk").

219. *See* BAGENSTOS, LAW AND CONTRADICTIONS, *supra* note 218, at 78–79 (discussing when it is permissible for entities to discriminate against disabilities when public health is at issue).

220. The rate of employment of people with disabilities since the passage of the ADA may have even declined. *See generally* THE DECLINE IN EMPLOYMENT OF PEOPLE WITH DISABILITIES: A POLICY PUZZLE (David C. Stapleton & Richard V. Burkhauser eds., 2003).

221. *See* Bagenstos, *supra* note 5, at 23 (attributing the continued un- and

civil rights legislation prohibits entities from discriminating on the basis of a protected trait, in the case of the ADA, disability.<sup>222</sup> However, individuals with disabilities encounter any number of structural barriers—such as an inability to access care and other assistive services—in their day-to-day lives.<sup>223</sup> These impediments prevent people with disabilities from *applying* for jobs, before they even have the opportunity to face *discrimination* by their actual or potential employers.<sup>224</sup> In short, antidiscrimination requirements that outlaw discrimination on the basis of disability may ultimately fail to address the underlying structural barriers. Thus, as a civil rights statute, the ADA is poorly suited to attacking these significant root causes.<sup>225</sup> Bagenstos, therefore, maintains that the future of disability law might in fact lie in social welfare legislation such as Medicaid and Medicare, not antidiscrimination protections.<sup>226</sup>

Moreover, many of the structural barriers to employment faced by people with disabilities relate directly to health-care

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under-employment of people with disabilities post-ADA to “the inherently limited nature of antidiscrimination requirements”).

222. *Id.* (“Antidiscrimination requirements can prohibit employers from discriminating against qualified people with disabilities who apply for jobs . . . .”); *see also id.* at 51 (“In the dominant conception, antidiscrimination requirements provide a remedy for the defendant’s own wrongful conduct rather than for the defendant’s failure to redress a broader societal wrong.”).

223. *Id.* at 25–34 (describing the structural barriers to employment faced by people with disabilities).

224. *Id.* at 25 (“[M]any individuals with disabilities face significant barriers to employment that operate well before they are ever in a position to be discriminated against by an employer.”).

225. *See, e.g., id.* at 23 (describing the “deep-rooted structural barriers” facing people with disabilities as the source of inequality and proposing that “[a]ntidiscrimination laws like the ADA are a singularly ineffective means of eliminating such structural barriers”); *see also id.* at 54 (“People with disabilities will not move into the workforce in more significant numbers unless the law addresses deep-rooted barriers to employment such as the unavailability of personal-assistance services, assistive technology, and accessible transportation, as well as the current structure of our health care system.”).

Although Bagenstos notes that the accommodation requirement of the ADA may seem to mandate some of the positive conduct necessary to eliminate structural barriers, he proposes that a restrictive interpretation of that requirement has rendered it more or less into a “classic” antidiscrimination mandate, requiring that covered entities only be responsible for their own individualized exclusionary actions. *Id.* at 24; *see also id.* at 42–50 (describing how courts’ interpretations of the “‘job-related’ rule” and the “‘access/content distinction” have effectively transformed accommodation into antidiscrimination).

226. *See generally id.*



access generally and health insurance specifically.<sup>227</sup> Consequently, Bagenstos dubs the lack of effective access to health insurance “the most significant obstacle to entering the workforce that people with disabilities collectively face.”<sup>228</sup> He attributes the centrality of health insurance to the traditionally medicalized understanding of “disability” and its related services, as well the disability community’s increased need for health services.<sup>229</sup> Bagenstos also asserts that because private health insurance fails to cover needed services and the public-benefits systems require beneficiaries be incapable of working, the traditional structure of American health insurance creates disincentives for re-entering the workforce.<sup>230</sup>

Given the ADA’s limited impact on the employment of people with disabilities and its failure to address numerous structural barriers that continue to impede access, Bagenstos has pushed disability rights advocates to look beyond the ADA, and the civil rights paradigm generally.<sup>231</sup> In particular, he identifies social welfare law as a possible vehicle for disability advocacy, despite the disability rights movement’s previous rejec-

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227. *Id.* at 26–34 (discussing the barriers to disabled people created by the structure of public and private health insurance).

228. *Id.* at 6.

229. *Id.* at 26–27 (“But far and away the most significant barrier to employment for people with disabilities is the current structure of our health insurance system. For two major reasons, health insurance is a matter of especial importance for those who have disabilities. First, because our society’s response to disability has historically been so heavily medicalized, many of the services people with disabilities need for independence and labor force participation—personal assistance and assistive technology being the most obvious—are typically regarded as ‘medical’ services for which the health insurance system is responsible. Second, even without considering those services (which might more appropriately be provided in a nonmedical context), it is nonetheless true that people with disabilities, on average, have greater health needs than do those without disabilities.”).

230. *Id.* at 27 (“In its current form, our health insurance system affirmatively disserves the interest of people with disabilities in moving into the workforce. The problem is not that people with disabilities are disproportionately uninsured; they are not. The problem is that private insurance—on which most nondisabled people rely for their health needs—fails to cover the services people with disabilities most need for independence and health. And public insurance is saddled with requirements that lock people with disabilities out of the workforce.”).

231. *See* Bagenstos, *supra* note 5, at 25 (“[A]ctivists must look past the ADA if they are to attack structural employment barriers effectively.”). He, however, does not suggest they abandon the civil rights paradigm entirely. *See* BAGENSTOS, LAW AND CONTRADICTIONS, *supra* note 218, at 11 (“Disability rights activists must not abandon the ADA model. They must build on it and, indeed, go beyond it.”).

tion of that legislative model.<sup>232</sup> Thus, while Bagenstos focuses his critique of the civil rights paradigm on its failures in the employment context, his analysis also pertains to issues of health-care access and delivery.

Ani Satz also criticizes the limitations of antidiscrimination law. She has identified what she calls “fragmentation” within disability rights law.<sup>233</sup> Satz defines fragmentation as “treating vulnerabilities associated with impairments as if they arise in discrete environments, such as the workplace or particular places of public accommodation.”<sup>234</sup> Fragmentation takes place when the law fails to reflect a person’s actual, lived experience accurately.<sup>235</sup> According to Satz, the “targeted legal approach,” which restricts its protections to certain situational contexts, such as employment, transportation or public accommodation,<sup>236</sup> “fragments the human experience.”<sup>237</sup>

The resulting legal protections are disjointed, at once implying that impaired individuals only experience disability in certain situations and failing to recognize humanity’s universal state of vulnerability.<sup>238</sup> By carving up people’s lives into dis-

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232. See BAGENSTOS, *LAW AND CONTRADICTIONS*, *supra* note 218, at 144–45 (arguing that social welfare programs targeted to people with disabilities would be stronger politics); *see also* Bagenstos, *supra* note 5, at 74 (“Health policy seems an extremely promising area in which to take a universalist approach. Until the 1990s, American disability rights activists were quite averse to urging a broadening of guaranteed health coverage. The movement had ‘worked so hard for so long to separate the issues of health and disability’ that demands for broader health coverage would seem to ‘resurrect[] harmful stereotypes.’ . . . [A] universal health care system . . . would not send the message that people with disabilities are uniquely in need of caretaking; it would send the message that we all need insurance against contingencies in life.”).

233. See Satz, *Disability, Vulnerability, and the Limits of Antidiscrimination*, *supra* note 5, at 541 (presenting a new critique to the antidiscrimination approach to disability discrimination based on “fragmenting disability protection”).

234. *Id.*

235. See Satz, *Overcoming Fragmentation*, *supra* note 5, at 281.

236. *Cf. id.* at 279 (“Legal protections start and stop in various places within the public realm and may not afford the continuity necessary for meaningful civic or social participation.”).

237. *Id.* at 278 (“The major weakness of this targeted legal approach is that individuals’ experiences and needs are not viewed holistically across civic and social realms, but in fragments defined by certain legally protected contexts. By varying protection based on context, the law fragments the human experience.”).

238. Satz, *Disability, Vulnerability, and the Limits of Antidiscrimination*, *supra* note 5, at 541 (“Generally speaking, [fragmentation] results in a patchwork of protections that do not coalesce to allow meaningful social participation. More specifically, viewing vulnerabilities as situational creates the false

crete legally protected spheres, existing laws stop and start in a way that denies the interconnectedness of daily living. Thus, current protections may mandate access to a building but not necessarily to the services provided within.<sup>239</sup> Likewise, a law may prohibit an employer from discriminating against a potential employee on the basis of her disability yet remain silent with regard to providing the home-health aide necessary to assist her in getting ready for work.<sup>240</sup> Further, restricting legal protections to specific circumstances focuses on the context of the discrimination or inequality, drawing attention away from the structural inequalities that underlie it.<sup>241</sup>

In response to fragmentation, Satz calls for a blending of legal protections related to disability through a lens of “universal vulnerability.”<sup>242</sup> She explains that vulnerability to illness and the resulting need for health care is not an issue of disability rights, but rather an essential aspect of the human condition.<sup>243</sup> Because universal health care serves the greater good, not just those with a heightened need for care,<sup>244</sup> everyone

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perception that individuals with significant impairments are not disabled in some environments. In addition, a situational approach to vulnerability disregards the benefits of conceptualizing vulnerability as universal for disabled and nondisabled individuals alike.”).

239. *Id.* at 544 (“As a result of laws treating vulnerability as arising in isolated transactions rather than as a part of an integrated experience, protections for disabled individuals are often interrupted, denying meaningful social participation. Someone may be able to enter a building but not partake in the services offered, for example.”).

240. *See* Satz, *Overcoming Fragmentation*, *supra* note 5, at 279 (“Thus, a fragmented approach to law fails to recognize or appreciate that barriers arising in an environment the law does not address, such as the home, may impact participation in other environments where the law does provide protections, such as the workplace.”).

241. *See* Satz, *Disability, Vulnerability, and the Limits of Antidiscrimination*, *supra* note 5, at 545 (“Viewing the vulnerabilities associated with disability as situational in this way also masks structural inequalities. Disability protections that target particular aspects of a disabled individual’s life, such as fulfilling the functions of her job or entering an insurance office, shift legal focus away from inequalities like wage disparities and health care policies that disfavor mental disability.”).

242. *See id.* at 522 (arguing that in order to reform disability law the blending of civil rights and social welfare models is required).

243. *See supra* note 112 and accompanying text (discussing Satz’s work on the universal nature of illness).

244. *See* Satz, *Disability, Vulnerability, and the Limits of Antidiscrimination*, *supra* note 5, at 561 (“Viewing illness as universal and constant vulnerability contributes a new perspective on the need for universal health care. Restructuring current health care institutions to support health care as a public good may be the best way to address vulnerability to illness and the vulnera-

stands to gain from access to expansive and affordable health care.<sup>245</sup> Thus, according to Satz, issues of health-care access must be addressed outside of the civil rights paradigm, which limits its protections to particular groups or traits in specific contexts.<sup>246</sup> Given her universalist orientation, she is critical of scholarly approaches that confine their analysis to the need for health law protections—particularly the provision of benefits—specifically for people with disabilities.<sup>247</sup>

Both Bagenstos and Satz have explored the deficiencies of the civil rights paradigm, albeit in different contexts. Bagenstos analyzes how antidiscrimination law has failed to have a meaningful impact on employment for people with disabilities because of its inability to target the structural barriers underlying their access to work.<sup>248</sup> Satz focuses her critique on how legal protections stop and start in particular protected spheres, thereby undermining the continuity of an individual's actual lived experience.<sup>249</sup> Thus, they have urged disability rights advocates to look beyond the civil rights model to promote equality, access, and integration for people with disabilities.

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While disability discrimination is undoubtedly a social issue, certain individuals with disabilities experience greater health-care needs.<sup>250</sup> Although civil rights legislation seeks to

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bilities that result from illness.”).

245. *Id.* at 531 (“[A]rguments may be made in the health care context, as everyone benefits from broad, affordable coverage, given universal vulnerability to illness and other impairments requiring medical attention.”).

246. *See id.* at 552.

247. *Id.* at 522 (“[F]ocusing on the issue of lack of material supports . . . both understates and overstates the problem. It overstates it in the sense that some of the pressing issues facing disabled persons—such as difficulty in qualifying for the protected class or receiving a preferred accommodation, remains tied to protected class status. These issues must be addressed within the civil rights framework. It understates matters in the sense that access to some material supports, such as health care, is not a disability discrimination issue but one of general social welfare.”).

248. *See Bagenstos, supra* note 5, at 25 (asserting that structural employment barriers can be effectively attacked, if activists look past the ADA).

249. *See Satz, Overcoming Fragmentation, supra* note 5, at 279 (asserting that legal protection may not be afforded for civil or social participation because legal protection is focused within the public sphere).

250. *See Crossley, Becoming Visible, supra* note 31, at 53 (noting that people with disabilities have extensive health care needs as a result of their disa-

promote equality, access, and integration, the Rehabilitation Act and the ADA have failed to eliminate the health disparities experienced by the disability community.<sup>251</sup> People with disabilities still face significant barriers to access and do not enjoy health outcomes on par with their non-disabled counterparts.<sup>252</sup> Thus, those statutes have not accomplished their civil rights goals in the context of health care. These failures can in part be attributed to certain fundamental limitations of the civil rights model.<sup>253</sup> Civil rights legislation prohibits discriminatory conduct but often leaves the bounds of its protection up to judicial interpretation. Courts have interpreted the meaning of discrimination very narrowly when it comes to issues of health, demonstrating a deference to state programs, insurers, individual physicians, and public health officials.<sup>254</sup> Health law may thus serve as an alternate tool to further disability rights in the context of health care.

### III. HEALTH-CARE REFORM AS DISABILITY RIGHTS LEGISLATION

On its face, the ACA is a health law.<sup>255</sup> Congress designed the statute to achieve explicitly health-related objectives: to improve access to health care and to promote the wellness of Americans. It contains provisions that fall into each of the substantive categories of health law previously discussed: (1) public health insurance and government benefits; (2) private health insurance law; and (3) public health law. Yet despite its health law purpose and content, the ACA has markedly civil rights results in terms of its potential effect on people with disabilities.

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bility).

251. See generally Waterstone, *supra* note 214 (summarizing the reasons that ADA failed to eliminate health disparities for people with disabilities).

252. NAT'L COUNCIL ON DISABILITY, *supra* note 28, at 1 (asserting that disabled persons experience more significant barriers compared to nondisabled persons).

253. See Crossley, *Becoming Visibility*, *supra* note 31, at 88–89 (asserting that ADA's failure to improve health-care access to disabled persons was attributed to ADA being a civil rights statute).

254. See *id.* at 53 (asserting that courts took a “hands-off approach to health care issues”).

255. The ACA does contain some antidiscrimination-style provisions, much like its predecessor HIPAA. However, the substance of the statute is entirely health-related. See generally ACA §§ 2001–202, Pub. L. No. 111-148, 124 Stat. 271 (2010).

This Part argues that health-care reform could succeed where antidiscrimination laws have failed, demonstrating that health law can perform the work of civil rights. The ACA, therefore, bridges the gap between the health law and civil rights law paradigms. It harnesses health law protections to facilitate the civil rights outcomes of equality, access, and integration in the context of health care. By taking an active role in the reform, disability rights advocates recognized the potentially transformative power of the ACA on disability rights. This Part begins by recounting how members of the disability rights movement rallied to reform health care. It then performs a close reading of portions of the statute that benefit individuals with disabilities. Finally, the Article ends by analyzing what champions of disability—and other civil—rights can learn from health-care reform, concluding that advocates should adopt an integrated legal approach to address disparities and to achieve access.

#### A. HEALTH-CARE REFORM AS A DISABILITY RIGHTS ISSUE

Despite the disability rights movement's initial discomfort with health law discussed in Part I, advocacy organizations recognized the shortcomings of the civil rights approach in targeting the health disparities faced by people with disabilities and embraced health-care reform as a necessary tool to promote disability rights. During the health-care reform debate, proponents of disability rights pushed Congress to consider the health disparities and wellness concerns faced by the disability community.<sup>256</sup>

Even before the 2010 health-care reform, advocates acknowledged health law as a means for promoting disability rights. As early as 1994 President Bill Clinton identified the significant role health-care reform could play for people with disabilities.<sup>257</sup> He explained that reforming the American health-care system would “finish what the ADA started.”<sup>258</sup>

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256. UNITED SPINAL ASS'N & THE NAT'L SPINAL CORD INJURY ASS'N (NSCIA), *IMPACT OF HEALTH CARE REFORM ON PEOPLE WITH DISABILITIES* 1 (2010) [hereinafter USA & NSCIA] (“The disability community has worked together tirelessly for more than a year to achieve health care reform.”); Joe Caldwell, *Implications of Health Care Reform for Individuals with Disabilities*, 48 INTELL. & DEV. DISABILITIES 216, 216 (2010) (“The disability community actively engaged in the legislative process and shaped the final outcome.”).

257. See SWITZER, *supra* note 77, at 115 (quoting Clinton as saying that reforming health care “would finish the business of the ADA”).

258. *Id.*

President Clinton, therefore, believed that the ADA alone would not achieve the degree of equality, integration, and access that the disability rights movement desired. Changing the structure and delivery of health care was also necessary.

In the years following the ADA, proponents of disability rights demonstrated a renewed interest in health law as tool for their cause.<sup>259</sup> In addition to filing civil rights suits, advocates have also lobbied for legislative change in the area of health care.<sup>260</sup> For example, in the late 2000s, the Promoting Wellness for Individuals with Disabilities Act garnered support from members of Congress.<sup>261</sup> Introduced in both the House and the Senate in 2006 and again in the House in 2009, the bill would have set standards for accessible medical equipment, created grant programs to promote wellness for people with disabilities, and instituted training programs for improving the disability competency of health-care professionals.<sup>262</sup> The law, however, never passed.<sup>263</sup> All three bills died in committee.<sup>264</sup>

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259. Ten years before Congress passed the ACA, Mary Crossley suggested that reforming health care could fill the gaps left by the ADA. *See* Crossley, *Becoming Visible*, *supra* note 31, at 88–89 (“[I]t is not fair to judge the ADA as a failure in the realm of health care, for the ADA is a civil rights statute, not a health-care reform statute. Although persons with disabilities may face barriers to accessing health care to a greater extent than the general population, the barriers posed by lack of insurance, underinsurance, and administrative constraints on accessing care are certainly not unique to persons with disabilities. Consequently, health care reform that addresses these barriers may play a greater role in improving the health care received by people with disabilities than the ADA ever can.”). She, therefore, encouraged disability rights advocates to pursue health-care reform. *See id.* at 89. More recently, Elizabeth Pendo has maintained that the ACA provides an alternate avenue to address barriers to health-care access that people with disabilities experience, particularly with respect to medical equipment. *See* Pendo, *supra* note 150, at 1073 (stating that the ACA “offers a new approach to these pervasive barriers”); *id.* at 1083 (proposing that “health care reform offers a new and complementary approach” for eliminating access barriers for people with disabilities).

260. Bagenstos, *supra* note 5, at 55 (“[B]oth the litigation dockets and legislative priorities of disability rights organizations have increasingly focused on social welfare rather than antidiscrimination laws. Disability rights advocates now frequently bring cases under social welfare law like Medicaid Act as well as under antidiscrimination laws like the ADA, and they lobby for changes in public health-insurance programs that would enhance the integration and employability of people with disabilities. To a far greater extent than commentators have appreciated, the disability rights movement has turned (back) to a social welfare approach to disability law.”).

261. Promoting Wellness for Individuals with Disabilities Act of 2006, S. 3717, 109th Cong. (2006).

262. *Id.*; H.R. 1938 111th Cong. (2009); *see also* Pendo, *Reducing Disparities*, *supra* note 150, at 1072–73 (discussing the Promoting Wellness for Individuals with Disabilities Act). The bill would have amended the Rehabilitation

Disability rights advocates have also actively lobbied for legislation to expand Medicaid and Medicare. For example, in 1999, they played a critical role in passing the Ticket to Work and Work Incentives Improvement Act (TWWIIA).<sup>265</sup> The statute extends Medicare benefits for over eight years after a previously eligible person with a disability re-enters the workforce.<sup>266</sup> Additionally, it expedites the process for reinstating the benefits of former recipients of Medicaid or Medicare, who returned to work, but again find themselves “disabled.”<sup>267</sup>

More recently, in its 2009 report on the state of health for people with disabilities, the National Council on Disability explained that health legislation was essential to address many of the barriers that patients with disabilities face in obtaining health care.<sup>268</sup> Thus, the Council urged reformers to consider the needs of the disability community when revamping the health-care system.<sup>269</sup> It proposed that Congress expand both public and private health insurance coverage to facilitate better access to care, as well as improve the availability of prescription drugs, accessible medical equipment, and assistive aids.<sup>270</sup>

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Act to require the Access Board to create and review accessibility standards for medical equipment, amended the Public Health Service Act to allow for the creation of relevant grant programs, and provided training programs. *See id.* at 1072–73.

263. *See Pendo, supra* note 150, at 1073 (stating that the Promoting Wellness for Individuals with Disabilities Act was introduced in 2006 and 2009, but was not enacted).

264. *Id.*

265. BAGENSTOS, LAW AND CONTRADICTIONS, *supra* note 218, at 140 (explaining the effects of TWWIIA and the role of people with disabilities in its passage).

266. 42 U.S.C. § 426(b) (Supp. IV 2010); *see also* BAGENSTOS, LAW AND CONTRADICTIONS, *supra* note 218, at 140.

267. 42 U.S.C. §§ 423(i), 1383(p) (Supp. IV 2010); *see also* BAGENSTOS, LAW AND CONTRADICTIONS, *supra* note 218, at 140.

268. NAT'L COUNCIL ON DISABILITY, *supra* note 28, at 16 (“Legislation will be required to address some of the key gaps and barriers to health care that affect people with disabilities, including access to wellness and prevention services, health and health disparities research, development of care models built on principles of patient-centered care, and professional training.”).

269. *Id.* at 16 (“Long-term health care reform must include the voices of people with disabilities, not only to advocate for improved health care insurance coverage, eligibility, and core benefits, but also to resolve issues of access to critical accommodations that ensure that health care is effective, such as payment coverage for sign language interpreters and requirements that providers demonstrate disability cultural competency.”).

270. *Id.* at 96 (“Congress should ensure that reform of the health care system in the United States responds to the basic needs of people with disabilities by making certain that health care coverage is available and affordable to all



This strong support for health legislation—particularly for measures expanding Medicaid—exhibited by disability rights advocates indicates their acknowledgement that antidiscrimination law by itself will not achieve the level of integration they seek.<sup>271</sup>

These efforts culminated in the context of health-care reform. Disability rights advocates organized, formed coalitions, and lobbied for changes to the health-care system that would improve the health disparities people with disabilities endure. One especially powerful organization was the Consortium for Citizens with Disabilities.<sup>272</sup> Over one hundred national disability rights organizations came together to form that coalition.<sup>273</sup> The Consortium exhorted reformers to view the proposed legislation through what one advocate called the “universal prism of disability.”<sup>274</sup> Understanding the needs of the disability community could inform the provision of health care for the general population. In other words, as Mary Andrus, Co-Chair of the Consortium for Citizens with Disabilities Health Care Task Force, testified before Congress, “as you look at proposals for healthcare reform, look at them through the experience of a person with a disability and if the proposal meets those needs, it’s highly likely to meet the needs of the rest of the population.”<sup>275</sup> The CCD and its membership organizations worked actively to urge Congress to reform health care.<sup>276</sup>

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people with disabilities without preexisting condition limitations. Benefits made available through either private or public coverage, or a combination, must include access to appropriate prescription medications, specialty care, care coordination, durable medical equipment and assistive devices, and long-term care services. Any coinsurance payments must be affordable, and annual or lifetime limits on these key benefits must not be permitted.”).

271. Bagenstos, *supra* note 5, at 69–70 (“[T]he fact that disability rights activists have placed such a high priority on the enactment of legislation expanding the Medicaid program is itself telling. It reflects a recognition by disability rights activists that the ADA alone is not sufficient to achieve community integration for people with disabilities. Social welfare law remains important as well.”).

272. Caldwell, *supra* note 256, at 218.

273. *Id.* For a list of member organizations, see CDC MEMBERSHIP DIRECTORY, [http://www.c-c-d.org/members/CCD\\_Membership\\_Directory\\_2011.pdf](http://www.c-c-d.org/members/CCD_Membership_Directory_2011.pdf) (last updated Aug. 8, 2011).

274. Caldwell, *supra* note 256, at 218–19.

275. *Healthcare Reform Roundtable (Part I): Hearing of the S. Comm. on Health, Educ., Labor, and Pensions*, 111th Cong. 32 (2009) (statement of Mary Andrus).

276. See Letter from the Consortium for Citizens with Disabilities to the U.S. Congress (Jan. 28, 2010), available at <http://www.aucd.org/docs/CCD%20sign-on%20ltr%20health%20care%20reform%20now%201-28-10.pdf> (pre-

In addition to their participation through the CCD, national disability advocacy organizations also launched their own initiatives in favor of health-care reform. For example, the National Multiple Sclerosis Society adopted a set of National Health Care Reform Principles, designed to ensure that legislative change would address the needs and concerns of the Multiple Sclerosis (MS) community.<sup>277</sup> The organization also encouraged members to sign and distribute a petition in favor of health-care reform.<sup>278</sup> Likewise, United Cerebral Palsy posted action alerts advising its membership to contact their Senators regarding the legislation's coverage of long-term care supports and services.<sup>279</sup>

State disability advocacy organizations also rallied in support of reforming health care. In California, the Disability Health Coalition issued a report analyzing health-care reform and making recommendations with regard to its effect on people with disabilities<sup>280</sup> and endorsed a series of principles designed to guide lawmakers.<sup>281</sup> Similarly, the Missouri-based Disability Coalition on Healthcare Reform drafted principles, signed by more than sixty organizations, sent to key members of the Senate.<sup>282</sup>

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senting the signatures of member organizations). For a list of the CCD Health Task Force's activities, see CONSORTIUM FOR CITIZENS WITH DISABILITIES, HEALTH TASK FORCE, [http://www.c-c-d.org/task\\_forces/health/tf-health.htm](http://www.c-c-d.org/task_forces/health/tf-health.htm) (last visited Apr. 22, 2013).

277. See NATIONAL MULTIPLE SCLEROSIS SOCIETY: NATION HEALTH CARE REFORM PRINCIPLES, available at <http://www.nationalmssociety.org/government-affairs-and-advocacy/position-papers--policies/index.aspx> (ensuring "that programs and activities that benefit individuals living with MS and their families receive the funding they deserve").

278. *Id.* (providing information on how one's Senators or Representatives can join Congressional Multiple Sclerosis Caucus).

279. See, e.g., *Action Alerts and Updates*, UNITED CEREBRAL PALSY, <http://ucp.org/public-policy/action-alerts-updates> (last visited Apr. 22, 2013) (providing an example an Action Alerts and Updates).

280. DISABILITY HEALTH COALITION: HEALTH CARE REFORM ANALYSIS AND RECOMMENDATIONS, <http://www.google.com> (search "analysis and recommendations" and "health care reform" and disability; then click the hyperlink "Ensure Greater Accessibility for People with Disabilities in Health").

281. *Health Care Reform Principles*, DISABILITY HEALTH COALITION (June 1, 2007), <http://dredf.org/healthcare/healthcare.shtml> (scroll down to click hyperlink "Read the California Health Coalition Health Care Reform Principles").

282. Letter from the Disability Coalition on Healthcare Reform et al., to Max Baucus and Chuck Grassley, U.S. Senators. (June 2, 2009), available at [http://www.healthpolicyproject.org/Publications\\_files/USHARE/Medicaidprinciplesstatesignonletter.pdf](http://www.healthpolicyproject.org/Publications_files/USHARE/Medicaidprinciplesstatesignonletter.pdf).

On top of cross-disability coalition building, champions of disability rights also joined forces with other kinds of advocacy groups. Working together, almost three hundred disability rights, faith-based, and elder rights organizations mounted an aggressive campaign of grass-roots activism—including phone-calls, emails, and office visits—to urge members of Congress to include long-term care in the reform.<sup>283</sup> These efforts were remarkable not only for their impact but also for their effect on future advocacy. Despite certain key shared interests, proponents of disability rights and proponents of aging rights have historically operated separately.<sup>284</sup> Health-care reform represents perhaps the first instance in which these two communities have worked in tandem toward a common goal.<sup>285</sup> Supporting health-care reform not only aligned people with differing kinds of disabilities but also coalesced the disability community and advocates for other groups to form a powerful lobby.<sup>286</sup> Disability rights advocates may have thus laid the foundation for important alliances going forward.<sup>287</sup>

Members of Congress acknowledged these substantial efforts. In describing the groundswell of support for health-care reform, Representative Carolyn Kilpatrick cited the work of numerous advocacy organizations, including those representing the disability community: “[t]he groups expressing their support include a broad range, including groups representing doctors, seniors, small business, youth, women, *persons with disabilities*, consumers and patients.”<sup>288</sup> Senator Harry Reid put a

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283. Caldwell, *supra* note 256, at 219 (“Over 275 national aging, disability, and faith-based organizations coordinated an advocacy campaign on long-term services and supports, generating literally thousands of calls, e-mails, faxes, and visits to Congressional offices—a force that could not have been mounted alone and one that could not be ignored.”).

284. *Id.* (noting that the two communities “traditionally worked in silos”).

285. *Id.* (describing the collaboration as “unprecedented”).

286. *See id.* (“Over 100 cross-disability organization joined together to urge Congress to address health disabilities and wellness for individuals with disabilities.”).

287. *Id.* (describing the collaboration between the disability rights and aging rights communities as “perhaps the most significant outcome of health reform”). This new alliance may well prove useful in future efforts to protect disability rights. *See id.* (“Although the rhetoric of health care reform in the popular media focused on the politics of division, there are powerful lessons to be learned in the disability community about working together to effect change, lessons we must carry forward as we move forward to implementation and ‘the work begins anew.’”).

288. 155 CONG. REC. H12,893 (daily ed. Nov. 7, 2009) (statement of Rep. Kilpatrick) (emphasis added).

human face on the need for reform, by reading several personal letters from individuals with disabilities describing the barriers they faced obtaining affordable health care.<sup>289</sup> Lastly, perhaps echoing President Clinton's remarks in the mid-nineties, Senator Tom Harkin described the proposed increase to state Medicaid funding for deinstitutionalizing people with disabilities as "a dream of the disability community since we passed the Americans With Disability Act [sic] in 1990."<sup>290</sup>

As stated, the ACA has a decidedly health law purpose and structure. However, given the involvement of disability rights advocates in the push for reform, it is not surprising that the resulting legislation contains many provisions that will both explicitly and implicitly benefit the disability community.<sup>291</sup> Insofar as health-care reform facilitates equality, access, and integration for people with disabilities, the ACA can be understood as a disability rights law.

#### B. IMPACT OF THE ACA ON PEOPLE WITH DISABILITIES

Health-care reform will benefit the disability community in a number of a ways.<sup>292</sup> In particular, people with disabilities will enjoy expanded access to public and private health-insurance coverage and recognition as a health disparities population. Thus, while the ACA is decidedly a *health law* in terms of its purpose and content, by promoting access, integration, and equality in health-care provision for people with disabilities, it will have a *civil rights* effect. This Article focuses on the ACA's positive impact for people with disabilities in the context of the three substantive areas of health law described in Parts I and II: (1) public health insurance and government benefits; (2) private health insurance; and (3) public health, specifically health disparities research.

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289. 155 CONG. REC. S13,645 (daily ed. Dec. 21, 2009) (statement of Sen. Reid) (drawing from several letters from constituents).

290. 155 CONG. REC. S13,848, (daily ed. Dec. 23, 2009) (statement of Sen. Harkin) (describing the six percent increase to state Medicaid funding for enacting legislation implementing the integration mandate articulated in *Olmstead v. L.C.*, 527 U.S. 581 (1999)).

291. See Caldwell, *supra* note 256, at 216 (stating that the lobbying efforts of the disability community shaped the legislation).

292. See, e.g., *id.* at 216–18 (describing the positive impact of the ACA on individuals with disabilities). See generally USA & NSCIA, *supra* note 256.

## 1. Public Benefits and the ACA

The ACA contains several provisions designed to expand and improve the public benefits system. These changes will benefit individuals with disabilities given their reliance on Medicaid and Medicare for health-insurance coverage.<sup>293</sup> While disability rights advocates successfully pushed to expand Medicare and Medicaid in the late 1990s,<sup>294</sup> those changes failed to eliminate significant shortcomings, mainly Medicare's limited eligibility for non-elderly individuals and its lack of adequate coverage for assistive devices.<sup>295</sup> The ACA addresses some of these deficiencies. For example, the legislation expands the Medicaid program. As written, the ACA would extend Medicaid eligibility to anyone under 65 with an income at or below 133% of the Federal Poverty Level, effective January 2014.<sup>296</sup> States could receive the additional funding provided under the statute early by extending their coverage immediately.<sup>297</sup> However, if a state did not expand its Medicaid program by the deadline, it would lose the entirety of its Medicaid funding.<sup>298</sup>

The broadening of Medicaid came under attack during 2012. In his plurality opinion in *National Federation of Independent Business v. Sebelius*, Chief Justice Roberts analyzed the constitutionality of the ACA's Medicaid expansion provisions.<sup>299</sup> He—along with Justices Breyer and Kagan—concluded that the severity of the accompanying penalty rose to the level of coercion, thereby exceeding Congress's authority under the Spending Clause.<sup>300</sup> Instead, the plurality decided that, while Congress could withhold additional funding for a state's failure

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293. See *supra* text accompanying note 35 (describing the reliance of people with disabilities on public insurance).

294. See *supra* notes 265–67 and accompanying text.

295. BAGENSTOS, LAW AND CONTRADICTIONS, *supra* note 218, at 141 (“Medicare was designed for a nonworking elderly population and does not serve the interest of the people with disabilities in community integration and to the labor market.”).

296. ACA §§ 2001–202, Pub. L. No. 111-148, 124 Stat. 271 (2010); see also USA & NSCIA, *supra* note 256, at 5.

297. ACA §§ 2001–202; see also USA & NSCIA, *supra* note 256, at 5.

298. 42 U.S.C. § 1396c (Supp. V 2011) (explaining that if a state does not comply with the ACA's Medicaid expansion provisions “further payments will not be made to the State”).

299. Nat'l Fed'n of Indep. Bus. v. Sebelius, 132 S. Ct. 2566, 2577 (2012) (plurality opinion).

300. *Id.* at 2607 (stating that Congress is not free to penalize states that choose not to partake in the new program by taking away existing Medicaid funding).

to comply with the Medicaid expansion, it was unconstitutional to threaten existing funding.<sup>301</sup> Thus, following the ruling, states may choose whether to expand their Medicaid programs without jeopardizing the funds they received prior to the ACA.

Yet even if a majority of states adopt the ACA's expansion of Medicaid, merely increasing coverage for public benefits may not be enough to have a lasting impact.<sup>302</sup> Both Medicaid and Medicare have historically failed to provide adequate benefits for at-home assistance for individuals with disabilities.<sup>303</sup> As a result, disability rights advocates also lobbied for—and won—better coverage for on-going, at-home health services during the health-care reform debate.

The statute improves services and supports for people requiring long-term care.<sup>304</sup> The ACA strengthens the Money Follows the Person (MFP) Program to facilitate transitioning individuals from institutions to community placements.<sup>305</sup> It also creates the Community First Choice (CFC) Option, designed to support state Medicaid plans in offering community-based care in conjunction with nursing homes and institutions.<sup>306</sup> CFC

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301. *Id.*

302. See BAGENSTOS, LAW AND CONTRADICTIONS, *supra* note 218, at 141–42 (arguing that expanded coverage is not sufficient to address disparities adequately); see also Bagenstos, *supra* note 5, at 61–62 (explaining that one type of limitation is the institutionalization of Medicaid).

303. See BAGENSTOS, LAW AND CONTRADICTIONS, *supra* note 218, at 141–42 (describing the need for at-home services and the proposed Medicaid Community-Based Attendant Services and Supports Act); see also Bagenstos, *supra* note 5, at 68.

304. USA & NSCIA, *supra* note 256, at 4 (describing provisions designed to expand support for at-home and community-based services); Caldwell, *supra* note 256, at 217 (“The healthcare legislation contains a robust package of reforms on long-term services and supports, including the Community Living Assistance Services (CLASS) Act and improvements in Medicaid.”).

305. ACA § 2403, Pub. L. No. 111-148, 124 Stat. 304 (2010) (amending Sections 6071(b) and 6071(h) of the Deficit Reduction Act of 2005, codified at 42 U.S.C. § 1396a (Supp. V 2011)). The ACA extends the program through 2016, supports its continuation in twenty-nine states, adds thirteen new states, and expands eligibility. Press Release, Dep’t of Health & Human Servs., Affordable Care Act Supports States in Strengthening Community Living (Feb. 22, 2011), available at <http://www.hhs.gov/news/press/2011pres/02/20110222b.html>; see also *Money Follows the Person*, MEDICAID.GOV, <http://www.medicaid.gov/Medicaid-CHIP-program-Information/By-Topics/Long-Term-Services-and-Support/Balancing/Money-Follows-the-Person.html> (last visited Apr. 22, 2013).

306. ACA § 2401.

mandates that states provide recipients with assistance for daily living, not just those activities related to health.<sup>307</sup>

It is also worth noting that the legislation, as passed, included the much-contested Community Living Assistance Services and Supports program (CLASS Act).<sup>308</sup> The CLASS Act would have established a voluntary, national insurance program designed to provide affordable community living services. The program, which would have applied to individuals in need of on-going care and support,<sup>309</sup> was fraught with controversy. On February 1, 2012, the House voted to repeal the CLASS Act.<sup>310</sup> Although the Obama administration did not support the legislative repeal, it had already deemed the program unworkable as of October 2011.<sup>311</sup>

Advocates for people with disabilities hope that, taken en masse, these changes to public health insurance will improve health-care delivery for the disability community, as well as the American population as a whole.<sup>312</sup>

Health-care reform expands public health insurance both in terms of the individuals who are eligible and the types of services it covers. As noted, people with disabilities may require more health services but have habitually encountered barriers to access, leading to widespread health disparities. Certain individuals with disabilities did not qualify for public benefits, and those that did may still have been unable to obtain needed care because of restrictions on coverage. However, by increasing eligibility and bolstering coverage, the ACA's changes to public health insurance hold the promise to elimi-

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307. *Id.*

308. *See* Community Living Assistance Services and Supports (CLASS) Act, 42 U.S.C. § 300*ll* (Supp. V 2011).

309. A determination by a "licensed health care practitioner" that an individual has a "functional limitation," as defined by the statute, "expected to last for a continuous period of more than 90 days" triggers benefits under the CLASS Act. 42 U.S.C. § 300*ll*-2(a)(1)(C).

310. Paige Winfield Cunningham, *House Votes to Repeal Part of Health Care Law*, WASH. TIMES, Feb. 2, 2012, at A4.

311. *Id.*; *see also* N.C. Aizenman, *Long-Term Care Program Scrapped*, WASH. POST, Oct. 15, 2011, at A1.

312. *See* Caldwell, *supra* note 256, at 219 (explaining that "the disability community challenged the very concept of *health*, moving the discussion beyond the narrow confines of acute care to a more inclusive framework of functioning, well being, and community participation"). Absent the efforts of disability rights advocates, the long-term care provisions would not have been included. *Id.* (noting that "long-term services and supports, which were absolutely nowhere on the initial policy agenda, are included in the final legislation").

nate at least some barriers previously experienced by people with disabilities and, consequently, to reduce existing health disparities. Thus, while these provisions fall under the health law umbrella substantively, insofar as they promote access, integration, and equality for people with disabilities, they will make a civil rights law impact.

## 2. Private Health Insurance and the ACA

Similarly, several modifications to the private health-insurance system will positively affect people with disabilities. The legislation does away with a number of health-insurance practices that have disproportionately disadvantaged individuals with disabilities. Effective immediately, health insurers can no longer impose lifetime caps on benefits.<sup>313</sup> In 2014, annual caps will be likewise prohibited; however, in the meantime, the Secretary of Health and Human Services can choose to restrict annual caps.<sup>314</sup> The caps on lifetime and annual limits are significant for people with disabilities because of their increased need for health services.<sup>315</sup>

The ACA also restricts decisions related to eligibility and underwriting decisions. The new law immediately creates a “pre-existing condition insurance plan”<sup>316</sup> and, when it takes full effect, will eliminate preexisting condition exclusions in both group and individual coverage.<sup>317</sup> Further, the law prohibits discrimination in underwriting; by 2014, group and individual insurers can no longer use health status when making eligibility decisions.<sup>318</sup>

Finally, the legislation will prevent insurers in the individual and small group markets (as well as the large-group insurers participating in the exchanges) from relying on health

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313. ACA § 1001, Pub. L. No. 111-148, 124 Stat. 130 (2010) (codified at 42 U.S.C. § 300gg-11 (Supp. V 2011)); *see also* USA & NSCIA, *supra* note 256, at 2.

314. ACA § 1001; *see also* USA & NSCIA, *supra* note 256, at 2.

315. *See* Caldwell, *supra* note 256, at 216.

316. ACA § 1101 (instituting a coverage option for individuals who have been denied insurance because of a preexisting condition); *see also* *Pre-existing Condition Insurance Plan*, HEALTHCARE.GOV, [https://pcip.gov/About\\_PCIP.html](https://pcip.gov/About_PCIP.html) (last visited Feb. 25, 2013).

317. ACA § 1201 (“A group health plan and a health insurance issuer offering group or individual health insurance coverage may not impose any preexisting condition exclusion with respect to such plan or coverage.”).

318. *Id.*



status when setting rates.<sup>319</sup> As of 2014, the relevant health insurers must rely on the following four factors: (1) individual vs. family coverage; (2) geographical location (community rating); (3) age; and (4) tobacco use.<sup>320</sup> Eliminating caps on coverage and the consideration of health-related factors in underwriting and rating decisions will have a positive impact on individuals with disabilities. Again, the effect of these changes can be understood in civil rights terms because they eliminate policies and practices that have disadvantaged people with disabilities. Doing away with those impediments will allow people with disabilities to obtain needed health care more readily, leading to better access and fewer inequalities.

Additionally, at least some of the barriers people with disabilities experienced obtaining routine preventative care prior to reform resulted from inaccessible equipment, such as scales, X-ray equipment, and exam tables.<sup>321</sup> Pursuant to the ACA, the Access Board, a federal agency charged with facilitating access for people with disabilities, will develop standards for medical diagnostic equipment.<sup>322</sup> These provisions will help remove some of the structural barriers that have impeded health-care access for people with disabilities. Thus, they likewise serve disability rights by promoting equality, access, and integration in health-care delivery.

### 3. Public Health and the ACA

Health-care reform also institutes several changes to public health law that impact people with disabilities. Significantly, the ACA is among the first federal legislation to recognize people with disabilities explicitly as a health disparities population. Historically, “health disparity” has not had a consistent meaning.<sup>323</sup> The National Institutes of Health Working Group has defined the term as “differences in the incidence, prevalence, mortality, and burden of diseases and other adverse health conditions that exist among specific population groups in the United States.”<sup>324</sup> Previously, health disparities research

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319. *Id.*

320. *Id.*

321. See Pendo, *Reducing Disparities*, *supra* note 150, at 1059–65.

322. ACA § 4203.

323. Pendo, *Reducing Disparities*, *supra* note 150, at 1076 (noting that “[h]ealth disparity” is a fluid term meaning many things to different agencies”).

324. *Id.* at 1077 n.129 (quoting Press Release, Nat’l Inst. of Health, NIH Announces Institute on Minority Health and Health Disparities (Sept. 27,

has focused almost exclusively on racial and ethnic minorities.<sup>325</sup>

Among the goals of health-care reform was reducing health disparities across multiple populations.<sup>326</sup> The ACA marks one of the first occasions that Congress has recognized people with disabilities as a population with its own specific health-care needs.<sup>327</sup> The legislation provides that—in addition to traditional health disparities populations—federally funded or supported health programs must collect and report data on disability.<sup>328</sup> The ACA allocates funds for the “development, evaluation, and dissemination of research, demonstration projects, and model curricula for cultural competency, prevention, public health proficiency, reducing health disparities, and aptitude for working with individuals with disabilities.”<sup>329</sup> Further, the legislation requires the federal government and federally funded entities to compile and report data on disability and health-care delivery. The Department of Health and Human Services must ensure that all federally supported health care or public health programs collect data regarding where people with disabilities access care, the availability of accessible facilities and medical equipment, which providers serve people with disabilities, and the extent of their disability competency train-

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2010)).

325. The Minority Health and Health Disparities Research and Education Act of 2000 defines “minority group” as “racial and ethnic minority group.” 42 U.S.C. § 287c-31(c)(3) (2006); *see also* Pendo, *Reducing Disparities*, *supra* note 150, at 1077 n.130 (citing 42 U.S.C. § 287c-31).

326. *See* ACA § 3011 (establishing a national strategy and priorities that includes improving health outcomes for all populations and “reducing health disparities across health disparity populations”).

327. Caldwell, *supra* note 256, at 217 (“This is one of the first times in federal legislation that health disparities for individuals with disabilities have been acknowledged with other minority populations and will assist with advancing future efforts.”).

328. ACA § 4302. To be clear, the legislation does not explicitly designate people with disabilities as a health disparities population. Instead, it lists “disability status” alongside traditional health disparities groups. *Id.*; Pendo, *Reducing Disparities*, *supra* note 150, at 1077 (“Although the section does not specifically provide that individuals with disabilities will be recognized as a health disparity population, this provision does include ‘disability status’ among previously recognized disparity populations and affords the same research benefits to this population.”).

329. ACA § 5307(a); *see also* USA & NSCIA, *supra* note 256, at 7–8 (explaining that the ACA provides grants and other incentives to create programs and model curricula for “disability awareness training to help reduce the health disparities that exist for people with disabilities”).

ing.<sup>330</sup> Disability rights advocates considered the inclusion of individuals with disabilities in this research as a “significant victory” for the disability community.<sup>331</sup> The civil rights implications of designating disability as a health disparities population are two-fold. To begin, it has an expressive value. Including the disability community alongside other socially recognized groups acknowledges that, like racial and ethnic minorities, people with disabilities have experienced systematic discrimination. More practically, compiling research will allow health-care providers to better serve people with disabilities, thereby reducing the disparities they currently experience.

### C. INTEGRATED PROTECTIONS: LESSONS FROM THE ACA

The ACA thus constitutes a departure from the historical schism in substantive legal protections for people with disabilities between the health law and civil rights law paradigms. Despite its health care purpose and substantive provisions, health-care reform effectively functions as a piece of disability rights legislation, by improving access to health care and facilitating equality and integration in its delivery.<sup>332</sup> Moreover, giv-

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330. ACA § 4302; *see also* Caldwell, *supra* note 256, at 217; USA & NSCIA, *supra* note 256, at 8.

331. Caldwell, *supra* note 256, at 217.

332. That is not to say the ACA is perfect with respect to its treatment of people with disabilities. Substantial room for improvement still exists. In the realm of private health insurance—even with the elimination of preexisting condition exclusions, health status-based rating, and caps—people with disabilities may still experience disadvantage, even after the ACA takes full effect. For example, employers can offer their employees reduced premiums for participating in wellness programs, initiatives designed to promote healthy living, in the hopes of lowering health-insurance costs down the line. ACA § 1201 (describing wellness programs). These employer-sponsored wellness programs could have an unintended adverse effect on certain individuals with disabilities. USA & NSCIA, *supra* note 256, at 8. Specifically, people with disabilities may not be able to participate in qualifying exercise regimens or other measures at the same rate as workers without disabilities. *Id.* (explaining that “a person with a disability may be unable to participate in an exercise program or another benchmark of the wellness program”). Consequently, disabled employees may not be eligible for the reduced premiums offered through the wellness programs, putting them in a position of disadvantage relative to their non-disabled colleagues. *Id.* Thus, advocates of disability rights have urged the disability community to take an active role in developing the qualifying programs by providing guidance to the Department of Health and Human Services. *Id.*

Moreover, while the ACA as of 2014 eliminates health status-based rating for certain insurers, the new factors could likewise negatively impact people with disabilities. Geographic location, age, and tobacco use are all *crude proxies* for health. *See* Roberts, *supra* note 18, at 1191. Thus, if health insurers dif-

en the interrelatedness of health care and access to other kinds of social goods such as employment,<sup>333</sup> the civil rights effect of the ACA extends beyond the health-care context, thus laying the groundwork for the improved social standing of people with disabilities in other areas.

With its use of health law to attack disparities and to promote access, the ACA represents a new approach to protecting disability rights. Although on its face the ACA is health legislation, the impact of several of its provisions sound in the register of civil rights. The statute can thus be understood as a health law that also functions as a disability rights law. However, this analysis does not end with health-care reform. The ACA provides a useful case study to demonstrate how integrating subject-specific legislation into the civil rights arsenal can further the rights of people with disabilities, as well as other historically disadvantaged groups. Thus, health-care reform demonstrates that non-civil rights statutes can have civil rights effects, a useful insight in the context of people with disabilities and health care, and beyond.

The nature of discrimination has changed since the first generation of civil rights laws passed.<sup>334</sup> Lawmakers initially

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ferentiate on the basis of those factors, they will end up disadvantaging the same individuals, albeit according to less accurate risk assessment criteria. *Id.* at 1191–94. The ACA can, therefore, be understood to eliminate facial discrimination on the basis of health status, but still have a disparate impact. *Id.*

Additionally, as Elizabeth Pendo has pointed out, while the ACA makes great strides in terms of ensuring the increased availability of accessible medical equipment, it leaves much to interpretation. Pendo, *Reducing Disparities*, *supra* note 150, at 1080–83. The Access Board will create guidelines for manufacturers and providers to follow; however, the term “meaningful access” remains ambiguous. *Id.* at 1081. The current law is silent as to just how much accessible equipment is enough. *Id.* This conundrum is no new problem for issues of access—similar issues have arisen in the context of Title II of the ADA. *Id.*

Further, although the ACA recognizes people with disabilities as a health disparities population, it does not designate them as “medically underserved.” The “medically underserved” designation holds special significance because it is connected with several federal programs designed to address health disparities and to facilitate access to health care. Caldwell, *supra* note 256, at 217. While people with disabilities meet many of the criteria necessary to qualify as medically underserved, including heightened levels of poverty and infant mortality, they have never been formally recognized as such. *Id.* Disability rights advocates have, therefore, encouraged the disability community to take action regarding their recognition. *Id.*

333. See *supra* notes 220–32 and accompanying text (discussing Bagenstos’s scholarship on this point).

334. Susan Sturm, *Second Generation Employment Discrimination: A Structural Approach*, 101 COLUM. L. REV. 458, 459–60 (2001) (explaining that

designed those protections to combat the intentional, categorical exclusion and subordination of people of color and women.<sup>335</sup> Thus, the wrongful conduct envisioned by the statutes was outright and explicit differential treatment on the basis of group status.<sup>336</sup> Yet, even after the enactment of those laws, disparities persisted, leading scholars to speculate as to the cause of the continuing inequality. Many concluded that implicit bias and institutional structures combine to form a more subtle variety of second-generation discrimination.<sup>337</sup> Perhaps unsurprisingly, legislation designed to attack first-generation discrimination has done little to dismantle the infrastructures responsible for second-generation discrimination.<sup>338</sup>

The civil rights paradigm is, therefore, a product of an earlier era in which overt discrimination and outright exclusion were the order of the day. While those protections remain necessary to the antidiscrimination project, acting alone, they are no longer sufficient. A world dominated by second-generation discrimination requires a more complex legal regime to address persistent structural inequities through actively promoting the

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the “[s]moking guns—the sign on the door that ‘Irish need not apply’ or the rejection explained by the comment that ‘this is no job for a woman’—are largely things of the past”). I borrow the “first generation” and “second generation” terminology from Susan Sturm’s seminal article on structural inequality.

335. *Id.* at 465–66 (“The first generation employment discrimination cases mirror the social and political conditions that led to the adoption of the civil rights legislation. Workplace segregation was maintained through overt exclusion, segregation of job opportunity, and conscious stereotyping. Dominant individuals and groups deliberately excluded or subordinated women and people of color.”).

336. *Id.* at 466 (identifying the “wrong” of first generation discrimination as “deliberate exclusion or subordination based on race or gender”).

337. *See, e.g., id.* at 460 (explaining that “second generation manifestations of workplace bias are structural, relational, and situational”); Samuel R. Bagenstos, *The Structural Turn and the Limits of Antidiscrimination Law*, 94 CALIF. L. REV. 1, 5–15 (2006) [hereinafter Bagenstos, *The Structural Turn*] (summarizing the literature on structural inequalities and attributing those disparities to unconscious bias and workplace structure); *see also* Tristin K. Green, *Discrimination in Workplace Dynamics: Toward a Structural Account of Disparate Treatment Theory*, 38 HARV. C.R.-C.L. L. REV. 91 (2003); Linda Hamilton Krieger, *The Content of Our Categories: A Cognitive Bias Approach to Discrimination and Equal Employment Opportunity*, 47 STAN. L. REV. 1161 (1995).

338. Several scholars have weighed in regarding how to address the problem of second-generation discrimination, including Bagenstos and Satz. *See* Bagenstos, *The Structural Turn*, *supra* note 337 (arguing for a moderate approach to structural discrimination); Satz, *Disability, Vulnerability, and the Limits of Antidiscrimination*, *supra* note 5, at 550 (citing the universal vulnerability perspective as a means to address second-generation discrimination).

rights of historically disadvantaged groups. The integrated legal approach, therefore, has two key components: (1) civil rights legislation (including claims for disparate impact) to attack discrimination and exclusion; and (2) non-civil rights legislation to confer substantive benefits. Just as issues of health-care availability and access necessitated a health law paradigm, disparities in different areas likewise require integrating other legal frameworks into the civil rights project.

The ACA can be read as conferring a number of rights and benefits on people with disabilities. Perhaps most clearly, the changes to the public health insurance system, including Medicaid expansion and increased supports for at-home care, confer tangible health-care benefits on qualifying individuals with disabilities. Less obviously, the changes to private insurance can also be read as creating certain entitlements. Pursuant to the mandate (with few exceptions), people who are not insured publically must acquire health insurance.<sup>339</sup> The legislation contains provisions to facilitate access to private insurance where there had not been access in the past, such as the temporary high-risk pools for people previously denied health insurance because of preexisting conditions, the low-income subsidy, and the state exchanges.<sup>340</sup> These policies and programs—read alongside the ACA’s prohibitions on caps, preexisting condition exclusions, and health status-based rating described above—can be understood as allocating a right to access health insurance where one had not previously existed. Moreover, some have even argued that the legislation may create a private right of action for discrimination in private health insurance.<sup>341</sup> Finally, the changes to public health law also benefit people with disabilities. The legislation allocates funds to address health disparities for the enumerated populations.<sup>342</sup> Thus, recognizing people with disabilities as a health disparities popula-

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339. ACA § 1501, Pub. L. No. 111-148, 124 Stat. 242 (2010) (amending the Internal Revenue Code, 26 U.S.C. § 5000A(a), to require “applicable individual[s]” to obtain minimum essential coverage).

340. See ACA § 1311 (providing consumer choice through health exchanges); ACA § 1331 (providing flexibility to states to establish health programs for low-income individuals not eligible for Medicaid); Press Release, HealthCare.gov, Temporary High Risk Pool Program (July 1, 2010), available at <http://www.healthcare.gov/news/factsheets/2010/07/temp-high-risk-pool-program.html>.

341. See, e.g., Sarah G. Steege, *Finding a Cure in the Courts: A Private Right of Action for Disparate Impact in Health Care*, 16 MICH. J. RACE & L. 439 (2011).

342. See *supra* notes 329–31 and accompanying text.

tion brings with it federal monies. While not a direct, individual entitlement like Medicaid benefits, the allocation of funds specifically to address the health disparities people with disabilities face represents a federal benefit designed to promote the civil rights goals of equality, access, and integration in the context of health care.

Taking a lesson from the ACA, this Article proposes an integrated approach, that is, using substantive, non-civil rights protections *in conjunction with* antidiscrimination protections. The ACA itself exemplifies the integrated legal approach to disability rights by including its own civil rights-style protection. In addition to the beneficial provisions outlined above, the ACA also includes a nondiscrimination section that indicates federally funded health programs cannot discriminate on the basis of disability and identifies the Rehabilitation Act as the proper enforcement mechanism.<sup>343</sup> It also authorizes the Secretary of Health and Human Services to promulgate regulations implementing that section.<sup>344</sup> Thus, the ACA recognizes the dual nature of the health disparities that face people with disabilities—the problem is both a matter of health-care access and a matter of civil rights.<sup>345</sup>

Importantly, advocates should not abandon the civil rights paradigm: its statutes serve important expressive and practical functions. On one level, civil rights laws frame the inequities they target as social problems.<sup>346</sup> On another, civil rights laws provide a means to attack discriminatory conduct.<sup>347</sup> Thus, proponents of disability rights should continue their support for the civil rights paradigm, both to keep disability rights framed as a social issue and to combat the more traditional forms of discrimination, even as they grow increasingly rare.

The integrated approach is not specific to health law (or even to disability). As the following example demonstrates, advocates have been combining civil rights laws and other types of legislation for decades to allow comprehensive coverage.

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343. USA & NSCIA, *supra* note 256, at 8.

344. *Id.*

345. Elizabeth Pendo has made a similar observation. *See Pendo, Reducing Disparities, supra* note 150, at 1058 (“The reframing of barriers and disparities faced by people with disabilities as an issue of health care access and quality under the [ACA]—in addition to an issue of civil rights under the ADA—appears promising.”).

346. *See SWITZER, supra* note 77, at 91 (describing the symbolic relevance of civil rights law as a remedy).

347. Regrettably, overt discrimination has not disappeared.

However, identifying this phenomenon as an effective strategy for combating inequalities and promoting access and integration allows reformers to bring this strategy to the forefront of their legislative agendas.

Education for minor children provides a useful example of integrated legal protections for people with disabilities outside health law. Congress originally passed the Individuals with Disabilities Education Act (IDEA), formerly the Education for All Handicapped Children Act, in 1975.<sup>348</sup> The law provides funding to states for “special education and related services” for children with disabilities.<sup>349</sup> Although schools are not required to maximize a student with a disability’s potential,<sup>350</sup> school districts must provide a free and appropriate public education.<sup>351</sup> The Rehabilitation Act and either Title II or III of the ADA also apply in educational settings.<sup>352</sup> The special education legislation and the civil rights legislation serve different, yet related purposes.

Because IDEA allows parents of children with disabilities to challenge “any matter” related to a child’s ability to obtain a free and appropriate education,<sup>353</sup> courts have held that claims against a school district that are “educational in nature” are “presumptively redressable” through IDEA’s administrative process, and therefore subject to its exhaustion requirement.<sup>354</sup> However, when parents Bob and Karen Ellenberg sued on behalf of their daughter S.E. under IDEA, the Rehabilitation Act, and the ADA, the Tenth Circuit held that their failure to exhaust the administrative remedies available under IDEA did not bar their other claims.<sup>355</sup> The court justified its decision to treat the civil rights claims separately because the Ellenbergs were “unable to obtain relief under the IDEA for their *pure discrimination claims* brought pursuant to the [Rehabilitation

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348. Individuals with Disabilities Education Act, 20 U.S.C. § 1400 (2006).

349. *Id.* § 1411(a)(1).

350. *See* Bd. of Educ. v. Rowley, 458 U.S. 176 (1982).

351. 20 U.S.C. § 1412(a)(1)(A) (2006).

352. The Rehabilitation Act prohibits discrimination in federally supported or conducted programs. 29 U.S.C. ch. 16 (2006). Title II of the ADA prohibits discrimination by public entities. 42 U.S.C. §§ 12111–12117 (2006). Title III of the ADA applies to public accommodations. *Id.* §§ 12181–12189. Depending how they are funded schools may be covered by a combination of these provisions.

353. 20 U.S.C. § 1415(b)(6)(A).

354. *See* Padilla *ex rel.* Padilla v. Sch. Dist. No. 1, 233 F.3d 1268, 1275 (10th Cir. 2000).

355. *Ellenberg v. N.M. Military Inst.*, 478 F.3d 1262, 1267 (10th Cir. 2007).



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Act] and ADA.”<sup>356</sup> Although IDEA mandates a free and appropriate education and the provision of special education and related services, the ADA and the Rehabilitation Act provide concurrent yet complementary protection by prohibiting schools from engaging in discriminatory practices. Thus, both kinds of laws, working together, are essential to a meaningful education for children with disabilities.

In a world of second-generation discrimination, traditional civil rights legislation, acting alone, may not achieve the desired levels of equality, access, and integration for historically disadvantaged groups. Thus, advocates should look outside the confines of the traditional civil rights model and support subject-specific legislation that confers tangible rights and benefits. While this Article focuses on people with disabilities, the integrated approach could likewise aid other populations who face structural inequality.

Given the positive impact it could have for people with disabilities, the ACA demonstrates that a statute within the “health law” paradigm may also function as a “civil rights law.” Health law and traditional civil rights law can work together to promote access and to reduce disparities. The use of non-civil rights legislation, in addition to existing antidiscrimination protections, represents an integrated approach to advancing the interests of historically disadvantaged groups. People with disabilities and health-care reform are but one example. This legislative strategy, which combines prohibitions on discrimination and exclusion with benefits designed to facilitate access and integration, may have currency in other areas of the law and for advocates of other subordinated populations.

#### CONCLUSION

The Affordable Care Act was a watershed moment for disability rights. Advocates of the disability community launched expansive campaigns and forged powerful alliances to ensure that the resulting legislation would address the significant health disparities they faced. However, this strategy represents a significant departure from the early part of the disability rights movement, when champions of disability rights actively shunned health law protections.

The ADA and the Rehabilitation Act constitute valuable symbolic victories by recognizing disability as an antidiscrimi-

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356. *Id.* (emphasis added).

nation category. However, those laws had a limited impact in achieving equality, access, and integration for the disability community, particularly in the area of health care. Although those statutes apply to health-care providers, people with disabilities continued to experience notable health disparities, due in no small part to the structural barriers they have historically encountered securing adequate insurance and obtaining needed services and devices. The civil rights paradigm was not the proper instrument to address the issues underlying those inequities. As a result, disability rights advocates rallied around Congress's effort to reform health care. The legislation thus contains many provisions that will benefit people with disabilities.

The Affordable Care Act represents a sea change for proponents of disability rights. It demonstrates that health law can function as civil rights law. It also exemplifies a particular approach to achieving antidiscrimination goals. The Affordable Care Act works with existing civil rights statutes to provide a comprehensive web of legal protections that both outlaw discrimination and promote access. By integrating other kinds of substantive protections into their civil rights agenda, advocates can address the subtle, second-generation discrimination that perpetuates existing inequalities. Moreover, the integrated legal approach could have broad implications for civil rights proponents generally, not just for disability rights. While glimmers of this strategy already exist within the antidiscrimination project, fully embracing it as a legislative agenda and a tool for change might garner substantial benefits for historically disadvantaged groups. The Affordable Care Act will have lasting benefits for people with disabilities, both in terms of its substantive protections and as a model for future reform, in health care and beyond.