

ARTICLE

## A Half Century of Change

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Firstly, I would like to thank George Annas, Wendy Mariner, and Fran Miller for nurturing the field of health law, and keeping the collaboration vibrant for more than half a century.

My path to health law began at Antioch College in the 1960s, where I was engaged in the struggle for racial equality and against unjust income inequality. I came to the Big Apple seeking a job as a community organizer. But in the 1960s, for women seeking a job, the question was how fast you could type. To be an effective advocate for human equality, a woman needed better credentials than a man.

At NYU School of Law, I was blessed with great civil rights colleagues and mentors. Norman Dorsen, general counsel of the ACLU, and Tony Amsterdam, leader of the fight against the death penalty, kept me busy as a research assistant. As a student, and then new lawyer, I worked on the case *Goldberg v. Kelly*.<sup>1</sup> The plaintiffs in *Goldberg* were indigent people who had been found eligible for need-based aid.<sup>2</sup> They were then terminated without notice of the reason or opportunity to protest.<sup>3</sup> While *Goldberg* involved indigent people, its power lies in the fact that it protects anyone who qualifies for an entitlement created by the state and is then disqualified without notice of the reasons and an opportunity to protest.<sup>4</sup> That is all of us. And as a practical matter, the privileged among us are much more likely to benefit from the protections created by *Goldberg*.

Ed Sparer, founding director of MFY Legal Services<sup>5</sup> and General Counsel to the National Welfare Rights Organization, introduced me to health law. Ed focused on class, the need to listen to and empower clients, and, most importantly, the power of representing the less affluent majority. In 1970, with the help of the Ford Foundation, Sparer created the first clinical law program devoted to health law at the University of Pennsylvania and recruited me to direct it.<sup>6</sup> The Legal Services Corporation was growing its back-up centers, including the (now awesome) Health Law Project in Los Angeles.

Then and now, our health care delivery “system,” functioned for well-connected, high-income people, and was an international disgrace in terms of access, cost, and quality for the most vulnerable.<sup>7</sup> In moving the focus of his work from means-tested welfare for the poor to decent health care for all, Sparer’s insight was that deep social change could best be achieved on behalf of the less affluent majority.

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<sup>1</sup>*Goldberg v. Kelly*, 397 U.S. 254 (1970).

<sup>2</sup>*Id.* at 255-56.

<sup>3</sup>*Id.* at 256.

<sup>4</sup>*Id.* at 261-62.

<sup>5</sup>This organization is currently known as “Mobilization for Justice.” See MOBILIZATION FOR JUSTICE, <https://mobilizationforjustice.org> (last visited Nov. 6, 2024).

<sup>6</sup>For an exploration of Sparer’s politics, see Edward V. Sparer, *Fundamental Human Rights, Legal Entitlements, and the Social Struggle: A Friendly Critique of the Critical Legal Studies Movement*, 36 STANFORD L. REV. 509 (1984).

<sup>7</sup>Howard Ennes, *The Insurance Industry Looks Ahead at Health Care in the 1970s*, 85 ABRIDGED INDEX MEDICUS 117, 117-18 (1970); Cynthia Cox et al., *Health Care Costs and Affordability*, KAISER FAM. FOUND. (May 28, 2024), <https://www.kff.org/health-policy-101-health-care-costs-and-affordability/>; Emma Wager & Cynthia Cox, *International Comparison of Health Systems*, KAISER FAM. FOUND. (May 28, 2024), <https://www.kff.org/health-policy-101-international-comparison-of-health-systems/>.

The book I coauthored with George Annas, Rand Rosenblatt, Ken Wing, David Frankfort, and eventually, Sarah Rosenbaum, follows a common pattern.<sup>8</sup> These books begin with an introduction to three big themes – access, quality, and costs—and a shorter treatment of a variety of other complex and important issues, including antitrust, fraud and abuse, long-term care, needs of particular groups such as people with disabilities, and women.<sup>9</sup>

In the twentieth century, most developed nations instituted programs assuring that their people could obtain access to essential medical services.<sup>10</sup> By contrast, the U.S. was slow to follow. In 1912, Teddy Roosevelt promoted the concept of universal access to health insurance—without success—as did Franklin Roosevelt, during the Great Depression, as part of the New Deal.<sup>11</sup> When Harry Truman became President in 1942, he sought to perpetuate Roosevelt’s legacy by supporting national health insurance; the effort failed.<sup>12</sup> In 1965, under the leadership of Lyndon B. Johnson, Congress adopted Medicare and Medicaid; the President traveled to Truman’s hometown in Independence Missouri to sign the bill in Truman’s presence.<sup>13</sup> In 1993, the Clinton administration made national health insurance a priority.<sup>14</sup> But the proposal never got off the ground.<sup>15</sup> As First Lady, Hillary Clinton sought, unsuccessfully, to persuade Congress to adopt national health insurance.<sup>16</sup> It was not until more than a decade later in 2010 that Congress passed the Affordable Care Act.<sup>17</sup>

Both the Pennsylvania Health Law Project and the Los Angeles health law backup center started with a focus on access to care.<sup>18</sup> Fifty years ago, people seeking essential medical care did not have legal rights. The common law rule was “no duty to treat.”<sup>19</sup> The Hill-Burton Act of 1946 recognized that the U.S. needed more hospitals, especially in rural areas, and provided funding to address this need.<sup>20</sup> Hospitals constructed with federal funds were required to end racial discrimination and provide a “reasonable volume of services to people unable to pay.”<sup>21</sup> Particularly in the South, discrimination on the basis of race was rampant, and inferior treatment to people who could not pay was common.<sup>22</sup> The Hill-Burton Act provided opportunities for local lawyers and, beginning in 1964, legal services lawyers to

<sup>8</sup>GEORGE J. ANNAS, ET AL., *American Health Law*, (Little, Brown & Co., 1st. ed. 1990); SARA ROSENBAUM ET AL., *Law and the American Health Care System*, (Foundation Press, 2d. ed. 2012).

<sup>9</sup>ANNAS, ET AL., *supra* note 8; ROSENBAUM ET AL., *supra* note 8.

<sup>10</sup>*Foreign Countries with Universal Health Care*, N.Y. DEP’T OF HEALTH (revised June 2022).

<sup>11</sup>*National Health Insurance – A Brief History of Reform Efforts in the U.S.*, KAISER FAM. FOUND. (Mar. 2009), <https://www.kff.org/wp-content/uploads/2013/01/7871.pdf>; Karen S. Palmer, *A Brief History: Universal Health Care Efforts in the US*, PHYSICIANS FOR A NAT’L HEALTH PROGRAM (1999), <https://pnhp.org/a-brief-history-universal-health-care-efforts-in-the-us/>.

<sup>12</sup>*National Health Insurance – A Brief History of Reform Efforts in the U.S.*, KAISER FAM. FOUND. (Mar. 2009), <https://www.kff.org/wp-content/uploads/2013/01/7871.pdf>.

<sup>13</sup>*Medicare and Medicaid Act (1965)*, NAT’L ARCHIVES (Feb. 8, 2022), <https://www.archives.gov/milestone-documents/medicare-and-medicaid-act>.

<sup>14</sup>Thomas F. A. Plaut & Bernard S. Arons, *President Clinton’s Proposal for Health Care Reform: Key Provisions and Issues*, 45 *Hospital and Cmty. Psychiatry* 871, 871 (1994).

<sup>15</sup>Adam Clymer, *The Health Care Debate: The Overview; National Health Program, President’s Greatest Goal, Declared Dead in Congress*, N.Y. TIMES (Sep. 27, 1994), <https://www.nytimes.com/1994/09/27/us/health-care-debate-overview-national-health-program-president-s-greatest-goal.html?pagewanted=all>.

<sup>16</sup>Plaut & Arons, *supra* note 14, at 871.

<sup>17</sup>Cynthia Cox & Jared Ortaliza, *The Affordable Care Act 101*, KAISER FAM. FOUND. (May 28, 2024), <https://www.kff.org/health-policy-101-the-affordable-care-act/>.

<sup>18</sup>*What We Do*, PA. HEALTH LAW PROJECT (last visited Nov. 12, 2024), <https://www.phlp.org/en/about/what-we-do>; The Los Angeles Health Law Backup Center is now known as the “National Health Law Program.” See *The History of the National Health Law Program*, NAT’L HEALTH LAW PROGRAM (last visited Nov. 12, 2024), <https://healthlaw.org/the-history-of-the-national-health-law-program/>.

<sup>19</sup>Kayhan Parsi, *Duty to Treat: Conscience and Pluralism*, 9 *AMA J. ETHICS* 362, 362-63 (2007).

<sup>20</sup>Karen K. Thomas, *Hill-Burton Act*, ENCYC. ALABAMA (Jan. 22, 2008), <https://encyclopediaofalabama.org/article/hill-burton-act/>.

<sup>21</sup>*Hill-Burton Free and Reduced-Cost Health Care*, HRSA (Nov. 12, 2024), <https://www.hrsa.gov/get-health-care/affordable/hill-burton>; Carole Bennett, *Healthcare Justice, Medicare, and the Racial Desegregation of Hospitals in the South*, 28 *OJIN* 1, 2 (2023).

<sup>22</sup>Bennett, *supra* note 21, at 2.

challenge these practices.<sup>23</sup> In 1964, Lyndon Johnson launched the War on Poverty, spearheaded by the Office of Economic Opportunity, supporting lawyers to represent low-income people.<sup>24</sup> In July 1965, Johnson signed the law creating the federally-funded Medicare program financing health care for the aged and disabled, and Medicaid, financing health services to low-income people.<sup>25</sup> In 1986, Congress passed the Emergency Medical Treatment and Active Labor Act (EMTALA), requiring hospitals participating in Medicare to provide emergency care to anyone who requests it, regardless of their inability to pay.<sup>26</sup> All these reforms, while important, still left the United States solidly in last place among developed nations in providing essential health care to low-income people.<sup>27</sup>

Under the leadership of Barack Obama and Nancy Pelosi, Congress passed the Affordable Care Act of 2010 (ACA), the most significant expansion of coverage since the adoption of Medicare and Medicaid in 1965. The adoption of the ACA was a political miracle.<sup>28</sup> Like today, Congress was closely divided. The ACA could have died with the death of Teddy Kennedy, one of its most passionate and influential supporters, but it did not.<sup>29</sup> Or it could have died without the vote of Republican John McCain, but it did not.<sup>30</sup> The ACA largely builds upon Medicare, Medicaid and employment-based private insurance and incorporates their weaknesses and strengths. It requires individuals to have health insurance, prohibits charges based on preexisting conditions or demographic factors, except for age,<sup>31</sup> and supports navigators who help people choose among plans available in their neighborhood.<sup>32</sup> For more than a decade, Republicans have sought to repeal the ACA.<sup>33</sup> Recently however, Republican opponents have generally not campaigned on repealing the ACA.<sup>34</sup>

The ACA is working. In 2024, 21.3 million people signed up for coverage under the ACA, setting an enrollment record for the third year in a row and almost doubling enrollment since 2020.<sup>35</sup> Among working-age Americans, the percentage of people who did not have health insurance decreased from 14.3% in 2019 to 10.9% in 2023.<sup>36</sup> Based on census data, between 2010 and 2022, the uninsurance rate for Black Americans declined from 20.9% to 10.8%; the rate for Latinos declined from 32.7% to 18%; for Asian Americans, Native Hawaiians and Pacific Islanders (AANHPI) it declined from 16.6% to 6.2%; and for American Indians and Alaska Natives (AI/AN) the decline was

<sup>23</sup>Kenneth R. Wing, *The Community Service Obligation of Hill-Burton Health Facilities*, 23 B.U. L. REV. 577, 601-02 (1982).

<sup>24</sup>Special Message to the Congress Proposing a Nationwide War on the Sources of Poverty 1964, 1 PUB. PAPERS 375 (Mar. 16, 1964).

<sup>25</sup>*Medicare and Medicaid Act (1965)*, *supra* note 13.

<sup>26</sup>*Emergency Medical Treatment & Labor Act (EMTALA)*, CTR. FOR MEDICARE & MEDICAID SERVS., <https://www.cms.gov/medicare/regulations-guidance/legislation/emergency-medical-treatment-labor-act> (last modified Sep. 10, 2024).

<sup>27</sup>Eric C. Schneider et al., *Mirror, Mirror 2021 Reflecting Poorly: Health Care in the U.S. Compared to Other High-Income Countries 3* (The Commonwealth Fund 2021).

<sup>28</sup>Nancy Pelosi, *The Art of Power: My Story as America's First Woman Speaker of the House*, 185-242 (Simon and Schuster 2024).

<sup>29</sup>Dylan Scott, *An Oral History of Obamacare's 7 Near-Death Experiences*, VOX (Aug. 7, 2017), <https://www.vox.com/policy-and-politics/2017/8/7/16082800/obamacare-8-lives>.

<sup>30</sup>*Id.*

<sup>31</sup>Jonathan Gruber, *The Impacts of the Affordable Care Act: How Reasonable are the Projections?*, 64 NAT'L TAX J. 893, 895-96 (2011).

<sup>32</sup>Louise Norris, *Navigator: What are Navigators*, HEALTH INSURANCE.ORG, <https://www.healthinsurance.org/glossary/navigator/> (last visited Nov. 21, 2024).

<sup>33</sup>See *Repealing the Job-Killing Health Care Law Act*, H.R. 2, 112th Cong. (2011); H.R. 45, 113th Cong. (2013); Gusmano et al., *Trump v. the ACA*, 16 HEALTH ECON. POL'Y AND L. 251 (2021).

<sup>34</sup>Sahil Kapur, *Republicans Abandon Obamacare Repeal*, NBC NEWS (Oct. 2, 2022), <https://www.nbcnews.com/politics/congress/republicans-abandon-obamacare-repeal-rcna49538>; Donald Trump (@realDonaldTrump), X (Oct. 31, 2024, 1:01 PM), <https://x.com/realDonaldTrump/status/1852033066157441249>.

<sup>35</sup>Noah Weiland, *It's Boom Times for Obama Care. Will They Last?*, N.Y. TIMES (Jan. 26, 2024), <https://www.nytimes.com/2024/01/25/us/politics/obamacare-open-enrollment.html>.

<sup>36</sup>U.S. Uninsured Rate Drops by 26% Since 2019, CDC (June 18, 2024), [https://www.cdc.gov/nchs/pressroom/nchs\\_press\\_releases/2024/20240618.htm#print](https://www.cdc.gov/nchs/pressroom/nchs_press_releases/2024/20240618.htm#print).

from 32.4% to 19.9%.<sup>37</sup> This barely scratches the surface of the huge issue of access to health insurance, much less access to actual care. In 2022 health care expenditures per person in the United States were \$12,555, over \$4000 more than any other high-income nations. Comparably wealthy countries spent \$6,651, on average, per person.<sup>38</sup> More important than the complexity of health care financing, is that there is no obvious constituency for economy. Quite sensibly, providers have powerful incentives to keep reimbursement high. Over the decades, a few insurance companies, progressive state insurance commissioners, and legislatures have sought to encourage spending constraints.<sup>39</sup> But it is far more difficult to build a cross-class constituency for holding down excessive costs than it is for access or quality.

The legal rules and professional practices that define rights of access, quality, and reasonable costs are all complex. A vast body of federal law creates expert agencies to promulgate and enforce standards for health and safety and for the past four decades, the Supreme Court has largely deferred to the expert judgments of agencies to provide the details.<sup>40</sup> In 2024, the Supreme Court rejected the principle that the Court should defer to the judgment of the expert agencies given responsibility for implementing the details of complex laws.<sup>41</sup>

While the huge health law issues, such as access, quality, and cost gain the most attention, health law courses focus on additional concerns, including antitrust, fraud and abuse, long-term care, and the needs of particular groups, such as women and those with disabilities. Each of these could be a full course or seminar. At NYU some are taught as separate seminar. Yet other issues present an opportunity to introduce students to practitioners who can teach the law in action. For example, to teach fraud and abuse law, I recruit experts from AG offices or Taxpayers Against Fraud to describe how the law plays out in practice. As another example, a class focusing on the needs of people with disabilities is taught as a seminar by Robert M. Levy, a federal magistrate and former lead counsel on the landmark *Willowbrook* litigation. During the HIV pandemic, I recruited a former law student who had left the law to become a doctor and leader on the medicine and politics of HIV to teach this complex subject. While I do substantial legal and policy work on reproductive freedom, in the law school, the subject has its own seminar and clinic taught by others.

This commemoration of fifty years of health law occurs as the Congress and Executive consider radical changes to the programs and principles developed over these decades.

<sup>37</sup> Assistant Secretary for Public Affairs, *Biden-Harris Administration Releases Data Showing Historic Gains in Health Care Coverage in Minority Communities*, HHS (June 7, 2024), <https://www.hhs.gov/about/news/2024/06/07/biden-harris-administration-releases-data-showing-historic-gains-health-care-coverage-minority-communities.html>.

<sup>38</sup> Emma Wager et al., *How Does Health Spending in the U.S. Compare to Other Countries*, KAISER FAM. FOUND. (Jan. 23, 2024), <https://www.healthsystemtracker.org/chart-collection/health-spending-u-s-compare-countries>.

<sup>39</sup> Maximilian Pany et al., *Price Regulation, Global Budgets, and Spending Targets: A Road Map to Reduce Health Care Spending, and Improve Affordability*, KAISER FAM. FOUND. (May 31, 2022), <https://www.kff.org/health-costs/report/price-regulation-global-budgets-and-spending-targets-a-road-map-to-reduce-health-care-spending-and-improve-affordability/>.

<sup>40</sup> *Chevron U.S.A. v. Nat. Res. Def. Counsel*, 467 U.S. 837 (1984). This is known as Chevron deference.

<sup>41</sup> *Lopez Bright Enter. v. Raimondo*, 144 S.Ct. 2244 (2024) (overruling *Chevron U.S.A. v. Nat. Res. Def. Counsel*, 467 U.S. 837 (1984) in a 6-2 decision).