

Chapter 1

Disparities in Health Care: The Pandemic's Lessons for Health Lawyers

Danielle Pelfrey Duryea

Boston University School of Law

Nicole Huberfeld

Boston University School of Law and Boston University School of Public Health

Ruqaiijah Yearby¹

Saint Louis University School of Law and Institute for Healing Justice & Equity

1.1 Introduction

Population-level disparities in health and health care came to the forefront of U.S. public consciousness in 2020.² As the racial,

¹ The authors would like to thank Professor Lindsay F. Wiley (American University Washington College of Law) for her important contributions to conceptualizing this chapter.

² See, e.g., Andi Egbert & Kristine Liao, *The Color of Coronavirus: 2020 Year in Review*, American Public Media Research Lab (Dec. 21, 2020), available at <https://www.apmresearchlab.org/covid/deaths-2020-review>.

“Health disparities” are differences between groups in health outcomes, such as rates of infection, disease, disability, or death. “Health care disparities” are differences among groups in access to and use of

ethnic, and socioeconomic stratification of COVID-19 infection and death rates emerged with chilling clarity,³ the Black Lives Matter protests of the summer focused millions of Americans on the complex, structural nature of inequity and its long-lasting effects.⁴ Near the end of the year, disparities in health care and disparities in health outcomes converged in the widely-reported story of Indiana physician Susan Moore.⁵ Already suffering from a chronic inflammatory disease experienced by Black Americans at about eight times the rate of white Americans,⁶ Dr. Moore died of COVID-19 after detailing poor treatment—including common forms of racial discrimination in medicine such as the devaluing of Black patients’

health care, including health insurance coverage, and quality of care. See Samantha Artiga et al., *Disparities in Health & Health Care: Five Key Questions & Answers*, Kaiser Family Foundation, (Mar. 4, 2020), available at <https://www.kff.org/racial-equity-and-health-policy/issue-brief/disparities-in-health-and-health-care-five-key-questions-and-answers/>.

³ See, e.g., Reis Thebault et al., *The Coronavirus is Infecting and Killing Black Americans at an Alarming High Rate*, WASH. POST (April 7, 2020), available at <https://www.washingtonpost.com/nation/2020/04/07/coronavirus-is-infecting-killing-black-americans-an-alarmingly-high-rate-post-analysis-shows/?arc404=true> (early reporting on racial disparities in COVID-19 morbidity and mortality). Peer-reviewed studies soon began to validate these reports. See, e.g., Eboni G. Price-Haywood et al., *Hospitalization and Mortality among Black Patients & White Patients with Covid-19*, 382 NEW ENGLAND J. MED. 2534 (2020), available at <https://www.nejm.org/doi/10.1056/NEJMsa2011686>; Gregorio A. Millett et al., *Assessing Differential Impacts of COVID-19 on Black Communities*, 47 ANN. OF EPIDEMIOLOGY 37 (2020), available at <https://doi.org/10.1016/j.annepidem.2020.05.003>; W. Holmes Finch & Maria E. Hernandez Finch, *Poverty and Covid-19: Rates for Incidence and Deaths in the United States During the First 10 Weeks of the Pandemic*, 5 FRONTIERS IN SOCIOLOGY 47 (2020).

⁴ See, e.g., Char Adams, *A Movement, A Slogan, A Rallying Cry: How Black Lives Matter Changed America’s View on Race*, NBCNews.com (Dec. 29, 2020), available at <https://www.nbcnews.com/news/nbcblk/movement-slogan-rallying-cry-how-black-lives-matter-changed-america-n1252434>.

⁵ See, e.g., John Eligon, *Black Doctor Dies of Covid-19 After Complaining of Racist Treatment*, N.Y. TIMES (Dec. 25, 2020), available at <https://www.nytimes.com/2020/12/23/us/susan-moore-black-doctor-indiana.html>.

⁶ See Mehdi Mirsaedi et al., *Racial Difference in Sarcoidosis Mortality in the U.S.*, 147 CHEST 438 (Sept. 4, 2014), available at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4314818/>.

reports of pain⁷—in a cell phone video recorded from her hospital bed.⁸

Access to quality health care is a “social determinant of health,” meaning that it is one of the “non-medical factors that influence health outcomes . . . the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life.”⁹ Although it may seem obvious that differential access to high-quality care results in differential health outcomes, less obvious are the ways that multiple factors—including facially neutral laws and organizational practices—interact over time to produce population-level disparities in care and outcomes. In 2021, all U.S. health lawyers should monitor and consider the following key developments, as we predict each will affect equitable access:

- The ongoing pandemic response and the disparate access to U.S. health care systems that it reveals;

⁷ See, e.g., Kelly M. Hoffman et al., *Racial Bias in Pain Assessment & Treatment Recommendations, & False Beliefs about Biological Differences Between Blacks and Whites*, 13 PROC. NAT’L ACAD. SCI. U.S. 4296 (2016); Laura D. Wandner et al., *The Perception of Pain in Others: How Gender, Race, and Age Influence Pain Expectations*, 13 J. PAIN 220 (2012); Karen O. Anderson et al., *Racial and Ethnic Disparities in Pain: Causes & Consequences of Unequal Care*, 10 J. PAIN 1187 (2009).

⁸ See, e.g., John Eligon, *Black Doctor Dies of Covid-19 After Complaining of Racist Treatment*, N.Y. TIMES (Dec. 25, 2020), available at <https://www.nytimes.com/2020/12/23/us/susan-moore-black-doctor-indiana.html>.

⁹ *Social Determinants of Health*, World Health Organization (2021), available at https://www.who.int/health-topics/social-determinants-of-health#tab=tab_1; See also *A Conceptual Framework for Action on the Social Determinants of Health*, World Health Organization Commission on the Social Determinants of Health (2010), available at https://www.who.int/sdhconference/resources/ConceptualframeworkforactiononSDH_eng.pdf?ua=1. Specifically, in the WHO framework, health care is an “intermediary” determinant of health, a material or environmental circumstance that affects health outcomes. Intermediary determinants are distinct from, but give material form to, root causes or “structural determinants” such as poverty or racial discrimination. *Id.* at 6.

- The ongoing expansion of Medicaid eligibility under the Patient Protection & Affordable Care Act (ACA)¹⁰ and the breadth of exceptions to federal requirements granted to state Medicaid programs;
- The continuing evolution in publicly-funded health insurance toward payment models that reward positive health outcomes (and punish poor ones); and
- The ongoing debate over federal law preventing discrimination in health care eligibility and delivery of care.

Differences in health outcomes between populations—defined not only by differences in race, ethnicity, and socioeconomic status, but also by disability status, age, geographic location, language, immigration status, gender, gender identity, and sexual orientation—are not new.¹¹ Nor are group differences in access to care, insurance coverage, and quality of care that closely align to social, economic, and/or other environmental disadvantage. But, with intensifying and warranted attention to health inequity and its financial and social costs, U.S. health lawyers across the system should be alert to the

¹⁰ We assumed in this chapter that the ACA would not be struck down in its entirety in *California v. Texas*, No. 19-840 (2021). This latest challenge to the ACA was argued before the Supreme Court in November 2020 and had not been decided as of this writing. See, e.g., Adam Liptak, *Key Justices Signal Support for Affordable Care Act*, N.Y. TIMES (Nov. 13, 2020), available at <https://www.nytimes.com/2020/11/10/us/supreme-court-obamacare-aca.html> (describing oral argument in *California v. Texas* as indicating that the ACA is “likely to survive its latest encounter with the court”).

It should be noted, however, that, if the ACA were to be struck down in its entirety, it would almost certainly increase racial disparities in health insurance coverage that have narrowed during the ACA era. See, e.g., Samantha Artiga, *Loss of the Affordable Care Act Would Widen Racial Disparities in Health Coverage*, Kaiser Family Foundation (October 2020), available at <https://www.kff.org/policy-watch/loss-of-the-affordable-care-act-would-widen-racial-disparities-in-health-coverage/>.

¹¹ Of course, the dimensions listed here are not mutually exclusive, and both health and health care disparities frequently appear along intersections among them. See, e.g., Artiga et al., *supra* note 2.

ways that facially neutral organizational practices and policies reinforce health care disparities and thereby contribute to disparate health outcomes.

1.2 Pandemic Response and Disparate Access to Testing, Treatments, PPE, and Vaccination

COVID-19 has disproportionately infected and killed racial and ethnic minority populations, except people of Asian descent. As of this writing, the COVID-19 death rate for Black people was 161 per 100,000 people, 156 for American Indian or Alaskan Native, 136 for Latinxs, 127 for Native Hawaiian/Other Pacific Islanders, 111 for Whites, and 92 people for Asians.¹² The COVID-19 infection rate is highest for Native Hawaiian/Other Pacific Islanders, who have 8,636 infections per 100,000 people, while American Indian or Alaskan Native have 7,760 infections, Latinxs have 7,112 infections, Blacks have 5,436 infections, Whites have 4,181 infections, and Asians have 2,926 infections.¹³ These disparities in infections and deaths have been associated with structural issues, including employment, housing, and lack of access to health care.¹⁴ Not everyone has

¹² *COVID-19 Racial Data Tracker*, The Atlantic (last visited May 21, 2021), available at <https://covidtracking.com/race>.

¹³ *Id.*

¹⁴ Lisa Dubay et al., *How Risk of Exposure to the Coronavirus at Work Varies by Race and Ethnicity and How to Protect the Health and Well-Being of Workers and Their Families*, Urb. Inst. (Dec. 2020), available at <https://www.urban.org/sites/default/files/publication/103278/how-risk-of-exposure-to-the-coronavirus-at-work-varies.pdf>; Ruqaiyah Yearby & Seema Mohapatra, *Law, Racism and the COVID-19 Pandemic*, 7 J.L. & BIOSCIENCES 1, 1–20 (June 29, 2020); Emily A. Benfer et al., *Eviction, Health Inequity, and the Spread of COVID-19: Housing Policy as a Primary Pandemic Mitigation Strategy*, J. URB. HEALTH (2021), available at <https://link.springer.com/article/10.1007/s11524-020-00502-1>; Emily A. Benfer, Seema Mohapatra, Lindsay Wiley & Ruqaiyah Yearby, *Health Justice Strategies to Combat the Pandemic: Eliminating Discrimination, Poverty, and Health Inequities During and After COVID-19*, 19 YALE J. HEALTH POL'Y L. & ETHICS 122, 122–171 (2020); Charles Taylor, Christopher Boulos, & Douglas Almond, *Livestock plants and COVID-19 transmission*, PROC. NAT'L ACADE. SCI. U.S. 1–2 (2020), available at <https://www.pnas.org/content/early/2020/11/25/2010115117.long>.

equal access to the health care system, even after the enactment of the ACA, which was designed to improve access to care through near-universal coverage, and COVID-19 economic relief laws, which provided COVID-specific and general health insurance measures meant to facilitate and maintain coverage. For example, undocumented immigrants in the United States cannot enroll in health insurance under the ACA,¹⁵ and many forgo care for fear of punitive immigration policies,¹⁶ such as increased Immigration and Customs Enforcement attention.¹⁷ Although the Coronavirus Aid, Relief, and Economic Security Act (CARES Act)¹⁸ provides Medicaid coverage for COVID-19 related testing and treatment, it did not fix these problems, in part because it does not cover undocumented immigrants or all workers in health care settings.¹⁹ In addition, home care workers, who are predominantly immigrants, are not covered by the CARES Act because home care industry advocates argued that there would be a worker shortage if home health workers were included.²⁰

¹⁵ See Medha D. Makhoul, *Health Justice for Immigrants*, 4 U. PA. J.L. & PUB. AFFS. 235 (2019).

¹⁶ Wendy E. Parmet, *Trump's immigration policies will make the coronavirus pandemic worse*, STAT NEWS (Mar. 4, 2020), available at <https://www.statnews.com/2020/03/04/immigration-policies-weaken-ability-to-fight-coronavirus/>.

¹⁷ See Wendy E. Parmet, *In the Age Of Coronavirus, Restrictive Immigration Policies Pose a Serious Public Health Threat*, HEALTH AFFS. (April 18, 2020), available at <https://www.healthaffairs.org/doi/10.1377/hblog20200418.472211/full/>.

¹⁸ Coronavirus Aid, Relief, and Economic Security Act, Pub. L. No. 116-136, 134 Stat. 281 (2020).

¹⁹ *Id.*

²⁰ See Andrew Donlan, *'I Deserve to Be Respected': Home Care Workers Make Emotional Plea for Better Treatment*, HOME HEALTH CARE NEWS (Apr. 15, 2020). Some home care companies have voluntarily implemented paid sick leave, and bonus pay, but not all. *Id.* Thus, many home care workers who may live in poverty, may not have health insurance, and work in close contact with those most likely to contract COVID-19 without protective gear, are exempted from additional pay and paid sick leave. *Id.*

A handful of statutes facilitate the federal response to a national emergency, laws that assume and depend on centralized dissemination of federal expertise, supplies, and funding, combined with state operationalization of the emergency response on the ground. The Secretary of Health and Human Services (HHS) declared the first COVID-19 public health emergency (PHE) effective January 27, 2020 under the Public Health Service Act. The PHE triggered authority for HHS to issue emergency grants, enter into contracts, access emergency funds, and increase regulatory flexibility and expires after three months if not renewed. Effective March 1, 2020, the President declared a national emergency under the National Emergencies Act, which made additional federal money and administrative support available.²¹ Together, these two emergency declarations authorized the HHS Secretary to issue emergency-related Section 1135 waivers under the Social Security Act (SSA). Yet the novel coronavirus response was marked by failure to coordinate on nearly every dimension of the emergency, deepening existing health care disparities and opening up new ones.

1.2.1 Current Environment

1.2.1.1 Testing

As noted above, many groups have experienced barriers to accessing COVID-19 testing, treatment, and vaccines. Numerous stories demonstrate examples of racial and ethnic minority communities not receiving equal access to testing. In Michigan, a statewide task force did not focus on race or expand testing in predominantly Black communities until late April.²² By that time, African Americans accounted for 33 percent of all COVID-19 infections and 41 percent of deaths, although they represent only

²¹ 85 Fed. Reg. 15337 (March 13, 2020).

²² Robert Samuels, Aaron Williams, Tracy Jan, & Jose A. Del Real, *This is What Happens to Us: How U.S. Cities Lost Precious Time to Protect Black Residents from the Coronavirus*, WASH. POST (June 3, 2020), available at <https://www.washingtonpost.com/graphics/2020/politics/coronavirus-race-african-americans/>.

14 percent of the population.²³ The predominantly Black city of Gary, Indiana got a mobile testing site after the state revealed that the Black community accounted for 20 percent of all COVID-19 deaths, although they only represented 10 percent of the population.²⁴ Yet, after two weeks, the mobile site moved to another city.²⁵ In another example, the “[p]redominantly [B]lack north St. Louis got its first testing site April 2, three weeks after the first sites went up in the suburbs,” and the “information campaign targeting [B]lack residents did not start until a week after that”; the first 12 COVID-19 deaths were among Black people.²⁶ According to Dr. Will Ross, the chairman of the St. Louis health advisory board making decisions about the area’s COVID-19 response, Black lives were unnecessarily lost.²⁷ In each of these examples, “race neutral” decisions by the government regarding testing sites ignored the fact that Black communities, which would predictably be most impacted by COVID-19, lacked access. This was exacerbated by the national shortage of testing supplies. Hospitals serving predominantly White and wealthy areas were able to secure ventilators and testing materials, as well as stockpile protective equipment in St. Louis, MO, Merrillville, IN, and Nashville, TN.²⁸

1.2.1.2 Treatment

A number of stories have documented racial and ethnic minority people being turned away from treatment. In one case, a Black

²³ *COVID-19 Has Already Killed More Detroiters than Homicides Have in the Past Two Years*, FOX 2 DETROIT (Apr. 16, 2020), available at <https://www.fox2detroit.com/news/covid-19-has-already-killed-more-detroiters-than-homicides-have-in-the-past-two-years-combined>.

²⁴ Samuels, Williams, Jan, & Del Real, *supra* note 22.

²⁵ *Id.*

²⁶ *Id.*

²⁷ *Id.*

²⁸ *Id.* Blake Farmer, *Long-Standing Racial and Income Disparities Seen Creeping Into COVID-19 Care*, National Public Radio (NPR) – Nashville Public Radio & Kaiser Health Network (Apr. 16, 2020), available at <https://khn.org/news/covid-19-treatment-racial-income-health-disparities/>.

teacher, Rana Zoe Mungin, was twice denied a COVID-19 test and her symptoms were dismissed by an emergency medical technician (EMT) as a panic attack.²⁹ She later passed away from COVID-19 at Brooklyn's Brookdale Hospital. However, her case was not singular. Deborah Gatewood, a 63-year-old Detroit health care worker, was turned away four times with COVID-19 symptoms from Beaumont Hospital, where she had worked for 31 years.³⁰ Other cases of Black people being turned away from care or released to family instead of being treated, and later dying, include Reginald Relf, a 50-year-old Chicago engineer,³¹ and Gary Fowler, a 56-year-old Detroit man.³² Research suggests that Black people visiting "hospitals with COVID-19 symptoms in February and March were less likely to get tested or treated than White patients."³³

1.2.1.3 Essential Workers and PPE

Racial and ethnic minorities are disproportionately employed as essential workers, with Black Americans most likely to be

²⁹ Arielle Mitropoulos & Mariya Moseley, *Beloved Brooklyn Teacher, 30, Dies Of Coronavirus After She Was Twice Denied A COVID-19 Test*, ABC NEWS (April 28, 2020), available at <https://abcnews.go.com/Health/beloved-brooklyn-teacher-30-dies-coronavirus-denied-covid/story?id=70376445>; Shamar Walters & David K. Li, *New York City teacher dies from COVID-19 after she was denied tests, Family Says*, NBC NEWS (April 29, 2020), available at <https://www.nbcnews.com/news/us-news/new-york-city-teacher-dies-covid-19-after-she-was-n1195516>.

³⁰ John Eligon & Audra D.S. Burch, *Questions of Bias in Covid-19 Treatment Add to Mourning for Black Families*, N.Y. TIMES (May 20, 2020), available at <https://www.nytimes.com/2020/05/10/us/coronavirus-african-americans-bias.html>; Janelle Griffith, *Detroit health care worker dies after being denied coronavirus test 4 times, daughter says*, NBC NEWS (Apr. 27, 2020), available at <https://www.nbcnews.com/news/us-news/detroit-health-care-worker-dies-after-being-denied-coronavirus-test-n1192076>.

³¹ Eligon & Burch, *supra* note 30.

³² Jericka Duncan, *Detroit Man with Virus Symptoms Dies After 3 ERs Turn Him Away, Family Says: "He Was Begging For His Life,"* CBS NEWS (April 22, 2020), available at <https://www.cbsnews.com/news/coronavirus-detroit-man-dead-turned-away-from-er/>.

³³ Eligon & Burch, *supra* note 30.

categorized as frontline or essential workers.³⁴ In the health care industry, “Black workers are about 50% more likely to work in the healthcare and social assistance industry and 40% more likely to work in hospitals, compared with white workers.”³⁵ Essential workers, especially racial and ethnic minority essential workers, have disproportionately been exposed to COVID-19 in the workplace because of the failure of emergency preparedness laws and policies to provide support for workers to stay at home when they or family members are sick with COVID-19. Research shows that without paid sick leave, working people are 1.5 times more likely to go to work with a contagious disease and three times more likely to go without

³⁴ See Petition for Emergency Rulemaking & Actions to Allocate, Finance & Compel the Manufacture of Personal Protective Equipment & Other Critical Materials to Safeguard Frontline Workers in the COVID-19 Crisis Pursuant to the Defense Production Act, Amalgamated Transit Union et al. to U.S. Dep’t of Health & Hum. Servs. & U.S. Dep’t of Homeland Sec. (Aug. 11, 2020), available at <https://biologicaldiversity.org/programs/energy-justice/pdfs/2020-08-11-APA-Petition-re-PPE-with-AFL.pdf> (citing Devan Hawkins, *The Coronavirus Burden is Falling Heavily on Black Americans. Why?*, GUARDIAN (Apr. 16, 2020), available at <https://www.theguardian.com/commentisfree/2020/apr/16/black-workers-coronavirus-covid-19>; and *Labor Force Statistics from the Current Population Survey*, U.S. Bureau of Labor Statistics (Jan. 2021), available at <https://www.bls.gov/cps/cpsaat18.htm>).

³⁵ Petition of Amalgamated Transit Union et al. for Emergency Rulemaking, *infra* note 45, at 7. It is unclear how many essential workers have been infected with COVID-19 and died because the federal government and some state governments have not required employers to report this information. See David Michaels, *OSHA’s ‘Absurd Reinterpretation’ of a Regulation Regarding Workers and Covid-19*, STAT NEWS (Nov. 24, 2020), available at <https://www.statnews.com/2020/11/24/osha-absurd-reinterpretation-regulation-workers-covid-19/>; A. Pattani et al., *OSHA Let Employers Decide Whether to Report Healthcare Worker Deaths. Many Didn’t*, KAISER HEALTH NEWS (Nov. 30, 2020), available at <https://khn.org/news/article/osha-let-employers-decide-whether-to-report-health-care-worker-deaths-many-didnt/>; Brianne Pfannenstiel, *Iowa officials won’t disclose coronavirus outbreaks at meatpacking plants unless media asks*, DES MOINES REGISTER (May 28, 2020), available at <https://www.desmoinesregister.com/story/news/politics/2020/05/27/iowa-wont-disclose-covid-19-outbreaks-businesses-unless-media-asks-kim-reynolds/5267413002/>; P. Chidambaram et al., *Racial and Ethnic Disparities in COVID-19 Cases and Deaths in Nursing Homes*, Kaiser Family Foundation (2020), available at <https://www.kff.org/coronavirus-covid-19/issue-brief/racial-and-ethnic-disparities-in-covid-19-cases-and-deaths-in-nursing-homes/>.

medical care compared to those with paid sick days.³⁶ This increases workplace exposure of infectious diseases like COVID-19.³⁷

The full account of the number of U.S. health care workers impacted by COVID-19 is unclear, as data collection has been uneven at best. The Occupational Safety and Health Administration (OSHA) and many states have either not required employers to record and report employees' COVID-19 infections and deaths, or refused to release the information, which is necessary for contact tracing and surveillance.³⁸ For example, nursing home residents account for eight percent of all COVID-19 cases and more than 40 percent of all COVID-19 deaths in the United States, but there is no data regarding how many nursing home workers have been infected or died, because OSHA has deferred to nursing homes the decision whether to report infections and deaths.³⁹

An additional risk factor is that many health care workers who have requested access to PPE or spoken out about the lack of PPE have not only received no PPE, but many were disciplined or fired.⁴⁰ For example, a registered nurse and colleagues filed multiple OSHA complaints regarding workplace safety violations at a Minnesota

³⁶ Emily A. Benfer & Lindsay F. Wiley, *Health Justice Strategies to Combat COVID-19: Protecting Vulnerable Communities During a Pandemic*, HEALTH AFFS. (March 19, 2020), available at <https://www.healthaffairs.org/doi/10.1377/hblog20200319.757883/full/>.

³⁷ Cf. Sandra Crouse Quinn et al., *Racial Disparities in Exposure, Susceptibility, and Access to Health Care in the US H1N1 Influenza Pandemic*, 101 AM. J. PUB. HEALTH 285, 285–93 (2011); Supriya Kumar et al., *The Impact of Workplace Policies and Other Social Factors on Self-Reported Influenza-Like Illness Incidence During the 2009 H1N1 Pandemic*, 102 AM. J. PUB. HEALTH 132, 134, 135–39 (2012).

³⁸ See Michaels, *supra* note 35; Pattani et al., *supra* note 35; Pfannenstiel, *supra* note 35.

³⁹ See Chidambaram et al., *supra* note 35; Pattani, *supra* note 35.

⁴⁰ See, e.g., Noam Scheiber & Brian M. Rosenthal, *Nurses and Doctors Speaking Out on Safety Now Risk Their Job*, N.Y. TIMES (April 27, 2020), available at <https://www.nytimes.com/2020/04/09/business/coronavirus-health-workers-speak-out.html>.

hospital.⁴¹ Although the hospital was eventually fined for failing to comply with the respiratory standard, the nurse was fired and the licensure board is investigating his conduct.⁴² In another example, an emergency physician in Washington state was fired for publicly identifying the hospital's failure to provide staff with adequate PPE and other gaps in COVID-19 protections.⁴³ Retaliation and lack of PPE was so problematic that several medical societies, including the Council of Medical Specialty Societies that represents 800,000 physicians, issued statements urging the government to ensure that health care workers had adequate PPE.⁴⁴ Then, on August 11, 2020, over 30 leading labor unions and environmental groups representing over 20 million workers and members, including the American Federation of Labor and Congress of Industrial Organizations (AFL-CIO) and the Service Employees International Union (SEIU), submitted an Emergency Rulemaking Petition for access to PPEs "pursuant to the Administrative Procedure Act, 5 U.S.C. § 551, et seq. demanding" that the federal government, including HHS, invoke delegated authorities under the Defense Production Act (DPA) to manufacture and allocate PPE for the protection of essential workers.⁴⁵ When essential workers' access to PPE did not improve and HHS did not use its powers to increase access to PPE,⁴⁶ on October 8, 2020 the same 30 leading labor unions and environmental groups filed a complaint

⁴¹ Ryan Basen, *Fired Nurse Faces Board Review for Wearing Hospital Scrubs*, MEDPAGE TODAY (Dec. 3, 2020), available at <https://www.medpagetoday.com/nursing/nursing/90015>; Sheila Mulrooney Eldred, *Nurses Disciplined, Fired for Wearing Hospital-Issued Scrubs*, MEDSCAPE (May 26, 2020), available at <https://www.medscape.com/viewarticle/931090>.

⁴² *Id.*

⁴³ Sheila Mulrooney Eldred, *Medical Societies Issue Bold Statement of Physician Support*, MEDSCAPE (Apr. 5, 2020), available at <https://www.medscape.com/viewarticle/928159>.

⁴⁴ *Id.*

⁴⁵ Petition of Amalgamated Transit Union et al. for Emergency Rulemaking, *supra* note 35; see also Compl., Amalgamated Transit Union et al. v. Azar, No. 20CV02876 (D.D.C. Oct. 8, 2020).

⁴⁶ See, e.g., Andrew Jacobs, *Despite Claims, Trump Rarely Used Wartime Law in Battle Against Covid*, N.Y. TIMES (Sept. 22, 2020), available at <https://>

for declaratory and injunctive relief in the U.S. District Court for the District of Columbia.⁴⁷ Meanwhile, health care workers continue to be infected, which has harmed racial and ethnic minorities. For example, a National Nursing Union report shows that nurses of Filipino descent comprise 31.5 percent of nurse deaths from COVID-19, but only account for four percent of the nursing population.⁴⁸

1.2.1.4 Vaccines

In the St. Louis region, where the first person to die from COVID-19 was a Black nurse,⁴⁹ data shows that 71 percent of those vaccinated were White people, while only 8 percent of Black people were vaccinated.⁵⁰ This is also true in Chicago, where Black people make up 30 percent of the population, 60 percent of the COVID-19 cases, but only 19 percent of those that have been vaccinated.⁵¹ As with testing and treatment, many vaccination sites are located in rich, White neighborhoods.⁵² Even when they are located in

www.nytimes.com/2020/09/22/health/Covid-Trump-Defense-Production-Act.html.

⁴⁷ Compl., Amalgamated Transit Union et al. v. Azar, *supra* note 45.

⁴⁸ Allana Akhtar, *Filipinos make up 4% of nurses in the US, but 31.5% of nurse deaths from COVID-19*, BUS. INSIDER (Sept. 29, 2020), available at <https://www.businessinsider.com/filipinos-make-up-disproportionate-covid-19-nurse-deaths-2020-9>.

⁴⁹ Rebecca Rivas, *Nurse Judy Wilson-Griffin is the first COVID-19 death in St. Louis Region*, ST. LOUIS AM. (Mar. 20, 2020), available at http://www.stlamerican.com/news/local_news/nurse-judy-wilson-griffin-is-first-covid-19-death-in-st-louis-region/article_1d422bea-6b06-11ea-83e1-17bbd703c8fb.html.

⁵⁰ KMOV.com Staff, *White population makes up vast majority of those vaccinated in the St. Louis area, causing alarm*, KMOV4 (Feb. 12, 2021), available at https://www.kmov.com/news/white-population-makes-up-vast-majority-of-those-vaccinated-in-st-louis-area-causing-alarm/article_8fdc9f8c-6d7b-11eb-9838-1f05d6020493.html.

⁵¹ Gloria Oladipo, *How Chicago's vaccine rollout is inhibited by long-standing inequality*, GUARDIAN (Feb. 5, 2021), available at <https://www.theguardian.com/us-news/2021/feb/05/chicago-blacks-latinos-vaccine-distribution>.

⁵² *Id.* Many have highlighted the fact that racial and ethnic minorities may be hesitant to getting the vaccine because of mistrust of the health care system; however, the problem is structural.

predominantly Black and Latino neighborhoods, Black and Latino residents have not been able to access vaccine appointments and doses.⁵³ For example, “Dallas County’s rollout plans for the vaccine included an inoculation hub in a neighborhood that is largely African-American and Latino. But when the sign-up website went live, the link speedily circulated throughout white, wealthier districts in North Dallas.”⁵⁴ When county officials tried to hold the doses for racial and ethnic minorities residing in these neighborhoods, the state threatened to withhold the county’s supplies.⁵⁵ In Prince George’s County, Maryland, a predominantly Black area, a majority of the initial vaccine doses were given to Montgomery County residents who were White.⁵⁶ Before Prince George’s County residents could register for appointments online, Montgomery County residents were able to register.⁵⁷

In the South, a majority of vaccine allocation sites are situated in predominantly White neighborhoods, and a study of counties in Pittsburgh found that Black residents would need to travel farther than White residents to get a vaccine.⁵⁸ Even when vaccine allocation prioritizes essential workers and the elderly, many racial and ethnic minorities and those with disabilities have been left out. For example, in Alabama, the vaccine has been allocated to those who

⁵³ Abby Goodnough & Jan Hoffman, *The Wealthy Are Getting More Vaccinations, Even in Poorer Neighborhoods*, N.Y. TIMES (Feb. 4, 2021), available at <https://www.nytimes.com/2021/02/02/health/white-people-covid-vaccines-minorities.html>.

⁵⁴ *Id.*

⁵⁵ *Id.*

⁵⁶ Tracee Wilkins, *Many Vaccines Given in Prince George’s Going to People that Live Outside the County*, NBC Washington (Jan. 21, 2021), available at <https://www.nbcwashington.com/news/local/prince-georges-county/many-vaccines-given-in-prince-georges-going-to-people-who-live-outside-the-county/2548775/>.

⁵⁷ *Id.*

⁵⁸ Sean McMinn et al., *Across the South COVID-19 Vaccine Sites Missing From Black and Hispanic Neighborhoods*, WBFO NPR (Feb 5, 2021), available at <https://www.npr.org/2021/02/05/962946721/across-the-south-covid-19-vaccine-sites-missing-from-black-and-hispanic-neighbor>.

are 75 years or older.⁵⁹ However, at least 83 percent of Alabama's Black population does not meet this age requirement for vaccine.⁶⁰ More specifically, "in 47 of the state's 67 counties, life expectancy among Black people is less than 75 years old."⁶¹

1.2.1.5 Role of Medicaid

Throughout 2020, the novel coronavirus emergency response was marked by governmental failure to coordinate at the federal level. Governors attempted to fill the void, but state containment policies have been wildly varied. Studies now show that this heterogeneity resulted in worse outbreaks in the states with less stringent disease containment measures.⁶²

Medicaid is a classic cooperative federalism program, a federal program run jointly with states and a critical part of any emergency response. Medicaid is a key feature in the regular health care landscape, insuring nearly one-quarter of all Americans and providing necessary care for low-income individuals, including children, parents, people with disabilities, and the elderly, including many nursing home residents. In the usual course, Medicaid offers federal funds to states to cover medical care, with funding increased in 2010 under the ACA to expand Medicaid coverage to other nonelderly adults. In 2012, the U.S. Supreme Court held that mandatory expansion was unconstitutionally coercive in *National Federation of Independent Business v. Sebelius*, effectively

⁵⁹ Naomi Thomas & Deidre McPhillips, *More than 90% of Alabama's Black Population Lived in a County where Life Expectancy Didn't Meet Eligibility, CNN Analysis Shows*, CNN (Feb. 10, 2021), available at <https://www.cnn.com/2021/02/10/health/alabamas-black-population-vaccine-eligibility/index.html>.

⁶⁰ *Id.*

⁶¹ *Id.*

⁶² Thomas Hale et al., *Variation in US states' responses to COVID-19*, University of Oxford (Dec. 2020), available at <https://www.bsg.ox.ac.uk/research/publications/variation-us-states-responses-covid-19>.

making state expansion of eligibility optional.⁶³ Even with this implementation hurdle, Medicaid expansion has narrowed persistent coverage gaps for low-wage workers, who are much less likely to be offered employer sponsored insurance, and narrowed coverage gaps for people of color. For example, between 2013–2017, Medicaid expansion decreased the coverage gap between Black and White populations from 11 to 5.3 percentage points, and between Hispanic and non-Hispanic White populations from 25.4 to 16.6 percentage points.⁶⁴

Federal law prescribes benefits and protections that secure beneficiary coverage and care as well as protection for state budgets. To receive federal funds, states agree to follow federal rules establishing Medicaid’s purpose and structure. Statutory flexibilities also enable states to make policy choices that further the purposes of the Medicaid program and offer more than federal law requires, such as adding prescription drug coverage. Many state options can be exercised by submitting a state plan amendment (SPA), which entails minimal review by HHS. States also may apply for statutory waivers from the Secretary of HHS under SSA Section 1115, which authorizes the Secretary to approve state proposals that seek to further the purposes of the Medicaid program through “demonstration projects” of limited duration.⁶⁵

Federal Medicaid funding is an entitlement for the states. The Federal Medical Assistance Percentage (FMAP) defines the federal share of Medicaid funding, which by law cannot be less

⁶³ Nat’l Fed’n of Indep. Bus. v. Sebelius, 567 U.S. 519 (2012). See discussion in Section 1.3 of this chapter regarding the impact of expanding Medicaid on diverse populations.

⁶⁴ A. Chaudery et al., *Did the Affordable Care Act Reduce Racial and Ethnic Disparities in Health Insurance Coverage?*, Commonwealth Fund (2019), available at <https://www.commonwealthfund.org/publications/issue-briefs/2019/aug/did-ACA-reduce-racial-ethnic-disparities-coverage>.

⁶⁵ *Medicaid 1115 Waivers By State*, National Conference of State Legislatures (Aug. 30, 2019), available at <https://www.ncsl.org/research/health/medicaid-1115-waivers-by-state.aspx>.

than 50 percent and can be as high as 83 percent for most services, based in part on the per capita income of each state.⁶⁶ States with lower incomes relative to the national average receive the greatest federal match. The federal match for the expansion population is higher than other categories of eligibility at 90 percent. Medicaid is countercyclical, as the same events that spark increased enrollment also cause reduced state tax revenue and put pressure on states to cut enrollment, services, or payment to reduce their costs. States must have balanced budgets, so they rely on the federal government's ability to deficit spend during economic downturns. Congress often temporarily increases the federal match by several percentage points (enhanced FMAP) to help states weather economic crises and includes "maintenance of effort" (MOE) requirements so states cannot limit enrollment or eligibility during an emergency.

Congress enhanced federal funding under Section 6008 of the Families First Coronavirus Response Act (Families First Act) contingent on state adherence to MOE requirements.⁶⁷ The Families First Act also allows states to cover COVID-19 testing and related services for uninsured people with full federal funding. Every state and the District of Columbia took up the enhanced federal match and are subject to the MOE.

During a PHE, extra Medicaid flexibility becomes available, including: (1) Section 1135 waivers may be approved by HHS to make health care services and providers more freely available; (2) states with Section 1915(c) waivers for home- and community-based long term care services and supports, which address avoidable institutional care, can amend waivers with an "Appendix K" emergency preparedness response request; (3) Disaster Relief SPAs allow limited-duration changes to state plans to improve access and coverage during a PHE; and (4) Section 1115 authority may expand,

⁶⁶ 42 C.F.R. § 433.10.

⁶⁷ Families First Coronavirus Response Act of 2020, Pub. L. No. 116-127, 134 Stat. 178 (2020).

allowing the Secretary to waive certain Medicaid provisions to allow states to implement temporary PHE-related demonstrations.⁶⁸ Every state and the District of Columbia used a combination of these emergency flexibilities to respond to the PHE.

Section 1135 waivers, disaster relief SPAs, and the Families First Act's enhanced FMAP expire when the PHE ends. Without renewals, states will lose many of the Medicaid tools they are using to respond to COVID-19.

1.2.2 Trends for the Next Year

Unfortunately, the recent vaccine rollout has not inspired confidence that the U.S. health care system will overcome disparities in access to COVID-19 care correlated with socioeconomic status, race and ethnicity, disability status, immigration and language status, gender identity and sexual orientation, and/or geographic location.

Disparities in access to quality care have long structural histories deeply embedded not only in health care institutions and the health care system writ large, but also in other societal institutions. Laws and policies that once mandated, then permitted, racial segregation in health care facilities and in residential mortgage lending, for instance, combined to structurally limit access to care for residents of low-income, hypersegregated neighborhoods. First, low-income Black patients were excluded from taxpayer-funded health care facilities in their own neighborhoods, worsening population health outcomes. Then, when required to integrate, hospitals in those neighborhoods began to move to largely White suburban neighborhoods, taking affiliated physicians with them. Hospitals and providers who remained were increasingly overstrained, causing care available to neighborhood residents to deteriorate over time,

⁶⁸ See *Medicaid Emergency Authority Tracker: Approved State Actions to Address COVID-19*, Kaiser Family Foundation (Mar. 1, 2021), available at <https://www.kff.org/coronavirus-covid-19/issue-brief/medicaid-emergency-authority-tracker-approved-state-actions-to-address-covid-19/>.

and deepening health care disparities that originated in intentional segregation.⁶⁹

Such histories will not be easy to overcome. Health care lawyers are well-placed to counsel health care institutions about options that avoid reinforcing existing health care disparities or actively counter them, whether in health care labor and employment practices or in protocols for allocating limited inpatient resources under pandemic conditions.⁷⁰ Policies and practices can incorporate steps to prevent health care disparities such as the significant gap in antibiotic treatment between Black Medicare patients admitted to hospitals for pneumonia and other Medicare patients.⁷¹ Communities freshly sensitized to structural inequities may have enhanced expectations around disparities for tax-exempt hospitals' next periodic community health needs assessments (CHNAs). Virtually every decision on which health care lawyers will counsel institutional clients during the pandemic has a health care disparities dimension, whether obvious or beneath the surface.

At the federal level, the Biden administration has strongly signaled that COVID-19 is the first policy priority. Any new pandemic relief legislation is likely to rely on the usual structure of a federal/state partnership, but the Biden administration initiated a number of executive actions upon entering office to address the

⁶⁹ See Yearby & Mohapatra, *supra* note 14, at 11–13; Ruqaiijah Yearby, *Racial Disparities in Health Status and Access to Healthcare: The Continuation of Inequity in the United States Due to Structural Racism*, 77 AM. J. ECON. & SOC. 1113, 1129–38 (2018).

⁷⁰ See generally *Examining How Crisis Standards of Care May Lead to Intersectional Medical Discrimination Against COVID-19 Patients*, Center for Public Representation (Feb. 12, 2021), available at <https://www.centerforpublicrep.org/wp-content/uploads/FINAL-Intersectional-Guide-Crisis-Care-PDF.pdf>; Rene Bowser, *Race & Rationing*, 25 HEALTH MATRIX 87 (2015).

⁷¹ Cf. John Z. Ayanian et al., *Quality of Care by Race & Gender for Congestive Heart Failure & Pneumonia*, 37 MED. CARE 1260, 1260–61, 1265 (finding that only 32 percent of Black patients with pneumonia were given antibiotics within six hours of admission, compared to 53 percent of all others) (discussed in Yearby & Mohapatra, *supra* note 14, at 14).

pandemic in a more strongly centralized fashion. For example, a set of Executive Orders issued on January 21, 2021 indicates the administration intends to exercise the executive power that federal law already facilitates in a PHE to distribute PPE, issue better guidance on vaccine priority, and use the Defense Production Act to fill supply chain needs.⁷² The administration is also centering health equity in its response to COVID and in other health policy.⁷³

The mechanism by which relief bills are enacted affects their substance. Budget reconciliation requires fewer Senate votes but can address only the narrower subject matter of financial issues (spending or taxing). The more traditional legislative negotiation process results in bills with broader reach for health reform, economic reform, and other pressing policy matters but require more political negotiation and compromise. Budget reconciliation looks to be the preliminary path. New legislation will likely facilitate a continued enhanced FMAP for Medicaid, which should be extended beyond the PHE so states can continue economic recovery.

While bills are being negotiated, the Biden administration has begun work on prompt and equitable vaccine distribution as well as attempting to improve access to care for those who become seriously ill with COVID-19. The “National Strategy for the COVID-19 Response and Pandemic Preparedness” reinvigorated the presidential COVID-19 task force and creates a new Health Equity Task Force.⁷⁴ Renewed PHE and National Emergency declarations facilitate the

⁷² See *Executive Order on a Sustainable Public Health Supply Chain*, White House (Jan. 21, 2021), available at <https://www.whitehouse.gov/briefing-room/presidential-actions/2021/01/21/executive-order-a-sustainable-public-health-supply-chain/>.

⁷³ *Executive Order on Ensuring an Equitable Pandemic Response and Recovery*, White House (Jan. 2021), available at <https://www.whitehouse.gov/briefing-room/presidential-actions/2021/01/21/executive-order-ensuring-an-equitable-pandemic-response-and-recovery/>.

⁷⁴ *National Strategy for the COVID-19 Response and Pandemic Preparedness*, White House (Jan. 21, 2021), available at https://cdn.vox-cdn.com/uploads/chorus_asset/file/22248564/National_Strategy_for_the_COVID_19_Response_and_Pandemic_Preparedness_press.pdf.

continuation of Section 1135 and Section 1115 waivers that states depend on for response efforts.

1.2.3 What Health Lawyers Need to Know Now

- Health care disparities result from deep structural and institutional histories as well as from individual bias, and addressing both requires intention and persistence on the part of health care providers and institutions.
- ZIP code influences health and access to care, which is exacerbated by factors such as socioeconomic status, race, ethnicity, disability, immigration status, language, gender, and LGBTQ+ identity.
- Avoiding discriminatory practices—even if neutral on their faces—that create liability and/or exacerbate the public health emergency will be important compliance matters for health care providers.
- Triage, or crisis standard of care, policies that are used during a spike in hospitalizations must not engage in discriminatory reasoning or rationing, such as protocols based on the basis of age or disability alone.
- Health care workforce relations may be strained by the long crisis, especially where policies or practices (even if facially neutral) have disproportionately affected lower-income and lower-status workers, potentially leading to more labor organizing and/or employment discrimination claims.
- In an era of increasing awareness of structural inequities, both regulators and local communities may have enhanced expectations for tax-exempt hospitals' community benefit compliance and corporate citizenship.
- While telehealth has been hailed both as a way to avoid infection risk during the pandemic and an equity-enhancing

measure, it should be implemented carefully to avoid further deepening health care disparities for older, more rural, and/or lowest-income populations without access to smart phones or broadband, and to protect patient privacy.

- Additional executive orders and subregulatory policies are likely to alter the Trump administration's approach to the PHE.
- Further PHE renewals and National Emergency declarations may issue and will impact the regulatory flexibilities states exercise as well as the flow of federal money to health care providers.
- New relief bills may continue an enhanced federal match in Medicaid, increase unemployment insurance, extend paid sick leave, and other more permanent workforce-oriented policies.

1.3 Ongoing Expansion of Medicaid Eligibility

As noted above, Medicaid is not only a critical facet of emergency response but also a major part of the regular health care landscape, insuring more than 74 million Americans and providing necessary care for low-income individuals.⁷⁵ Prior to the beginning of the pandemic, 36 states and the District of Columbia had expanded Medicaid eligibility under the ACA.⁷⁶ The ACA positioned state Medicaid and Children's Health Insurance (CHIP) programs to respond better to emergencies by expanding coverage and facilitating streamlined eligibility and enrollment systems. People unemployed during the pandemic qualify more easily for Medicaid in states that have expanded coverage. However, millions

⁷⁵ *September 2020 Medicaid & CHIP Enrollment Data Highlights*, CMS (Jan. 15, 2021), available at <https://www.medicaid.gov/medicaid/program-information/medicaid-and-chip-enrollment-data/report-highlights/index.html>.

⁷⁶ *Status of State Medicaid Expansion Decisions: Interactive Map*, Kaiser Family Foundation (Feb. 22, 2021), available at <https://www.kff.org/medicaid/issue-brief/status-of-state-medicaid-expansion-decisions-interactive-map/>.

of people fall through holes in the safety net because some states had not chosen to expand Medicaid,⁷⁷ and some states implemented policies that limit Medicaid's availability under guidance crafted by the Trump administration.⁷⁸ These choices are particularly important for people of color, low-income populations, and rural populations, which are infected and dying at higher rates from novel coronavirus, especially when income and exposure are factored into racial disparities.

1.3.1 The Current Environment

The ACA positioned state Medicaid and CHIP programs to be more responsive to changes, like health and economic emergencies, by expanding coverage and facilitating streamlined eligibility and enrollment systems that help to make populations more resilient. People unemployed during the pandemic qualify more easily for Medicaid in states that have expanded eligibility. However, as of April 2021, 12 states have not opted in to Medicaid expansion,⁷⁹ two states (Oklahoma and Missouri) are in the process of implementing expansion and so eligibility has not begun, and other states implemented policies that limit Medicaid's reach during the four years of the Trump administration.

From day one, the Trump administration wanted to eradicate the ACA or to diminish its reach if Congress did not repeal it.⁸⁰ The administration discouraged Medicaid expansion and encouraged policies that thwart the statutory protections in Medicaid that make it uniquely reliable for low-income people and for states.

⁷⁷ *Id.*

⁷⁸ See, e.g., Abby Goodnough, *Trump Administration Unveils a Major Shift in Medicaid*, N.Y. TIMES (Jan. 30, 2020), available at <https://www.nytimes.com/2020/01/30/health/medicaid-block-grant-trump.html>.

⁷⁹ *Status of State Medicaid Expansion Decisions: Interactive Map*, Kaiser Family Foundation (Feb. 22, 2021), available at <https://www.kff.org/medicaid/issue-brief/status-of-state-medicare-expansion-decisions-interactive-map/>.

⁸⁰ *Id.*

The controversial and novel policies inviting waivers that allow work requirements⁸¹ and block granting of federal Medicaid funds⁸² are unlawful. Other policies, such as reduced coverage of non-emergency medical transportation and frequent eligibility redeterminations, impeded the program's purpose by weakening coverage and access to care. These policy choices affected Medicaid's emergency safety net role, as the nonexpansion states faced an insurance coverage gap exceeding two million people before the pandemic began, which climbed steeply throughout 2020. HHS approved Section 1115 waivers for states to impose new barriers, with HHS allowing states to impose work reporting requirements, enforceable cost-sharing, more frequent eligibility redetermination, and at the very end, block grant or capped spending for federal Medicaid financing in Tennessee.⁸³ To date, federal courts uniformly have struck down work requirement waiver approvals.⁸⁴ The primary reason is that Medicaid's purpose is to provide medical care, and HHS did not account for the significantly decreased coverage such waivers would cause. Arkansas and New Hampshire were the only states to implement a work requirement demonstration waiver. In Arkansas 18,000 people lost coverage within five months,⁸⁵ while nearly 17,000 stood to lose coverage within two months of New Hampshire's

⁸¹ Executive Order 13765 (Jan. 20, 2017), 82 Fed. Reg. 8351.

⁸² *Medicaid Waiver Tracker: Approved and Pending Section 1115 Waivers by State*, Kaiser Family Foundation (Feb. 25, 2021), available at <https://www.kff.org/medicaid/issue-brief/medicaid-waiver-tracker-approved-and-pending-section-1115-waivers-by-state/>.

⁸³ See, e.g., *Tennessee Medicaid Block Grant Waiver Amendment Approved by Federal Government*, Tennessee Office of the Governor (Jan. 8, 2021), available at <https://www.tn.gov/governor/news/2021/1/8/tennessee-medicaid-block-grant-waiver-amendment-approved-by-federal-government.html>.

⁸⁴ *Medicaid Waiver Tracker: Approved and Pending Section 1115 Waivers by State*, Kaiser Family Foundation (Feb. 25, 2021), available at <https://www.kff.org/medicaid/issue-brief/medicaid-waiver-tracker-approved-and-pending-section-1115-waivers-by-state/>.

⁸⁵ See, e.g., Harris Meyer, *D.C. Circuit nixes Arkansas Medicaid work requirement*, MODERN HEALTHCARE (Feb. 14, 2021), available at <https://www.modernhealthcare.com/legal/dc-circuit-nixes-arkansas-medicaid-work-requirement>.

implementation, which the state's health commissioner suspended before a federal court stayed the waiver.⁸⁶ As of this writing, the Biden administration is beginning to unwind the policies allowing such waivers, the U.S. Supreme Court has removed oral arguments from its calendar, and no state is implementing work requirements because the Families First Act MOE requirements effectively paused such initiatives as they prevent enrollment and result in loss of coverage.

The evidence indicates that Medicaid expansion benefits beneficiaries, providers, and states. More than 400 studies show that Medicaid expansion is a crucial tool in improving both individual and public health.⁸⁷ Medicaid expansion improves social determinants of health such as job and housing stability, and has begun to improve entrenched health disparities. In short, Medicaid expansion improves coverage, access, and health for Black and other communities of color and improves screening, treatment, and outcomes for common cancers, heart disease, and other preventable illnesses. Medicaid expansion also prevents rural hospital closures and helps to stabilize state budgets. In most nonexpansion states, professional organizations support expansion and are seeking to support either ballot initiatives or legislature-initiated expansion.⁸⁸

Nonexpansion states' preexisting health and economic disparities have deepened due to the convergence of the pandemic and the recession. Nonexpansion states' residents tend to depend

⁸⁶ Benjamin D. Sommers et al., *Medicaid Work Requirements—Results from the First Year in Arkansas*, NEW ENG. J. MED. (Sept. 12, 2019), available at <https://www.nejm.org/doi/full/10.1056/NEJMSr1901772>.

⁸⁷ Madeline Guth et al., *The Effects of Medicaid Expansion under the ACA: Updated Findings from a Literature Review*, Kaiser Family Foundation (Mar. 2020), available at <https://www.kff.org/medicaid/report/the-effects-of-medicaid-expansion-under-the-aca-updated-findings-from-a-literature-review/>.

⁸⁸ See, e.g., Christopher Brown, *Medicaid Expansion Ballot Measures Brewing in Three More States*, BLOOMBERG LAW (Jan. 26, 2021), available at <https://news.bloomberglaw.com/health-law-and-business/medicaid-expansion-ballot-measures-brewing-in-three-more-states>.

on sectors that have been affected most by the recession like agriculture, retail, and other low-wage jobs, which usually do not provide employment benefits like health insurance.⁸⁹ These states experience high levels of chronic diseases and other health disparities that exacerbate the impact of the novel coronavirus.⁹⁰ Medicaid's divided, federal/state structure allows states great flexibility, which can be beneficial but also leads to variable coverage and benefits across states, which in turn exacerbates disparities in coverage, access to care, and health outcomes. Medicaid expansion is a priority for improving the short- and long-term health of individuals remaining in the coverage gap and for improving the resilience of vulnerable populations going forward.

1.3.2 Trends for the Next Year

President Biden issued an Executive Order in his second week of office directing HHS to begin taking actions to reinvigorate the ACA.⁹¹ In addition to initiating a federal health insurance exchange special enrollment period, the Executive Order directs HHS and other agencies that regulate health care to review all agency actions that have undermined the ACA and hinder the Medicaid program.⁹² This review will include evaluating regulations, policies, waivers, and any other agency action that undercut the universal coverage goals of the ACA. Biden made it clear that he supports and wants to build upon the ACA during his campaign, and this Executive Order reflects both his health reform philosophy and his immediate focus on the health and economic crisis presented by the

⁸⁹ See, e.g., Gregorio A. Millett et al., *Assessing Differential Impacts of COVID-19 on Black Communities*, 47 ANN. OF EPIDEMIOLOGY 37 (2020), available at <https://doi.org/10.1016/j.annepidem.2020.05.003>.

⁹⁰ See, e.g., *id.*

⁹¹ *Executive Order on Strengthening Medicaid and the Affordable Care Act*, White House (Jan. 28, 2021), available at <https://www.whitehouse.gov/briefing-room/presidential-actions/2021/01/28/executive-order-on-strengthening-medicare-and-the-affordable-care-act/>.

⁹² *Id.*

pandemic. Stabilizing Medicaid will improve the circumstances of disadvantaged populations hit hardest by COVID-19 into the future. Many expect the coverage gap to be addressed through Medicaid expansion in nonexpansion states, expansion of subsidies in the exchanges, or both. Signed on March 11, 2021, the American Rescue Plan Act approved a two-year increased FMAP for states that had not implemented Medicaid expansion, so ballot initiative states Missouri and Oklahoma benefit from the increased federal match in addition to the twelve holdout states.⁹³

Some executive actions are straightforward, and others take time to implement. The Biden HHS issued letters to states rescinding approval of work requirements and revoked the 2018 State Medicaid Director Letter (SMD) titled “Opportunities to Promote Work and Community Engagement Among Medicaid Beneficiaries,” which allowed states to require work or other “community engagement” as a condition of Medicaid eligibility. Medicaid work requirements are not authorized by federal law, and Biden’s January 28 Executive Order states that such policies are harmful in the COVID environment and contrary to the program’s purpose.⁹⁴ HHS’s letters to states rescinding approval for work requirements used this framework.

Fifteen states received HHS approval for demonstration projects that include work requirements, and three states voluntarily withdrew their waivers while four states have had their Section 1115 waivers stayed by federal courts (Arkansas, Kentucky, Michigan, New Hampshire).⁹⁵ Seven other states have waivers pending at HHS that include work requirements. Some of the states, such as Arkansas,

⁹³ American Rescue Plan Act of 2021, Pub. L. 117-2 (2021).

⁹⁴ *Executive Order on Strengthening Medicaid and the Affordable Care Act*, White House (Jan. 28, 2021), available at <https://www.whitehouse.gov/briefing-room/presidential-actions/2021/01/28/executive-order-on-strengthening-medicaid-and-the-affordable-care-act/>.

⁹⁵ *Medicaid Waiver Tracker: Approved and Pending Section 1115 Waivers by State*, Kaiser Family Foundation (Feb. 25, 2021), available at <https://www.kff.org/medicaid/issue-brief/medicaid-waiver-tracker-approved-and-pending-section-1115-waivers-by-state/>.

had expanded Medicaid and focused work requirements on the expansion population, but other states, such as South Carolina, had a work requirement waiver approved without Medicaid expansion.⁹⁶ As the 2018 policy is revoked, HHS will reject demonstration waiver applications seeking to implement work requirements.

When HHS approves waiver applications, the Secretary retains authority to amend or withdraw approval (or eliminate funding) if HHS determines that a waiver or any part of it would no longer be in the public interest or promote Medicaid's objectives. The Biden administration withdrew approval of specific waiver elements, but states can appeal these decisions. All approved demonstration projects contain multiple elements, so efforts to eliminate work requirements and other enrollment barriers are complicated and may require further dialogue with states. HHS may invite states to re-negotiate the waivers to remove work requirements while keeping other provisions intact. States also could terminate waivers granted by the Trump administration voluntarily, which could save time, money, and undue confusion for beneficiaries.

In addition, on January 8, 2021, more than a year after submission, HHS approved the Tennessee block grant waiver amendment application for 10 years.⁹⁷ The Biden administration is likely to withdraw the Healthy Adult Opportunity policy that unlawfully initiated capped spending and revoke approval of the waiver. The legality of the Tennessee waiver will be challenged in federal court if the waiver is not revoked, as Section 1115 does not provide the Secretary authority to waive Section 1903 of the Medicaid Act, which governs the federal matching payments to states.

⁹⁶ *Id.*

⁹⁷ *Tennessee Medicaid Block Grant Waiver Amendment Approved by Federal Government*, Tennessee Office of the Governor (Jan. 8, 2021), available at <https://www.tn.gov/governor/news/2021/1/8/tennessee-medicaid-block-grant-waiver-amendment-approved-by-federal-government.html>.

A complicating factor for any waiver revocation is a late CMS letter to state Medicaid Directors asking them to “amend” all existing waiver approvals with a new appeal review process. The letter purported to create a new appeal process and delayed waiver revocation for nine months.⁹⁸ This letter did not adhere to standard notice and comment processes, which would be necessary for modifying federal regulations such as this appeal process. Nonetheless, it adds to the complexity of the current waiver landscape.

1.3.3 What Health Lawyers Need to Know Now

- Watch for regulatory reviews performed by HHS, CMS, and other sub-agencies that undo Trump-era efforts to undercut the ACA. Such reviews will probably extend beyond Medicaid waivers to commercial insurance markets that must abide by federal rules (such as qualified health plans sold on exchanges).
- Keep an eye on state/federal negotiations to end work requirements; the first state will become a model for others and signal what it is possible for states to keep among their policy preferences.
- Medicaid enrollment is likely to increase during the Biden administration, which should stabilize safety net hospitals and other providers who serve vulnerable populations.
- Community health centers have played an important frontline role during the pandemic and may see increased funding in the near future.

⁹⁸ *Letter from Ctrs. for Medicare & Medicaid Svcs. Admin. Seema Verma to State Medicaid Dirs.*, CMS (Jan. 4, 2021), available at <https://energycommerce.house.gov/sites/democrats.energycommerce.house.gov/files/documents/Pallone%20Wyden%20Ltr%20to%20CMS%201.19.21%20UPDATED.pdf> (attachment to Letter from Rep. Frank Pallone, Jr., & Sen. Ron Wyden to Ctrs. for Medicare & Medicaid Svcs. Admin. Seema Verma (Jan. 19, 2021)).

1.4 The Implications of Value-Based Payment Models for Health Care Equity⁹⁹

At the turn of the 21st century, with U.S. health care spending having tripled as a percentage of the nation's gross domestic product since 1960,¹⁰⁰ both public and private third-party payers sought systemic changes to control health care costs. On the provider/supply side, conventional fee-for-service payment, in which a health care provider is paid for each procedure, test, or office visit they order, incentivizes more care and more expensive care, not necessarily better care. Alternative models could remove such incentives by linking reimbursement to cost savings and care quality metrics.

The ACA included various reforms to facilitate such value-based payment models, such as creating the voluntary Medicare Shared Savings Program's Accountable Care Organization (ACO) model and establishing the Center for Medicare and Medicaid Innovation, which develops new payment and service delivery models. Since the ACA's passage, the number and variety of alternative payment models have proliferated.

Because value-based arrangements factor both the cost of patient care and patient health outcomes into their payment models,

⁹⁹ This chapter uses "value-based payment" as a catch-all description of models that tie reimbursement, incentives, and/or penalties both to efficiencies in care and to quality of care and/or health outcomes. In addition to the ACO model, other value-based models include episodic and bundled payment programs tied to quality improvement metrics, episodic payment models for the treatment of specific health conditions, capitated payment arrangements in primary care, two-sided risk contracts, and others. *See, e.g., Benjamin Durie & Stephanie Gross, Value-Based Payment Programs: Compliance Challenges for Current and Future Payment Models*, in AM. HEALTH L. ASS'N, AHLA HEALTH LAW WATCH 111 (2020); Health Care Payment Learning & Action Network, *APM Measurement: Progress of Alternative Payment Models* 15, Health Care Payment Learning & Action Network (2019), available at <http://hcp-lan.org/workproducts/apm-methodology-2019.pdf>.

¹⁰⁰ *See* Charles Roehrig, *A Brief History of Health Spending Since 1965*, HEALTH AFF. (Sept. 19, 2011), available at <https://www.healthaffairs.org/doi/10.1377/hblog20110919.013778/full>; <https://www.healthaffairs.org/doi/10.1377/hblog20110919.013778/full>.

the models can incentivize providers to address “upstream,” non-medical causes of poor health that disproportionately burden Black, indigenous, and other people of color (BIPOC), low-income people, and people from other historically marginalized populations. Yet other dynamics inherent to current value-based payment models can put patients—especially low-income and/or medically complex patients—and providers on what one commentator calls a “collision course,”¹⁰¹ actually deepening population-level disparities in health care and health outcomes.

1.4.1 The Current Environment

Over the past two decades, and particularly in the last several years, value-based payment (VBP) models have proliferated across the private and public payer landscapes. With nearly 36 percent of total U.S. health care payments linked to value-based alternative payment models in 2018—up from 23 percent in 2015¹⁰²—it is important to recognize these models’ potential both to exacerbate and to ameliorate health care disparities.

VBP models can create perverse incentives for health care providers to “cherry-pick” (or “cream-skim”) and “lemon-drop” patients.¹⁰³ Where compensation is significantly tied to providing care to patients at lower costs, provider groups are rewarded for choosing to treat patients who are already healthy and likely (or perceived to be likely) to remain so, while excluding patients who are already sickest and/or likely (or perceived to be likely) to become

¹⁰¹ Jessica Mantel, *How Efforts to Lower Health Care Costs are Putting Patients & Providers on a Collision Course*, 44 OHIO NORTHERN U. L. REV. 371 (2018).

¹⁰² See APM Measurement: Progress of Alternative Payment Models, *supra* note 99, at 15 (2019).

¹⁰³ For these metaphors, see, e.g., Daniel L. McFadden et al., *Remedies for Sick Insurance*, Nat’l Bur. Econ. Research Working Paper No. 17938, 10 (2012), available at https://www.nber.org/system/files/working_papers/w17938/w17938.pdf.

less healthy.¹⁰⁴ Where compensation is tied to positive health outcomes, similar incentives apply. VBP models that incorporate capitation—a fixed per-patient payment—for all costs related to treating a particular health condition (e.g., joint replacement) may also incentivize undertreating the patient.¹⁰⁵

Lower socioeconomic status (SES) and BIPOC populations are overrepresented among the patients likeliest to be “lemon-dropped” from provider groups participating in VBP programs, in significant part because of the influence of intermediary social determinants of health. Health status has long been known to track SES. People of color in the U.S. experience higher rates of chronic diseases—including diabetes, obesity, stroke, heart disease, and cancer—than White people. BIPOC communities also live with multi-generational health effects of historic exclusion from access to quality care, environmental discrimination, and toxic stress caused by experiencing discrimination.¹⁰⁶ Lower income and lack of paid sick leave associated with low-income employment may cause patients to delay needed care, making them more medically complex when they do access care.

Perception may be as important as reality in VBP-incentivized lemon-dropping. People with certain disabilities may be—or may be perceived to be—more expensive to treat. Providers may

¹⁰⁴ See, e.g., Jessica Mantel, *Refusing to Treat Noncompliant Patients is Bad Medicine*, 39 CARDOZO L. REV. 127, 142–70 (2017). Upcoding is another frequently-cited risk of VBP arrangements. See, e.g., Sherri Rose et al., *Variation In Accountable Care Organization Spending And Sensitivity To Risk Adjustment: Implications For Benchmarking*, HEALTH AFF. (Mar. 2016), available at <https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2015.1026> (explaining that, because a Medicare ACO qualifies for increased compensation on its ability to provide care below a spending target based on previous years’ Medicare spend on the patients attributed to it, ACOs are incentivized to upcode in order to raise their future spending benchmark).

¹⁰⁵ See, e.g., McFadden et al., *supra* note 103, at 12.

¹⁰⁶ See, e.g., Ruqaiyah Yearby, *Sick & Tired of Being Sick & Tired: Putting an End to Separate & Unequal Health Care in the U.S. 50 Years after the Civil Rights Act of 1964*, 25 HEALTH MATRIX 1, 6–21 (2015).

intentionally or unintentionally discriminate against patients from populations perceived to be less likely to “comply” with health care treatment recommendations, since patient noncompliance could result in less positive health outcomes, in turn resulting in lower VBP compensation.¹⁰⁷ Lemon-dropping incentives to providers engaged in efforts to reduce health care costs on the supply side may also collide with cost-sharing mechanisms intended to reduce health care costs on the demand side, leading providers in VBP programs simply to avoid low-income patients in high-deductible or other health plans who may have delayed or forgone care because they could not afford the cost-sharing.¹⁰⁸ In addition, experiencing stigma in the health care setting can make patients less likely to seek care and to comply with health care recommendations, worsening health outcomes and increasing costs to the health care system in the long term.¹⁰⁹

The ACA sought to prevent payers from directly cherry-picking and lemon-dropping patients by pairing two key restrictions, guaranteed issue and community rating, supported by additional mechanisms to spread the risk of enrolling patients across payers. The former requires insurers to enroll all applicants for a given insurance product regardless of health status. The latter forbids insurers from charging different prices to different individuals for the same insurance product on the basis of actual or demographically predicted differences in health status. Similarly, some commentators propose that risk adjustments across VBP program participants in a geographic area would address the risk that provider groups that serve sicker patients will be unfairly penalized and that those who serve healthier patients will be unfairly rewarded.

But such risk adjustments are inadequate to fully counter the perverse incentives for provider groups in VBP arrangements

¹⁰⁷ See Mantel, *Noncompliant Patients*, *supra* note 104, at 130.

¹⁰⁸ See Mantel, *Collision Course*, *supra* note 101, at 372–74.

¹⁰⁹ See Mantel, *Noncompliant Patients*, *supra* note 104, at 158–59.

and the accompanying population-level effects on health care equity. First, to the extent that risk adjustments are based on retrospective data, providers participating in VBP arrangements may be additionally incentivized to cherry-pick healthier patients going forward to ensure that they can provide care at or below their historical spending target.¹¹⁰ Second, a risk adjustment methodology must accurately reflect why patients' health status varies across provider groups in the program, and limited data suggests that current methodologies do not account for all variation in patient health status.¹¹¹ Third, VBP programs have yet to find an optimal balance between risk adjustments that encourage provider groups to serve high-need patients and rules intended to discourage provider groups from artificially inflating their annual spending targets.¹¹² Finally, traditional risk adjustment mechanisms consider only medical complexity in a service population, not the upstream social determinants of health.¹¹³

At the same time, VBP can also be seen as payers' long-overdue recognition of the influence of non-medical factors on health, and VBP models have significant potential to address intermediary social determinants of health that particularly affect low-income and other

¹¹⁰ See, e.g., *id.*

¹¹¹ See, e.g., Rose et al., *supra* note 104 (finding that neither geography nor the variables used for risk adjustment in the Medicare Shared Savings Program ACO program, the longest-running VBP program, accounted for all variation in patient health status across ACOs).

¹¹² See Adam A. Markovitz et al., *Risk Adjustment In Medicare ACO Program Deters Coding Increases But May Lead ACOs To Drop High-Risk Beneficiaries*, 38 HEALTHAFF. 253 (Feb. 2019) (finding that “high-risk beneficiaries and clinicians with higher-risk patient panels were disproportionately likely to exit [Medicare Shared Savings Program] ACOs. MSSP exit was particularly concentrated among beneficiaries with increased risk-score growth while in the MSSP and after their exit from the program.”); see also *supra* note 104.

¹¹³ See, e.g., Hannah L. Crook et al., *How Are Payment Reforms Addressing Social Determinants of Health? Policy Implications and Next Steps*, Duke University Margolis Center for Health Policy 7-8 (Feb. 2021), available at https://www.milbank.org/wp-content/uploads/2021/02/Duke-SDOH-and-VBP-Issue-Brief_v3-1.pdf (also noting “practical problems in operationalizing social risk adjustment with existing data and methods”).

marginalized patient populations.¹¹⁴ Services that assist patients with applying for Supplemental Nutrition Assistance Program benefits or finding stable housing can improve health outcomes as well as reduce costs associated with treating health conditions caused or worsened by poor nutrition or homelessness. This promise remains significantly underrealized, however.¹¹⁵

1.4.2 Trends for the Next Year

In 2018, HHS announced a “Regulatory Sprint to Coordinated Care” with the goal of “accelerat[ing] the transformation to a value-based [health care] system that includes care coordination.”¹¹⁶ To launch the Sprint, CMS, the HHS Office of the Inspector General, and the HHS Office for Civil Rights each announced requests for public input on “unnecessary barriers to coordinated care, real or perceived,”¹¹⁷ in federal patient privacy and health care fraud laws.¹¹⁸ In November 2020, HHS announced final rules that, *inter alia*, create new compensation exceptions under the Stark Law and new safe harbors under the Anti-Kickback Statute specifically for

¹¹⁴ See generally, e.g., *id.*; John V. Jacobi, *The Tools at Hand: Medicaid Payment Reform for People with Complex Medical Needs*, 28 ANNS. HEALTH L. & LIFE SCI. 135, 143–45 (2019).

¹¹⁵ See generally, e.g., Crook et al., *supra* note 113; Jessica Mantel, *Tackling the Social Determinants of Health: A Central Role for Providers*, 33 GA. ST. L. REV. 217, 256–74 (2017) (discussing mismatches between common VBP incentives and provider efforts to address social determinants of health).

¹¹⁶ 83 Fed. Reg. 29524, 29524 (June 25, 2018) (announcing Centers for Medicare and Medicaid Services’ request for information (RFI) on the “undue regulatory impact and burden of the physician self-referral law,” also known as the Stark Law). See also generally Kathryn S. Burnett & Russell C. Ramzel, *Proposed Changes to Stark and Anti-Kickback Rules May Spur Care Coordination*, AM. HEALTH L. ASS’N, AHLA HEALTH LAW WATCH 1 (2020).

¹¹⁷ 83 Fed. Reg. 29524.

¹¹⁸ *Id.*; 83 Fed. Reg. 43607 (Aug. 27, 2018) (announcing the HHS Office of Inspector General’s RFI on the Anti-Kickback Statute and Beneficiary Inducements Civil Monetary Penalty law); 83 Fed. Reg. 64302 (Dec. 14, 2018) (announcing the HHS Office for Civil Rights’ RFI on the Health Insurance Portability and Accountability Act privacy and security rules).

value-based arrangements.¹¹⁹ While the status of these final rules under the new presidential administration was initially uncertain,¹²⁰ the amended Stark Law, Anti-Kickback Statute, and Civil Monetary Penalty rules are now effective.¹²¹ As a result, providers may feel freer to explore VBP arrangements than under the previous regulations. If the new compensation exceptions and safe harbors to the health care fraud laws do in fact draw more providers into VBP programs, cream-skimming and lemon-dropping can be expected to rise across the U.S. health care system as a whole.

In addition to these regulatory changes aimed at expanding VBP participation generally, HHS continued in 2020 to expand VBP in Medicare and Medicaid. In September, HHS issued a new “roadmap” for accelerating adoption of value-based care in

¹¹⁹ 85 Fed. Reg. 77492 (Dec. 2, 2020), to be codified at 42 C.F.R. §§ 1001, 1003 (new Stark Law rules); 85 Fed. Reg. 77684 (Dec. 2, 2020), to be codified at 42 C.F.R. §§ 1001, 1003 (new Anti-Kickback Statute and Beneficiary Inducements Civil Monetary Penalty rules).

¹²⁰ See Hannah L. Cross et al., *New Stark Law and AKS Final Rules at Risk of Delay or Replacement Due to GAO Finding of Technical Deficiency and Biden Administration’s Regulatory Hold Memo*, Nat’l L. Rev. (Jan. 26, 2021) (explaining that the final rules failed to comply with the Congressional Review Act’s required delay between transmittal of major new regulations to Congress and their effective date; see also *infra notes* 156-157 and accompanying text (describing CRA’s mechanism for congressional disapproval of final regulations)), available at <https://www.natlawreview.com/article/new-stark-law-and-aks-final-rules-risk-delay-or-replacement-due-to-gao-finding>.

¹²¹ See Thomas Sullivan, *Stark Law Final Rule Is Effective*, Pol’y & Med. (Mar. 8, 2021) (quoting CMS statement that “The regulations finalized in CMS-1720-F (Medicare Program; Modernizing and Clarifying the Physician Self-Referral Regulations) are effective, except for the revisions to 42 CFR 411.352, which have the delayed effective date set forth in the final rule in order to give physician practices that qualify as ‘group practice’ time to comply with any changes that may affect their physician compensation models.”); Edward S. Kornreich, Krusheeta R. Patel, Elizabeth R. Siegel, *New Opportunities for Value-Based Care with HHS Finalization of Stark Law, Anti-Kickback Statute, and Civil Monetary Penalties Law Reforms*, Nat’l L. Rev. (Mar. 3, 2021), available at <https://www.natlawreview.com/article/new-opportunities-value-based-care-hhs-finalization-stark-law-anti-kickback-statute>.

Medicaid.¹²² The letter encourages states to consider implementing value-based elements into fee-for-service as well as episode-of-care and total-cost-of-care programs through flexibility in state plans or through managed care authority, and downplays use of Section 1115 waivers (what the CMS press release terms “time-consuming, complex demonstrations or waivers”) for this purpose.¹²³

Having set in 2019 the goal of moving all traditional Medicare and Medicare Advantage providers to two-sided risk models by 2025,¹²⁴ CMS announced in December 2020 a new voluntary direct contracting program to implement regionally coordinated care in which providers assume downside as well as upside risk for patient health outcomes.¹²⁵

1.4.3 What Health Lawyers Need to Know Now

The expansion of VBP arrangements seems unlikely to slow. To prevent VBP expansion from exacerbating disparities in access to quality health care, several programmatic changes are required:

- Enhance risk adjustment methodologies to incorporate not only the traditional measures of medical complexity, but also social risk factors, such as differences in education,

¹²² *Letter from Anne Marie Costello & Brad Smith, Ctrs. for Medicare & Medicaid Servs., to State Medicaid Directors: Value-Based Care Opportunities in Medicaid*, CMS (Sept. 15, 2020), available at <https://www.medicare.gov/Federal-Policy-Guidance/Downloads/smd20004.pdf>.

¹²³ *Press Release: CMS Issues New Roadmap for States to Accelerate Adoption of Value-Based Care to Improve Quality of Care for Medicaid Beneficiaries*, Ctrs. for Medicare & Medicaid Servs (Sept. 15, 2020), available at <https://www.cms.gov/newsroom/press-releases/cms-issues-new-roadmap-states-accelerate-adoption-value-based-care-improve-quality-care-medicare>.

¹²⁴ Kelly Gooch, *New Goals Set for Value-Based Payments*, BECKER'S HOSPITAL CFO REPORT (Oct. 25, 2019), available at <https://www.beckershospitalreview.com/finance/new-goals-set-for-value-based-payments.html>.

¹²⁵ Fact Sheet: Geographic Direct Contracting Model (“Geo”), Ctrs. for Medicare & Medicaid Servs. (Dec. 3, 2020), available at <https://www.cms.gov/newsroom/fact-sheets/geographic-direct-contracting-model-geo>.

income, employment, social support, neighborhood, physical environment, and community resources.¹²⁶

- Develop mechanisms for incentivizing long-term improvements to patient health as well as short-term.
- Rebalance VBP shared savings and other reward methodologies to adequately compensate providers for investing in costlier social determinants interventions that result in greater system savings, including for non-patients.¹²⁷

1.5 Nondiscrimination in Care and Coverage

Incorporating elements of four major civil rights statutes, Section 1557 of the ACA forbids exclusion from or discrimination against individuals in protected categories in any health program or activity that receives federal financial support, thereby promoting access to health care for individuals who may otherwise encounter discriminatory barriers.¹²⁸ It was the first federal law to attempt an expansive prohibition on discrimination in health care (including private health insurance), as well as the first to forbid sex discrimination in health care.¹²⁹ As a result, the first set of regulations implementing Section 1557 (the 2016 Rules) focused significantly, though not exclusively, on discrimination “on the basis of sex.”¹³⁰

In June 2020, HHS issued final revised regulations on Section 1557 that repealed sections of the 2016 Rules and significantly

¹²⁶ See, e.g., Crook et al., *supra* note 113, at 7.

¹²⁷ See Mantel, *Tackling*, *supra* note 115, at 257–60.

¹²⁸ 42 U.S.C. § 18116 (2020) (incorporating prohibited grounds for discrimination from (1) Title VI of the Civil Rights Act of 1964 (42 U.S.C. §§ 2000d, *et seq.*) (race, color, national origin), (2) Title IX of the Education Amendments of 1972 (20 U.S.C. §§ 1681, *et seq.*) (sex), (3) The Age Discrimination Act of 1975 (42 U.S.C. §§ 6101, *et seq.*) (age), and (4) Section 504 of the Rehabilitation Act of 1973 (29 U.S.C. §§ 701, *et seq.*) (disability)).

¹²⁹ See Valarie K. Blake, *Civil Rights as a Treatment for Health Insurance Discrimination*, 2016 WIS. L. REV. FORWARD 37, 37–38 (2016).

¹³⁰ 45 C.F.R. §§ 92.4, 92.206, 92.207 (2016).

narrowed the scope of others.¹³¹ Many of the changes focused on the sex discrimination provisions, eliminating protections related to gender identity and sexual orientation, and offering blanket abortion and religious objection exemptions to health care providers and institutions.¹³² Other parts of the 2020 regulations narrowed the range of entities subject to 1557, and, although some of the 2020 regulations have been enjoined by federal district courts, many of their provisions remain on the books.¹³³

1.5.1 The Current Environment

In 2016, HHS issued final regulations (the 2016 Rules) implementing Section 1557 of the ACA.¹³⁴ Incorporating elements of four major civil rights statutes, Section 1557 forbids exclusion from or discrimination against individuals in commonly-protected categories in any health program or activity that receives federal financial support.¹³⁵ It was the first federal law to attempt an expansive prohibition on discrimination in health care, as well as the first to forbid sex discrimination in health care—including, for the first time, private health insurance.¹³⁶

The 2016 Rules defined the range of entities covered by Section 1557's nondiscrimination requirements broadly, incorporating all

¹³¹ See generally *Nondiscrimination in Health and Health Education Programs or Activities, Delegation of Authority*, 85 Fed. Reg. 37160 (June 19, 2020).

¹³² *Id.*

¹³³ Amending or repealing those parts of 2020 final rules that are not enjoined will require formal notice and comment rulemaking, which may take many months or years. See *infra* notes 156-57 and accompanying text.

¹³⁴ 81 Fed. Reg. 31375 (May 18, 2016).

¹³⁵ 42 U.S.C. § 18116 (incorporating prohibited grounds for discrimination from (1) Title VI of the Civil Rights Act of 1964 (42 U.S.C. §§ 2000d, *et seq.*) (race, color, national origin), (2) Title IX of the Education Amendments of 1972 (20 U.S.C. §§ 1681, *et seq.*) (sex), (3) The Age Discrimination Act of 1975 (42 U.S.C. §§ 6101, *et seq.*) (age), and (4) Section 504 of the Rehabilitation Act of 1973 (29 U.S.C. § 701, *et seq.*) (disability)).

¹³⁶ See Blake, *Health Insurance Discrimination*, *supra* note 129, at 37–38.

entities for which HHS “plays a role” in funding.¹³⁷ While the language of the statute itself clearly reached at least some private insurers,¹³⁸ the 2016 Rules established that, if an insurer participated in the ACA exchange, all of its plans—on or off the exchange—would be bound by Section 1557 nondiscrimination requirements.¹³⁹ As a leading commentator has observed, “This [wa]s a major change in insurance policy in America, as private health insurers were previously free to discriminate, except for any state law” forbidding discrimination.¹⁴⁰

Further, the 2016 Rules defined discrimination “on the basis of sex” to include discrimination on the basis of gender identity, transgender status, gender stereotyping, and a variety of pregnancy-related conditions, including seeking an abortion.¹⁴¹ HHS expressly declined, in 2016, to import Title IX’s broad exemption of religious institutions from the general prohibition on sex discrimination, explaining that other federal laws, such as the Religious Freedom Restoration Act (RFRA)¹⁴² and other portions of the ACA, adequately protected religious institutions and individual providers claiming conscientious objections.¹⁴³

The 2016 Rules also elevated existing subregulatory guidance on adequate language assistance for every patient with limited

¹³⁷ 81 Fed. Reg. 31375, 31384 (May 18, 2016). HHS declined to extend the 2016 Rules to health programs and activities receiving federal financial support from departments other than HHS itself. *Id.* at 31379.

¹³⁸ 42 U.S.C. § 18116(a).

¹³⁹ 81 Fed. Reg. 31375, 31428 (May 18, 2016).

¹⁴⁰ VALARIE K. BLAKE, LEXIS CIVIL RIGHTS & STRATEGY SERIES: FEDERAL HEALTH CARE LAW § 6.03[1][b][ii] (2020).

¹⁴¹ 45 C.F.R. § 92.4 (2016). The 2016 Rules did not resolve the question of whether discrimination on the basis of sexual orientation alone (without sex stereotyping) was prohibited.

¹⁴² 42 U.S.C. §§ 2000bb, *et seq.*

¹⁴³ *See* 81 Fed. Reg. 31375, 31378–80 (May 18, 2016) (responding to comments on proposed rule urging HHS to adopt Title IX’s “blanket religious exemption” and noting that Section 1557 itself does not mention a religious exemption).

English proficiency (LEP) and required certain accessibility-related measures to address discrimination against people with disabilities (although it did not set specific accessibility standards).

Finally, the 2016 Rules clearly recognized a private right of action under Section 1557 and the availability of monetary damages for violations. This recognition was particularly important for two reasons. First, it re-established a private right of action for race-based disparate impact claims in health care, which had been unavailable since the Supreme Court generally disallowed individual claims of disparate racial impact in federally-funded activities in 2001.¹⁴⁴ Second, the right to allege disparate impact claims was especially important in the context of guarantees against discrimination in insurance coverage because it would be difficult to meet the standard for intentional discrimination for many forms of health insurance discrimination.¹⁴⁵

Several states and religiously-affiliated health care and health insurance providers soon challenged the 2016 Rules in federal district court in Texas.¹⁴⁶ The court concluded that HHS was not entitled to discard Title IX's broad religious exemption or its "binary definition of 'sex.'"¹⁴⁷ In addition, the court found that RFRA would also protect Franciscan Alliance, Inc., and the other private plaintiffs' sincere religious belief that performing, referring for, and/or paying for abortion or gender transition services would "harm their patients and force their employees to 'engage in material cooperation with evil.'"¹⁴⁸ In late 2016, the court temporarily enjoined "the prohibition of discrimination on the basis of 'gender identity' and 'termination

¹⁴⁴ *Alexander v. Sandoval*, 532 U.S. 275 (2001) (finding that Title VI of the Civil Rights Act of 1964 creates a private right of action only for claims of intentional discrimination).

¹⁴⁵ *See* BLAKE, *supra* note 140, § 6.03[1][b][v].

¹⁴⁶ *Franciscan All., Inc. v. Burwell*, 227 F. Supp. 3d 660 (N.D. Tex. 2016).

¹⁴⁷ *Id.* at 687 (finding that Section 1557 incorporated Title IX and engaging in an "original meaning" analysis of the 1972 statute).

¹⁴⁸ *Id.* at 691–92.

of pregnancy”¹⁴⁹ in October 2019, the court permanently enjoined and vacated these elements of the 2016 Rules.¹⁵⁰

In June 2020, HHS issued final revised regulations on Section 1557 (the 2020 Rules) that repealed sections of the 2016 Rules and significantly narrowed the scope of others.¹⁵¹ Many of the changes focused on the sex discrimination provisions, repealing the 2016 Rules’ specific protections for gender-nonconforming people against discrimination in care and coverage and the definition of “on the basis of sex,” which thereby also eliminated protections related to pregnancy, childbirth, and gender stereotyping. In addition, the 2020 Rules offered health care providers and institutions broad abortion and religious objection exemptions from the general ban on sex discrimination, expressly incorporating the blanket exemption from Title IX.¹⁵² In addition, the 2020 Rules:

- Significantly restricted the range of covered entities, programs, and activities to:
 - Only those entities “principally engaged in the business of providing healthcare,” specifically carving out most insurers,¹⁵³ and
 - Only those programs and activities that HHS administers through the ACA exchange;

¹⁴⁹ *Franciscan All.*, 227 F. Supp. 3d at 695 (“[b]ecause the Rule includes a severability provision, none of the unchallenged provisions are enjoined. Only . . . the prohibition of discrimination on the basis of “gender identity” and “termination of pregnancy” . . . is hereby enjoined”) (internal citations omitted).

¹⁵⁰ *Franciscan All., Inc. v. Azar*, 414 F. Supp. 3d. 928, 942–47 (N.D. Tex. 2019) (“**VACAT[ing]** only the portions of the Rule that are unlawful under the APA and RFRA (*id.* at 945, n.7) and “**ADOPT[ing]** its prior reasoning from the preliminary injunction” (*id.* at 947) (capitalization and boldface type in the original)).

¹⁵¹ See generally *Nondiscrimination in Health and Health Education Programs or Activities, Delegation of Authority*, 85 Fed. Reg. 37160 (June 19, 2020).

¹⁵² *Id.*

¹⁵³ 45 C.F.R. § 92.3 (2020).

- Eliminated prohibitions on discrimination in health insurance issuance, coverage, cost-sharing, marketing, and benefit design;
- Withdrew HHS recognition of a private right of action under Section 1557, leaving the question to be determined by the courts;
- Reduced language access requirements;
- Removed protection against discrimination based on association with someone belonging to a protected class; and
- Eliminated provisions requiring covered entities to provide public notice of nondiscrimination policies and institute mechanisms for organizational compliance.

Just a few days before the 2020 Rules were finalized, the Supreme Court determined, in *Bostock v. Clayton County*, that Title VII’s prohibition on employment discrimination “because of sex” includes discrimination on the basis of gender identity and sexual orientation.¹⁵⁴ *Bostock* decision in hand, litigants in New York and Washington, DC, won temporary injunctions blocking some key provisions of the 2020 Rules from taking effect.¹⁵⁵

As these court challenges to the 2020 Rules unfolded in the second half of the year, it initially seemed that the 2020 Rules might be subject to expedited repeal *in toto* under the Congressional Review Act (CRA). The CRA permits a new Congress to disapprove, by joint resolution, major regulations finalized within the last 60 working days of the previous Congress.¹⁵⁶ However, because the

¹⁵⁴ *Bostock v. Clayton County*, 140 S. Ct. 1731 (2020) (interpreting Title VII of the Civil Rights Act of 1964, 42 U.S.C. § 2000e–2 (2020)).

¹⁵⁵ *Walker v. Azar*, 20-CV-2834 (E.D.N.Y. Oct. 29, 2020); *Whitman-Walker Clinic v. U.S. Dep’t of Health & Hum. Servs.*, No. 20-1630 (D.D.C. Sept. 2, 2020).

¹⁵⁶ *See generally* Congressional Review of Agency Rule Making Act, 5 U.S.C. §§ 801–900. The lookback period is the last 60 working days of either chamber in the previous Congress. 5 U.S.C. § 801. The procedure requires only

116th Congress remained in session late into December 2020 to pass COVID-19 relief legislation, the House and the newly Democratic-majority Senate were unable to consider nullifying the 2020 Rules in their entirety.¹⁵⁷

1.5.2 Trends for the Next Year

Among a suite of executive orders signed on Inauguration Day 2021, one announced a Biden administration policy of applying the *Bostock* reasoning—recognizing discrimination on the basis of gender identity as a form of sex discrimination—to all laws that prohibit sex discrimination and directing all agency heads to reconsider any agency actions inconsistent with that policy.¹⁵⁸ In May 2021, citing *Bostock*, HHS Secretary Xavier Berrera announced that its Office of Civil Rights would “interpret and enforce Section 1557 and Title IX’s prohibitions on discrimination based on sex to include: (1) discrimination on the basis of sexual orientation; and (2) discrimination on the basis of gender identity.”¹⁵⁹ This position expands beyond the interpretation held by the Obama administration, which did not include sexual orientation as an independent category.

simple majority of each chamber unless the President vetoes the resolution, in which case a two-thirds majority vote in each chamber is required to override the veto. *Id.*

At the beginning of 2020, the projected House of Representatives calendar placed the earliest date of the lookback period for 2020 on May 20, 2020. See Daniel R. Pérez, *Upcoming CRA Deadline has Implications for Regulatory Oversight by Congress*, George Washington University Regulatory Studies Center (Dec. 11, 2019), available at https://regulatorystudies.columbian.gwu.edu/sites/g/files/zaxdzs3306/f/downloads/Commentaries/GW%20Reg%20Studies_CRA%20Lookback_DPe%CC%81rez_.pdf.

¹⁵⁷ See, e.g., Jonathan Nicholson, *Democrats Eye Trump-Era Rule Rollbacks, But Their Reach Will Be Limited*, MarketWatch (Jan. 12, 2021), available at <https://www.marketwatch.com/story/democrats-eye-trump-era-rule-rollbacks-but-their-reach-will-be-limited-11610485808>.

¹⁵⁸ Exec. Order No. 13988, 86 Fed. Reg. 7023 (Jan. 20, 2021).

¹⁵⁹ *Press Release: HHS Announces Prohibition on Sex Discrimination Includes Discrimination on the Basis of Sexual Orientation and Gender Identity*, U.S. Dep’t of Health & Hum. Servs. (May 10, 2021), available at <https://www.hhs.gov/about/news/2021/05/10/hhs-announces-prohibition-sex-discrimination-includes-discrimination-basis-sexual-orientation-gender-identity.html>.

In recent litigation filings, HHS has announced its intention to begin formal rulemaking to “reconsider[] many or all of the changes” in the 2020 Rules¹⁶⁰—no doubt prompting further legal challenges. Regardless of whether the 2020 Rules or future revised Rules are under consideration, courts will have to consider (1) whether *Bostock* applies to Section 1557 and (2) whether “sex” can have a different meaning in the health care setting than elsewhere in antidiscrimination law, as argued by HHS in the preamble to the 2020 Rules.¹⁶¹

While the time-consuming process of formal rulemaking is ongoing, a version of the 2020 Rules, modified by court stays, remains in place. Practitioners should note that, because of the 2020 Rules’ sweeping changes to the architecture of the 2016 Rules, the effects of key judicial stays are not simple to parse.¹⁶² In *Franciscan Alliance*, the court enjoined “enforcing the [2016] Rule’s prohibition against discrimination on the basis of gender identity or termination of pregnancy,” but did not specify which provisions were thereby vacated.¹⁶³ When considering challenges to the 2020 Rules, federal district courts in New York and Washington, DC recognized that they did not have the power to revive what the District Court in

¹⁶⁰ Joint Status Report at 2, *Whitman-Walker Clinic v. U.S. Dep’t of Health & Hum. Servs.*, No. 20-5331 (D.D.C. May 14, 2021), *available at* <https://affordablecareactlitigation.files.wordpress.com/2021/05/dcc-joint-status-report-5-14-21.pdf> (quoted in MaryBeth Musumeci et al., *Recent & Anticipated Actions to Reverse Trump Administration Section 1557 Non-Discrimination Rules*, Kaiser Family Foundation (June 9, 2021), *available at* <https://www.kff.org/racial-equity-and-health-policy/issue-brief/recent-and-anticipated-actions-to-reverse-trump-administration-section-1557-non-discrimination-rules/>).

¹⁶¹ See *Nondiscrimination in Health and Health Education Programs or Activities, Delegation of Authority*, 85 Fed. Reg. 37160, 37178–79 (June 19, 2020) (stating that the 2020 Rules “revert[] to, and rel[y] upon, the plain meaning of the term [“sex”] in the statute . . . its original and ordinary public meaning refers to the biological binary of male and female that human beings share with other mammals”).

¹⁶² As of this writing, neither the last official printing of Title 45 of the Code of Federal Regulations nor the unofficial Electronic Code of Federal Regulations had incorporated the judicial stays discussed in this paragraph.

¹⁶³ *Franciscan All.*, 227 F. Supp. 3d at 696.

Texas had vacated, but issued overlapping preliminary injunctions that nevertheless provided protections to the plaintiffs, who were transgender individuals and their health care providers. The New York district court preserved the 2016 Rules' definitions of "on the basis of sex," "gender identity," and "sex stereotyping"¹⁶⁴ as well as the section of the 2016 Rules that required health care providers to treat individuals in accord with their gender identity except where doing so would enable the provider to deny medically-necessary treatment.¹⁶⁵ The D.C. district court stayed the blanket abortion and religious objection exemption while also preserving "sex stereotyping" as a form of discrimination.¹⁶⁶ The rest of the 2020 Rules—including the repeal of former Section 92.207, which prevented insurers from categorically excluding or limiting health services related to gender transition—have been allowed to go into effect.¹⁶⁷

Fresh rounds of rulemaking will not settle the scope of abortion-related and other religious objection exemptions. As one leading commentator observes, "two questions seem destined for the Supreme Court. The first is whether Title IX's blanket exemption or RFRA's more nuanced inquiry will apply. The second is, if RFRA does apply, how will the Court balance the competing interests:

¹⁶⁴ *Walker*, 20-CV-2834 at *19–20, *27–28.

¹⁶⁵ *Walker*, at *8-9 (enjoining 2020 Rules' repeal of parts of former 45 C.F.R. § 92.4 and of former 45 C.F.R. § 92.206). Some of these elements were arguably subjects of the *Franciscan Alliance* permanent injunction.

¹⁶⁶ *Whitman-Walker*, No. 20-1630 at *149.

¹⁶⁷ As of this writing, three other pending cases have challenged the 2020 Rules: *Chinatown Serv. Ctr. v. U.S. Dep't of Health & Hum. Servs.*, 21-CV-00331 (D.D.C. Feb. 5, 2021) (challenging the 2020 Rules' relaxed language interpretation requirements); *NY v. U.S. Dep't of Health & Hum. Servs.*, 20-CV-5583 (S.D.N.Y. July 20, 2020) (coalition of 23 states challenging multiple aspects of the 2020 Rules); and *Boston All. of Gay, Lesbian, Bisexual & Transgender Youth v. U.S. Dep't of Health & Hum. Servs.*, 20-CV-11297 (D. Mass. July 7, 2020) (challenging multiple aspects of the 2020 Rules).

Will it follow *Hobby Lobby*, [o]r will it look more like *Franciscan Alliance*?”¹⁶⁸

In *Hobby Lobby*, as HHS noted in proposing the 2016 Rules, the Court’s RFRA analysis had engaged in an individualized balancing of important interests; finding that the ACA contraception mandate did substantially burden the religious beliefs attributable to a closely-held corporation, the Court nevertheless recognized that ensuring access to contraception was a compelling government interest.¹⁶⁹ To the Court, the existence of an already-available alternative mechanism to ensure ongoing employee access to contraception with less burden to the plaintiffs’ religious beliefs could fully accommodate both interests.¹⁷⁰

In *Franciscan Alliance*, by contrast, the district court in the Northern District of Texas theorized a wide range of hypothetical alternatives for providing gender transition care and other health services to gender-nonconforming individuals that it found were less restrictive alternatives for purposes of the RFRA analysis.¹⁷¹ The Texas court found that a possible future government program was an adequate accommodation of the government’s interest in ensuring health care, and did not seem to consider continuity of service as the Supreme Court had in *Hobby Lobby*.

1.5.3 What Health Lawyers Need to Know Now

The blanket religious exemption from nondiscrimination requirements, incorporated into the 2020 Rules from Title IX, is on hold.

¹⁶⁸ Brietta R. Clark et al., *Sex-Based Discrimination in Healthcare Under Section 1557: The New Final Rule & Supreme Court Developments*, Loyola Law School, Los Angeles Legal Studies Research Paper No. 2020-31 9-10, 12 (Dec. 2020), available at <https://ssrn.com/abstract=3742446>.

¹⁶⁹ See generally *Burwell v. Hobby Lobby Stores, Inc.*, 134 S.Ct. 2751 (2014).

¹⁷⁰ *Id.*

¹⁷¹ *Franciscan All.*, 227 F. Supp. 3d at 691.

- While courts have largely allowed the 2020 Rules to stand, exactly how the stays on elements of the 2020 Rules interact with previous stays to the 2016 Rules can create uncertainty.
- Health care institutions should consider operational and reputational risks as well as risk of regulatory enforcement when choosing how to respond to the 2020 Rules' less stringent antidiscrimination requirements.
- With Section 1557 implementing rules in flux, states may continue to take the opportunity to strengthen their own laws on nondiscrimination in care and coverage; just under half the states, for example, now protect transgender people from being categorically excluded from insurance coverage.¹⁷²

¹⁷² See *Healthcare Laws & Policies*, Movement Advancement Project (Feb. 11, 2021), available at https://www.lgbtmap.org/equality-maps/healthcare_laws_and_policies.