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**About the Wiley A. Branton/
Howard Law Journal Symposium:**



WILEY AUSTIN BRANTON

Each year, Howard University School of Law and the *Howard Law Journal* pay tribute to the life and legacy of our former dean, Wiley A. Branton. What began as a scholarship award ceremony for the first-year student who completed the year with the highest grade point average has grown into a day-long symposium that focuses on an area of legal significance inspired by Branton's career as a prominent civil rights activist and exceptional litigator. The symposium is then memorialized in the *Journal's* spring issue following the symposium. The expansive nature of Branton's work has allowed the *Journal* to span a wide range of symposium topics throughout the years, and the *Journal* is honored to present this issue in honor of the great Wiley A. Branton. Past symposium issues include:

BROWN@50

The Value of the Vote: The 1965 Voting Rights Act and Beyond

*“What Is Black?”: Perspectives on Coalition Building
in the Modern Civil Rights Movement*

Katrina and the Rule of Law in the Time of Crisis

Thurgood Marshall: His Life, His Work, His Legacy

*From Reconstruction to the White House:
The Past and Future of Black Lawyers in America*

KEYNOTE ADDRESS

HONORABLE DONNA M. CHRISTENSEN*

I would like to take this opportunity to thank Dean Kurt Schmoke, the *Howard Law Journal*, the law firms of Sidley Austin and Debevoise & Plimpton, National Bar Association President Daryl Parks, and members of the Branton family for inviting me to speak at this year's Wiley A. Branton/*Howard Law Journal* Symposium. It is truly an honor to speak at this prestigious institution due to the tremendous impact it has had in shaping the jurisprudence of not only my district, but countless others as well. The special relationship that my district shares with Howard Law School was cemented when President Truman selected William Henry Hastie, the Dean of Howard Law School from 1939 to 1946, to become the first African American governor of the U.S. Virgin Islands from 1946 to 1949.¹

Over the past eight symposia, the *Howard Law Journal* has looked at leaders like Wiley A. Branton² in an attempt to address the various issues African Americans face in this country. In doing so, the *Howard Law Journal* has taken an introspective and often critical look at the legal profession as a whole. While attempting to define the needs of our modern civil rights movement, the *Howard Law Journal*

* Delegate to Congress, Donna M. Christensen, is a Democrat representing the U.S. Virgin Islands in the U.S. House of Representatives. As a member serving her eighth term in the 112th Congress, she is the first female physician in the history of the U.S. Congress, the first woman to represent an offshore territory, and the first woman delegate from the U.S. Virgin Islands. In the 112th Congress, Delegate Christensen serves on the Committee on Energy and Commerce and its subcommittees on Oversight, Communications, and Technology. Congresswoman Christensen is the First Vice-Chair of the Congressional Black Caucus and chairs the Congressional Black Caucus' Health Braintrust, which oversees and advocates minority health issues nationally and internationally. Congresswoman Christensen is recognized as a champion and expert on health, minority health, and the elimination of health disparities.

1. See Interview by Jerry N. Hess with William H. Hastie, Judge, 3rd Circuit Court of Appeals, in Phila., Pa. (Jan. 5, 1972), available at <http://www.trumanlibrary.org/oralhist/hastie.htm> (explaining the circumstances surrounding his appointment).

2. Wiley A. Branton served as the Dean of Howard Law School from 1978 to 1983 and was a partner with Sidley Austin LLP from 1983 to 1988. As a civil rights leader, Branton played a significant role in the landmark case of *Cooper v. Aaron*, 358 U.S. 1 (1958), which helped to end segregation in Arkansas.

has examined the impact that the legal profession has on African American communities in every corner of our country. Today is no different; the legal profession plays a significant role in helping African American communities battle the health challenges that we face.

On behalf of Chairman Emmanuel Cleaver³ and all of my colleagues in the Congressional Black Caucus, I want to thank you for bringing the issue of health disparities—an issue that we deem a modern civil rights issue—to light. Sadly, for many of our brothers and sisters, health disparities remain a critical issue. In tackling this modern civil rights issue, the concern remains that there has not yet been a significant movement towards progress. Admittedly, until recently, I had not looked critically at the reasons I became involved in the health disparity fight. Interestingly enough, I was recently interviewed by a graduate student at one of our local universities and was asked that very same question. Is it something that naturally follows by virtue of being a healthcare provider? The answer to that question is yes. Naturally, being a healthcare provider makes one acutely aware of the pressing issues of the day. However, this problem runs deeper.

The facts regarding the health conditions of African Americans and other people of color in this country ought to incite outrage in each and every one of us. Today alone, well over 100 African Americans will die unnecessarily and prematurely from preventable causes.⁴ African Americans suffer disproportionately high rates of almost all major diseases including heart disease, diabetes, cancer, obesity, and HIV/AIDS.⁵ While African Americans only make up roughly fourteen percent of the population, African Americans account for forty-eight percent of the new HIV/AIDS diagnoses in the United States.⁶

3. Emmanuel Cleaver, II is now serving his fourth term representing Missouri's Fifth Congressional District, the home district of President Harry Truman. *Full Biography*, CONGRESSMAN EMANUEL CLEAVER, II, <http://cleaver.house.gov/about-me/full-biography> (last visited Apr. 2, 2012). Cleaver was unanimously elected the 20th chair of the Congressional Black Caucus of the 112th Congress. *Id.*

4. See *More African-Americans Die from Causes that Can Be Prevented or Treated*, SCIENCE DAILY (Apr. 23, 2009), <http://www.sciencedaily.com/releases/2009/04/090423132916.htm> (stating that two-thirds of the difference between death rates among African Americans and Caucasians are now due to causes that could be prevented or cured).

5. See generally MICHAEL HALLE ET AL., HEALTH DISPARITIES: A CASE FOR CLOSING THE GAP (2009), available at http://www.healthreform.gov/reports/healthdisparities/disparities_final.pdf.

6. See CTR. FOR DISEASE CONTROL AND PREVENTION, CDC FACT SHEET: HIV AND AIDS AMONG AFRICAN AMERICANS 1 (2011), available at <http://www.cdc.gov/nchstp/newsroom/docs/FastFacts-AA-FINAL508COMP.pdf>.

However, race, standing alone, cannot be blamed for the elevated incidences of these diseases and the resulting inequalities in the health of African Americans. The root problem of these disparities is social inequality.⁷ It is imperative that we make strides towards changing the status quo so that those in vulnerable communities have the health care they need and deserve in order for them to lead healthy and happy lives.

It is important to note that insurance plays a significant role in this fight. Insurance often acts as the gatekeeper to accessing quality healthcare. Access to healthcare contributes to the disparities faced by African Americans in regards to the treatment of various illnesses and diseases. The uninsured tend, disproportionately, to be African American. While about 12.8 % of the entire population under sixty-five is uninsured,⁸ 16.3% of African Americans are uninsured.⁹ African Americans represent roughly twenty percent of the uninsured.¹⁰ Generally, even those African Americans who do have health insurance coverage receive less coverage than their white counterparts, ultimately impacting access to quality healthcare.¹¹

With its mission of advocating for and defending the rights of all, especially African Americans, this issue hits close to home for the *Howard Law Journal* and its audience. This is truly a national crisis. Not only is this a national crisis for the humanitarian reasons I have already noted, this is a national crisis from a financial standpoint. The heavy cost of healthcare threatens to weaken our entire country. The United States outspends nearly every other country when it comes to healthcare by more than thirty percent, spending nearly eight thou-

7. See generally COMM'N ON SOC. DETERMINANTS OF HEALTH, WORLD HEALTH ORG., CLOSING THE GAP IN A GENERATION: HEALTH EQUITY THROUGH ACTION ON THE SOCIAL DETERMINANTS OF HEALTH (2008), available at http://www.searo.who.int/LinkFiles/SDH_SDH_FinalReport.pdf (noting that those with a higher social position in society live longer and healthier lives).

8. See MICHAEL E. MARTINEZ & ROBIN A. COHEN, DIV. OF HEALTH INTERVIEW STATISTICS, NAT'L CTR. FOR HEALTH STATISTICS, CTR. FOR DISEASE CONTROL & PREVENTION, HEALTH INSURANCE COVERAGE: EARLY RELEASE OF ESTIMATES FROM THE NATIONAL HEALTH INTERVIEW SURVEY, JANUARY-SEPTEMBER 2011, at 2 (2011), <http://www.cdc.gov/nchs/about/major/nhis/released200212/figures011-13.htm> (follow "Health Insurance Coverage: Estimates From the National Health Interview Survey, January-September 2011").

9. U.S. DEP'T OF HEALTH & HUMAN SERVS., OVERVIEW OF THE UNINSURED IN THE UNITED STATES: A SUMMARY OF THE 2011 CURRENT POPULATION SURVEY 5 tbl. 1 (2011), available at http://aspe.hhs.gov/health/reports/2011/CPSHealthIns2011/ib.shtml#_Toc303600549.

10. See *id.* at 5.

11. See generally CTR. FOR BUDGET AND POLICY PRIORITIES, THE NUMBER OF UNINSURED AMERICANS CONTINUED TO RISE IN 2004 (2005), available at <http://www.cbpp.org/cms/?fa=view&id=631> (analyzing findings derived from the numbers released by the Census Bureau pertaining to the uninsured).

sand dollars per capita every year.¹² However, due to our failure to prioritize prevention, the United States lags behind almost every industrial nation in so many key categories.¹³ For example, the United States ranks thirty-ninth in infant mortality, thirty-sixth in life expectancy, and thirty-seventh among the world's health systems.¹⁴

Since the cost of healthcare is at the forefront of the national dialogue, now is an important time to attempt to right some of the healthcare wrongs that have been perpetuated against the African-American community. The cost of healthcare currently represents seventeen percent of our Gross Domestic Product ("GDP") and is expected to rise to over thirty-seven percent in 2030.¹⁵ Something must be done; this course of action is not sustainable. With an eye to the overall cost of healthcare, we attempted to address all the factors that limit access for African Americans in the Patient Protection and Affordable Care Act ("Affordable Care Act" or "the Act").¹⁶ Had we been able to eliminate health disparities, we could have paid for a more robust Affordable Care Act. The bill we passed had a final cost of roughly \$930,000,000,000.¹⁷ Unfortunately, we were unable to pass the better House bill,¹⁸ which would have resulted in a cost of over a trillion dollars, but would have had the effect of still reducing the deficit by approximately two trillion in the same ten-year period.¹⁹

The question that remains to be answered is whether healthcare reform or the Affordable Care Act will actually help vulnerable communities. Will the Affordable Care Act help African American communities to get better access to healthcare? Will that healthcare be of better quality and more culturally appropriate? In short, the answer to all these questions is yes. With the help of the legal community, we

12. See Ctrs. for Medicare & Medicaid Servs., *NHE Fact Sheet*, CMS.GOV (Feb. 23, 2012, 9:04 AM), https://www.cms.gov/NationalHealthExpendData/25_NHE_Fact_Sheet.asp.

13. See Katy Heslop, *How Does US Healthcare Compare to the Rest of the World?*, THE GUARDIAN (July 30, 2010, 3:47 PM) <http://www.guardian.co.uk/news/datablog/2010/mar/22/us-healthcare-bill-rest-of-world-obama>.

14. Christopher J.L. Murray et al., *Ranking 37th Measuring the Performance of the U.S. Health Care System*, NEW ENGLAND J. MED., Jan. 14, 2010, at 98, available at <http://www.nejm.org/doi/full/10.1056/NEJMp0910064#t=article>.

15. See Ctrs. for Medicare & Medicaid Servs., *supra* note 13.

16. See generally Patient Protection and Affordable Care Act, Pub. L. No. 111-148, 124 Stat. 119 (2010) (codified as amended at 42 U.S.C. § 18001 (Supp. 2010)).

17. See generally Affordable Health Care for America Act of 2009, H.R. 3962, 111th Cong. (2009).

18. See *id.*

19. See David Espo, *Landmark Health Bill Passes House on Close Vote*, PHYSORG.COM (Nov. 8, 2009), <http://www.physorg.com/news176878805.html>.

can work to fiercely protect what the TriCaucus worked so hard to achieve.

The Affordable Care Act is a landmark piece of legislation, a “game changer,” and a “playing field leveler.” We cannot afford to allow this legislation to be taken away from us. The door to wellness has finally been opened to many who have never before had access, and we cannot afford to have it slammed shut again. In crafting the Affordable Care Act, we used our signature bill, the Health Equity and Accountability Act,²⁰ as a guide for the provisions that would be included. The key health provisions that were included are: (1) a provision that prohibits discrimination and makes health disparities elimination a goal, or measure, in every research activity; (2) an expansion of healthcare coverage and consumer protections; (3) provisions that strengthen capacity at the community level; (4) a provision that mandates data collection by race, ethnicity, and other factors; (5) provisions aimed at expanding the healthcare workforce, more specifically the diversity of the country’s health professionals, including support for HBCU’s and other minority-serving institutions; (6) provisions providing for improvements in cultural competency in all aspects of the system; (7) a provision that provides for a major increase in prevention programs and funding; and finally, (8) a provision elevating the Center of Minority Health Disparity Research to an institute with greater authority.²¹

While it is appropriate to celebrate the successes we have achieved, this landmark legislation reflects just the beginning of our journey. We continue to build on the legislation in the fifth Health Equity and Accountability Act,²² which was introduced this year by the Congressional Asian Pacific American Caucus. The Health Equity and Accountability Act aims to fine-tune many of the provisions of the Affordable Care Act.²³

As we move forward with the healthcare fight, it is important to remember that there are land mines all around us. However, with the help of our entire community, particularly the legal community, we can work to deactivate these land mines. Too many lives are at stake.

20. *See generally* Health Equity and Accountability Act of 2011, H.R. 2954, 112th Cong. (2011).

21. *See generally id.*

22. *See generally id.*

23. *Compare* Patient Protection and Affordable Care Act, Pub. L. No. 111-148, 124 Stat. 119 (2010) (codified as amended at 42 U.S.C. § 18001 (Supp. 2010)), *with* H.R. 2954.

In addition, the success of our community is at stake; the strength and competitiveness of our country are at stake; and, most importantly, the wellness and future of our children are at stake. President Obama, working with the 111th Congress, has offered better and longer lives to members of vulnerable communities through health-care reform.²⁴

Through the lens of the Affordable Care Act, we can begin to envision a future where our men and women can enjoy the social security they have been paying into their entire lives; where our young men and women, who are working their way out of poverty, can have healthcare coverage for the very first time; where those government agencies responsible for our health actually pay attention to the poor health of vulnerable communities; and finally, where all agencies and levels of government work in collaboration with us and our community leaders to create communities where health is not only possible, but actively planned for and fostered. All of us have been working for a very long time to level the healthcare landscape. It is with great pleasure and cautious optimism that I say, “we are almost there.” However, we cannot get there without the help of the legal community. The Affordable Care Act is being attacked from all angles, and together we must fight back. This fight must include amicus briefs in support of the Act, legal action at the state level where mandated programs may not be implemented, and even victories in the Supreme Court.²⁵

We have been given the opportunity to reform our healthcare system so that it equitably serves the needs of not only the vulnerable, but all Americans. The keys to success are in our hands and, if we lose this fight, we may never again be given the opportunity to reform our healthcare system. This is an awesome responsibility and, as I look at all of your faces, I am acutely aware that each and every one of you understands the magnitude of the moment. The moment is calling upon us to be the Wiley A. Branton of our time. Our choices

24. See Joseph Lazzaro, *Health Care Reform: How Benefits Portability Will Strengthen the Economy*, DAILYFINANCE (Mar. 17, 2011, 9:00 AM) <http://www.dailyfinance.com/2011/03/17/health-care-reform-how-benefits-portability-economy/> (stating that healthcare reform will increase the freedom of the typical American and strengthen the U.S. economy).

25. See, e.g., Catholic Health World, *CHA Joins in Position Briefs Supporting Affordable Care Act*, CHA (Mar. 15, 2012) http://www.chausa.org/CHA_joins_in_position_briefs_supporting_Affordable_Care_Act.aspx (explaining that CHA has joined other health groups in a legal battle to support healthcare reform).

Keynote Address

in the healthcare fight will make all of the difference in how our history will be written. The poor and the vulnerable need us.

Thank you for your gracious invitation, for the honor of giving this keynote address, for your kind attention, and most importantly, for the choice that I know all of us will make.

Tax-Exempt Hospitals, Community Health Needs and Addressing Disparities

MARY CROSSLEY*

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INTRODUCTION

Assessing the impact of the Patient Protection and Affordable Care Act¹ (the "Act" or "ACA") on the health and well-being of vulnerable populations is an ambitious and gargantuan enterprise. A comprehensive assessment would require the consideration of the implications of one of the most complex, detailed, and multi-faceted pieces of legislation in modern U.S. history, for one of the most complex and seemingly intractable problems facing health policy makers.

* Dean and Professor of Law, University of Pittsburgh School of Law. My thanks go to Emily Harper, for her helpful research assistance; to the participants at the Wiley Branton Symposium, for their valuable comments on my presentation and to the student editors of the *Howard Law Journal*, for organizing an important and thought-provoking symposium.

1. Patient Protection and Affordable Care Act (PPACA), Pub. L. No. 111-148, § 3011, 124 Stat. 378, 937 (2010).

Health disparities based on race and ethnicity, as well as disability, gender, and socio-economic status, are numerous, pervasive, and tenacious. Researchers are still striving mightily to understand and document the complex and interacting factors that produce and perpetuate the differences in health status and health outcomes, so that steps can be taken to diminish and eliminate those instances of inequality.

Of course, addressing disparities is not the central or most commonly known concern of the Affordable Care Act, which may be most widely known for its provisions reforming markets for health insurance and requiring that individuals have health insurance coverage. The drafters of the legislation, however, were by no means oblivious to the problem of disparities, and indeed one goal expressly stated in the ACA is to reduce health disparities across populations.² Embedded throughout the Act are numerous provisions that explicitly seek to diminish disparities, whether by addressing access to health care for persons with disabilities³ or by taking steps to increase the diversity of the health care workforce and to enhance workers' cultural competency.⁴ Moreover, to the extent that the Act is eventually effective in providing health coverage to most of the Americans who are currently uninsured (a disproportionate percentage of whom are non-white), it will predictably lessen existing disparities in rates of health insurance coverage,⁵ which *may* translate into a salutary effect on the disparities

2. § 3011. The Act also calls for the Secretary of Health and Human Services to ensure that federally supported health programs collect and report "data on race, ethnicity, sex, primary language, and disability status for applicants, recipients or participants." § 4302.

3. See §§ 3011, 4203, 4302, 5307(a); Elizabeth Pendo, *Reducing Disparities Through Health Care Reform: Disability and Accessible Medical Equipment*, 2010 UTAH L. REV. 1057, 1073-80 (2010) (describing and citing to specific provisions of the ACA).

4. See § 5307; see also Howard K. Koh et al., *Reducing Racial and Ethnic Disparities: The Action Plan from the Department of Health and Human Services*, 30 HEALTH AFF. 1822, 1823-24 (2011) (describing elements of the ACA that address health disparities and citing to ACA section 5307). The ACA also created the National Institute on Minority Health and Health Disparities ("NIMHD") at the National Institute of Health by elevating the existing National Center on Minority Health and Health Disparities. See *We Have Unfinished Business: Minority Health Center Now an Institute*, THE NIH RECORD (Oct. 1, 2010), available at <http://nihrecord.od.nih.gov/newsletters/2010/10-01-2010/story3.htm>.

5. For example, the ACA's expansion of Medicaid eligibility is likely to increase the percentage of minority populations that have health insurance coverage. According to the Kaiser Commission on Medicaid and the Uninsured, in 2009, 27% of black Americans and Hispanic Americans (a total of 23 million people) were covered by Medicaid, in contrast to 11% of non-Hispanic white Americans. The Commission estimates that the ACA's expansion of Medicaid will extend eligibility to nearly 4 million black Americans and nearly 8 million Hispanic Americans. See Kaiser Comm'n on Medicaid and the Uninsured, "Medicaid's Role for Black Americans" (May 2011), available at <http://www.kff.org/medicaid/8188.cfm>; Kaiser Comm'n on Medicaid and the Uninsured, "Medicaid's Role for Hispanic Americans" (May 2011), available at <http://www.kff.org/medicaid/8189.cfm>. Because the Medicaid program is administered by the

in health outcomes and health status experienced by members of racial and ethnic minorities.⁶

Beyond the statutory sections that explicitly seek to address disparities, and those that predictably may have some effect on disparities, are the large bulk of the Act's provisions, which are apparently entirely unconcerned with disparities. This Essay focuses on a section that falls into the latter group—a provision establishing new requirements for federally tax-exempt hospitals⁷—that has the potential to play a meaningful role in addressing disparities. In particular, I will consider the possibility that the new requirement that hospitals engage in regular community health needs assessments might be used as a mechanism for both gaining a better understanding of concrete and particular instances of disparities and developing approaches to responding to those disparities.

This Essay suggests that the community health needs assessment (CHNA) requirement could be implemented in such a way that it would function as a valuable addition to the existing toolkit for addressing disparities. After providing a brief background on hospital tax exemption and a description of the new requirement imposed by the ACA in Parts I and II, respectively, in Parts III and IV I will sketch out several ways in which the CHNA may add value. Of particular note is the potential that the community-orientation inherent in the CHNA may encourage hospitals' use of a wider-angled lens and the incorporation of public health expertise in examining and responding to disparities. Realizing this potential value, however, is by no means assured, for several significant barriers exist to a thoughtful, coordinated, disparities-sensitive application of the CHNA requirement. Part V highlights several of these potential barriers, and Part VI concludes by suggesting some steps to increase the likelihood that this new requirement might help diminish the disparities that exist in

states, however, states' decisions on how to handle specific implementation issues will determine whether changes will actually improve or instead exacerbate disparities. Cf. Michael Campbell, *Did I Do That? An Argument for Requiring Pennsylvania to Evaluate the Racial Impact of Medicaid Policy Decisions Prior to Implementation*, 82 *TEMPLE L. REV.* 1163, 1164 (2010) (recommending the requirement that a "racial impact statement accompany proposed policy decisions by the Medicaid agency and its major contractors"); John V. Jacobi et al., *Implementing Health Reform at the State Level: Access and Care for Vulnerable Populations*, 39 *J.L. MED. & ETHICS* 69, 69 (Supp. 1 2011).

6. Cf. Calvin B. Johnson, *Health Care Reform, the Law, and Eliminating Disparities*, 82 *TEMPLE L. REV.* 1137, 1137 (2010) ("[S]ome of the enacted changes have clear implications for impacting health disparities. Perhaps the most recognizable example with measurable impact is the effect of broader insurance coverage on disparities in access to care.").

7. See 26 U.S.C. § 501(r) (2006).

communities across the country and add to our collective understanding of what interventions are effective in reducing disparities.

I. BRIEF BACKGROUND REGARDING FEDERAL TAX-EXEMPTION STANDARDS FOR HOSPITALS

The historical evolution of the standards applicable to nonprofit hospitals seeking the benefit of federal tax exemption has been thoroughly detailed elsewhere,⁸ and need not be repeated at any length here. Several aspects of that history merit noting, however, as providing important context for understanding the new CHNA requirement. First, most nonprofit hospitals achieve their tax-exempt status through reliance on Section 501(c)(3) of the Internal Revenue Code as institutions that are “organized and operated exclusively for . . . charitable . . . purposes,”⁹ but the regulatory approach to how hospitals demonstrate such operation has changed over the decades. Prior to 1969, the Internal Revenue Service (“IRS”) test asked whether a hospital operated “to the extent of its financial ability for those not able to pay.”¹⁰ The IRS largely abandoned this explicit focus on providing free care as the *quid pro quo* for the benefits of tax exemption in 1969, after the creation of the Medicare and Medicaid programs left hospitals concerned that there would no longer be a robust need for charity care.¹¹ That year the IRS promulgated the “community benefit” standard for judging hospitals’ entitlement to tax-exempt status, a standard that has endured for over four decades.¹² The Revenue Ruling¹³ establishing the community benefit standard articulated a series of fairly general, non-quantitative factors¹⁴ deemed relevant to judging

8. See generally Jessica Berg, *Putting the Community Back into the “Community Benefit” Standard*, 44 GA. L. REV. 375 (2010) (providing background on tax-exempt hospitals and the current community benefit standard); Daniel M. Fox & Daniel C. Schaffer, *Tax Administration as Health Policy: Hospitals, the Internal Revenue Service, and the Courts*, 16 J. HEALTH POL. POL’Y & L. 251 (1991) (linking the recent history of health policy with the assumptions that govern the making of tax policy).

9. 26 U.S.C. § 501(c)(3) (2006).

10. See Rev. Rul. 56-185, 1956-1 C.B. 202, available at <http://www.irs.gov/pub/irs-tege/rr56-185.pdf>.

11. See Berg, *supra* note 8, at 381.

12. *Id.*

13. Rev. Rul. 69-545, 1969-2 C.B. 117, available at <http://www.irs.gov/pub/irs-tege/rr69-545.pdf>.

14. These factors include whether a hospital: (1) operates an emergency room open to all persons needing emergency treatment; (2) provides care to all persons able to pay directly or through insurance; (3) serves a public rather than private interest; (4) maintains a medical staff available to all qualified physicians in the area; and (5) uses surplus revenues to improve the quality of patient care, facilities, medical training, education, and research. *Id.*

whether a hospital is providing sufficient community benefit, leaving to hospitals a significant degree of latitude in how exactly they provided the community benefits.

In general, tax-exempt hospitals' accountability for providing quantifiable community benefits has been quite limited for most of the time since the standard was adopted. Over the past few decades, however, the attention of policy makers, and even at times the public,¹⁵ has focused sporadically on what kinds of benefits communities actually receive from the operation of tax-exempt hospitals and whether those benefits justify the substantial tax revenue forgone as a result of that tax exemption.¹⁶ That attention has been magnified as the for-profit segment of the hospital industry has grown¹⁷ (raising questions as to whether the conduct of tax-exempt hospitals provides benefits distinct from those provided by for-profit hospitals)¹⁸ and as news accounts of hospitals treating patients unable to pay for care in a distinctly uncharitable fashion¹⁹ and paying their executives handsome sums have suggested that some hospitals place a higher value on revenue generation and private benefit than on caring for fitting subjects of charity.²⁰ In recent years, the IRS has beefed up hospitals' reporting requirements with respect to what they do to satisfy the community benefit requirement and has systematically inquired into

15. See, e.g., Scott Allen & Marcella Bombardieri, *Much is Given by Hospitals, More is Asked; Nonprofits Reaping More in Tax Breaks than They Report in Charity Work. Some Say That Must Change*, BOS. GLOBE, May 31, 2009, at 1; Jim Doyle, *Nonprofit Hospitals' Huge Tax Breaks Under Increasing Scrutiny*, STLTODAY.COM (Oct. 23, 2011), available at http://www.stltoday.com/business/local/article_4a0dcd17-40b3-589f-b0e7-c3dc14b62804.html.

16. Reliable and up-to-date estimates of the aggregate value of hospitals' tax-exemption are hard to come by. As of a decade ago, the estimated value of the federal tax-exempt status enjoyed by hospitals in the United States was \$6,100,000,000. CONG. BUDGET OFFICE, NON-PROFIT HOSPITALS AND THE PROVISION OF COMMUNITY BENEFITS 3, 5 (2006), available at <http://www.cbo.gov/publication/18256>. This figure, which does not include the value of exemption from state and local taxes such as property taxes and sales taxes, includes hospitals' forgone federal income tax liability, their ability to receive tax-deductible donations, and their ability to issue tax-exempt bonds.

17. See Michael I. Sanders, *Health Care Joint Ventures Between Tax-Exempt Organizations and For-Profit Entities*, 15 HEALTH MATRIX 83, 84 (2005).

18. See Frank A. Sloan, *Commercialism in Nonprofit Hospitals*, 17 J. POL'Y ANALYSIS & MGMT. 234, 247 (1998) (cited in Lawrence O. Gostin et al., *Restoring Health to Health Reform: Integrating Medicine and Public Health to Advance the Population's Well Being*, 159 U. PA. L. REV. 1777, 1786 n.31 (2011)).

19. See Amanda W. Thai, *Is Senator Grassley our Savior?: The Crusade Against "Charitable" Hospitals Attacking Patients for Unpaid Bills*, 96 IOWA L. REV. 761, 770-72 (2011).

20. See Doyle, *supra* note 15.

hospitals' community benefit activities.²¹ At the same time, members of Congress voiced growing concerns about the lack of accountability and clear standards for tax-exempt hospitals.²² In short, the years preceding the ACA's enactment saw the growth of a vigorous discussion among both policy makers and scholars on whether and how to make the test for hospital tax exemption more exacting.²³

II. THE ACA'S NEW REQUIREMENTS FOR TAX-EXEMPT HOSPITALS

So what does all of this talk about hospital tax exemption have to do with health care reform? One of the less publicized provisions of the massive ACA creates a new § 501(r) of the Internal Revenue Code,²⁴ detailing new requirements for hospitals wishing to obtain or retain federal tax-exempt status. Under this new Code provision, hospitals must do the following:

1. establish written policies regarding patient eligibility for financial assistance and the provision of emergency care;
2. limit the amount charged to patients eligible for financial assistance for emergency or medically necessary care to the amount generally billed for insured patients;
3. refrain from pursuing "extraordinary collection actions" without first inquiring whether a patient is eligible for financial assistance; and
4. at least once every three years, conduct a "community health needs assessment" and adopt an "implementation strategy" to respond to the needs identified by the assessment.²⁵

This provision of the ACA was co-authored by Senator Charles Grassley,²⁶ one of the most vocal critics of hospitals' lack of accountability to demonstrate quantifiable community benefits in return for

21. See Bobby A. Courtney, Note, *Hospital Tax-Exemption and the Community Benefit Standard: Considerations for Future Policy Making*, 8 IND. HEALTH L. REV. 365, 372-74 (2010-11) (describing revisions to Form 990 and the IRS's Hospital Compliance Project).

22. *Id.* at 374-76.

23. See, e.g., Berg, *supra* note 8, at 377-78 (advocating for a population health oriented approach to the community benefit standard).

24. PPACA, Pub. L. No. 111-148, § 9007(a), 124 Stat. 119, 855-57 (2010), amended by PPACA, Pub. L. No. 111-148, § 10903(a), 124 Stat. 119, 1016 (to be codified at 26 U.S.C. § 501(r) (and redesignating existing § 501(r) as § 501(s))).

25. *Id.*

26. See Press Release, Senator Chuck Grassley, Grassley's Provisions for Tax-Exempt Hospital Accountability Included in New Health Care Law (Mar. 24, 2010), available at http://www.grassley.senate.gov/news/Article.cfm?customel_dataPageID_1502=25912#.

their tax exemption and the egregious practices some hospitals engaged in with respect to uninsured patients.²⁷ The first three requirements listed above respond directly to concerns about these practices and, more generally, hospitals' lack of transparency regarding indigent care. They stop well short, however, of requiring hospitals to provide any particular quantum of free care to patients unable to pay.²⁸

The final element of section 501(r)(3), requiring hospitals to perform periodic "community health needs assessments," takes a different tack in establishing a seemingly novel—at least from the perspective of federal tax policy—requirement for tax-exempt hospitals. The CHNA requirement actually entails a bundle of requirements. First, a hospital must conduct a CHNA at least once every three years, taking into account "input from persons who represent the broad interests of the community served by the hospital facility, including those with special knowledge of or expertise in public health."²⁹ Once the CHNA has been completed, the hospital must make the assessment "widely available to the public."³⁰ Then the hospital must adopt an "implementation strategy to meet the community health needs identified through such assessment,"³¹ and, finally, it must report to the IRS "how the organization is addressing the needs identified" and "a description of any such needs that are not being addressed together with the reasons why such needs are not being addressed."³² By establishing this multi-step process, the ACA seeks to ensure that tax-exempt hospitals are in fact providing community benefits by requiring them first to assess what specific health needs their communities have, then to take steps to meet those needs, and, finally, to report what they are doing to the IRS.³³ A tax-exempt hospital that fails to comply with these requirements will be subject to a \$50,000 excise tax.³⁴

27. See Press Release, Senator Chuck Grassley, Grassley: IRS Non-Profit Hospitals Study Is Helpful, Treasury Should Look at Restoring Charity Care Standards (Feb. 12, 2009), available at http://www.grassley.senate.gov/news/Article.cfm?custom1_dataPageID_1502=19329.

28. As one commentator notes, these requirements do not affirmatively require hospitals to act charitably; instead, they focus on "stopping manifestly uncharitable behavior To refrain from behaving badly is not, or should not be, equated to behaving well." Roger Colinvaux, *Charity in the 21st Century: Trending Toward Decay*, 11 FLA. TAX REV. 1, 51 (2011).

29. 26 U.S.C. § 501(r)(3)(A)(i) (2006); see also § 501(r)(3)(B)(i).

30. § 501(r)(3)(B)(ii).

31. § 501(r)(3)(A)(ii).

32. PPACA § 9007(d), 124 Stat. 119, 858 (to be codified at 26 U.S.C. § 6033(b)(15)(A)).

33. See *supra* notes 29-32.

34. PPACA, § 9007(b), 124 Stat. 119, 857 (to be codified at 26 U.S.C. § 4959).

Although an obligation to conduct CHNAs in order to retain tax-exempt status represents an entirely new and daunting requirement for most hospitals, hospitals in a dozen states have been subject to similar requirements for some time.³⁵ These states have each adopted some kind of requirement that hospitals seeking tax exemption at the state level must have some kind of process for assessing and responding to the health needs of their communities.

To give hospitals subject to the ACA's new requirements a more complete sense of exactly what they will need to do to satisfy the CHNA requirement,³⁶ in July 2011, the IRS issued a Notice and Request for Comments specifically on this requirement, describing provisions that the Treasury Department and the IRS anticipate will appear in proposed regulations.³⁷ The Notice addresses a number of specific issues, ranging from how hospital organizations with multiple facilities must comply, to how the community served by a hospital should be defined, to how a hospital should document the CHNA it conducts.³⁸ The regulatory guidance, however, does not specifically address how the CHNA requirement might have some bearing on health care disparities or vulnerable populations,³⁹ and it remains to be seen whether any final regulatory action by the Treasury and the IRS will do so. The balance of this Essay will suggest that the new CHNA requirement presents a valuable opportunity to engage hospitals, with their central and at least potentially coordinating role in the health care delivery system, in addressing why vulnerable populations bear a dis-

35. CATHOLIC HEALTH ASS'N, SURVEY OF STATE LAWS/OVERSIGHT RELATED TO COMMUNITY HEALTH NEEDS ASSESSMENTS AND IMPLEMENTATION STRATEGIES (2010), available at http://www.chausa.org/Pages/Our_Work/Community_Benefit/Advocacy_and_Public_Policy/.

36. The CHNA requirements are effective for taxable years beginning after March 23, 2012.

37. NOTICE AND REQUEST FOR COMMENTS REGARDING THE COMMUNITY HEALTH NEEDS ASSESSMENT REQUIREMENT FOR TAX-EXEMPT HOSPITALS, NOTICE 2011-52 (2011) [hereinafter NOTICE 2011-52], available at <http://www.irs.gov/pub/irs-drop/n-11-52.pdf>.

38. For a summary of the IRS Notice, see generally SARA ROSENBAUM, IRS NOTICE AND REQUEST FOR COMMENTS REGARDING THE COMMUNITY HEALTH NEEDS ASSESSMENT REQUIREMENTS FOR TAX-EXEMPT HOSPITALS, available at <http://healthreformgps.org/wp-content/uploads/CHNA-Sara.pdf>.

39. In addressing what a hospital must do in order to satisfy the ACA's requirement that a CHNA must take into account input from persons who represent the broad interests of the community, the Notice does state that a CHNA must at least take into account input from, among others, "leaders, representatives, or members of medically underserved, low-income, and minority populations, and populations with chronic disease needs, in the community served by the hospital facility." ROSENBAUM, *supra* note 38, at 3. The Notice further states that hospitals may also seek input from other persons, including, among others, "community-based organizations, including organizations focused on one or more health issues; health care providers, including community health centers and other providers focusing on medically underserved populations, low-income persons, minority groups, or those with chronic disease needs." NOTICE 2011-52, *supra* note 37, § 3.06.

proportionate burden of morbidity and mortality in many communities.

III. THE CHNA REQUIREMENT AND EFFORTS TO ADDRESS DISPARITIES

How does the ACA's requirement that tax-exempt hospitals begin conducting and responding to community health needs assessments relate to the impact of health care reform on vulnerable communities? A brief examination of one example of the kinds of community health needs that an assessment called for by the ACA might identify quickly reveals the CHNA's potential relevance to addressing health disparities and vulnerable populations.

In October 2011, the *New York Times* published an article titled "Tackling Infant Mortality Rates Among Blacks," describing a particularly alarming disparity in infant mortality rates between black babies and white babies in Pittsburgh, Pennsylvania.⁴⁰ As the *New York Times* article reports, while the overall infant mortality rate in the U.S. (at 6.7 deaths per 1,000 live births) is among the highest in the industrialized world, the infant mortality rates for African Americans (at 13.3) is nearly double that.⁴¹ In Allegheny County, where Pittsburgh is located, the infant mortality rate for African American babies was a whopping 20.7 in 2009, compared to a rate of 4.0 for white babies.⁴² A starker racial disparity with respect to a central measure of health status may be hard to find.

The *New York Times* article goes on to highlight some of the possible reasons behind this disparity, which include a laundry list ranging from some "usual suspects" like the county's privatization of health care services for pregnant women and inequitable access to health care to the possibility that stress may be a factor or that black women may have shorter birth canals. Although the primary causes for the growing gap between black and white infant mortality rates remain a puzzle,⁴³ it seems that the fact that one in fifty black babies in Alle-

40. Timothy Williams, *Tackling High Infant Mortality Rates Among Blacks*, N.Y. TIMES, Oct. 15, 2011, at A10.

41. *Id.*

42. *Id.*

43. *Id.*

Recent studies have shown that poverty, education, access to prenatal care, smoking and even low birth weight do not alone explain the racial gap in infant mortality, and that even black women with graduate degrees are more likely to lose a child in its first year than are white women who did not finish high school.

Id.

gheny County dies before its first birthday would likely be a “community health need” that at least some tax-exempt hospitals in the county might identify as a result of their CHNA. And once the need is identified, under the ACA, the hospital has some accountability for either developing a strategy for addressing that need or explaining to the IRS why it chooses not to address an identified need in its plan.⁴⁴

Given the number and variety of disparities in health access, status, and outcomes already documented in the health services literature, one can imagine that when tax-exempt hospitals across the country go through the process of assessing the health needs in their communities, many will find needs that reflect the disproportionate burden of morbidity and mortality borne by vulnerable populations—at least if those assessments are conducted with some degree of attentiveness towards finding and understanding disparities. And if a hospital’s CHNA identifies health needs that include disparities, then we might hope that the hospital’s strategies for responding to those needs might actually work both to diminish some disparities existing in a particular community and to produce a better understanding of what interventions are and are not successful in reducing disparities so that successes can be replicated in other communities.

Several aspects of the ACA’s requirement that tax-exempt hospitals seek to identify and respond to health needs existing in their communities suggest that this requirement has the potential to be a valuable addition to the existing “toolkit” for addressing disparities.⁴⁵ The next section of this Essay will sketch out some of those aspects.

IV. LEVERAGING THE NEW CHNA REQUIREMENT TO ADDRESS DISPARITIES

The ACA explicitly calls for tax-exempt hospitals, when assessing community health needs, to gather and take into account “input from persons who represent the broad interests of the community served . . . , including those with special knowledge of or expertise in public health.”⁴⁶ This provision is central to the potential that hospi-

44. *See supra* notes 31-32.

45. *See* LEIYU SHI & GREGORY D. STEVENS, VULNERABLE POPULATIONS IN THE UNITED STATES 185-98 (2010) (describing programs seeking to eliminate racial and ethnic disparities). The Federal Government has identified eliminating disparities as one of the four overarching goals of its Healthy People 2020 initiative and in 2011, the Federal Department of Health and Human Services released its first comprehensive Action Plan to Reduce Racial and Ethnic Health Disparities. *See* Koh et al., *supra* note 4, at 1822.

46. *See* 26 U.S.C. § 501(r)(3)(B)(i) (2006).

tals, as they engage in CHNAs, may offer for addressing disparities. Obliging tax-exempt hospitals to give voice to local community members and to incorporate public health perspectives in their assessment of needs makes it more likely that the CHNA process might contribute to producing a community benefit by addressing disparities.

The importance of requiring hospitals that are assessing needs to listen to individuals with public health expertise lies in the potential to shift hospitals' traditional institutional focus on individual health to a perspective that incorporates some level of commitment to a broader conception of community health. Hospitals' traditional focus on individual patient welfare is a product of their historical evolution during the twentieth century as so-called "physicians' workshops," providing a venue for physicians to care for patients too ill to be cared for in their homes.⁴⁷ As such, hospitals have usually been understood as part of the "health care system" or "medical care system," and not as actors within the "public health system." Gostin and his co-authors describe the common understanding of these systems as being distinct:

The health care system is devoted primarily to improving individual health outcomes, focusing on "financing, organizing, and delivering . . . personal medical services." The public health system is devoted primarily to "safeguarding and improving health outcomes in the population," focusing on community-wide interventions to reduce morbidity and premature mortality. Thus, health care is concerned with the individual's care and treatment, while public health is concerned with the health and well-being of populations.⁴⁸

This potential broadening of a hospital's understanding of its role with respect to its community, if it in fact occurs, could be significant and beneficial. Even though, prior to the passage of the ACA, the IRS standard for determining hospitals' tax-exempt status centered on whether the hospital provided a "community benefit," discussions of how to measure community benefit regularly focused on a hospital's provision of charity care—essentially, whether the hospital provided individual-oriented, uncompensated medical care to enough persons in the community.⁴⁹ By contrast, the inclusion of public health input as part of health reform's CHNA requirement signals that hospitals should understand the *quid pro quo* for the value of their tax exemption to be benefits flowing to the community as a population, and not

47. PAUL STARR, *THE SOCIAL TRANSFORMATION OF AMERICAN MEDICINE* 178 (1982).

48. Gostin et al., *supra* note 18, at 1783 (citations omitted).

49. *See id.* at 1790.

simply to individuals within the community. Some scholars have praised the CHNA provision of the ACA for this reason, suggesting that it illustrates a desirable “emerging integration” between the health care and public health systems.⁵⁰

Those advocating more generally for greater attentiveness to public health expertise and research in health policy debates emphasize that many of our society’s health problems—of which disparities are but one group—are better understood as collective problems, rather than simply individual problems (or even the aggregation of individual problems).⁵¹ As a result, the inclusion of public health thinking—with its appreciation for social determinants of health—may permit interventions to address problems most effectively on a structural, rather than individual, level.⁵² Recognizing the potential contribution of a structural approach to remedying disparities, as contrasted with an approach focusing on individual dynamics, parallels the growing recognition in other areas of inequality law (e.g., employment discrimination law) that structural approaches may prove more effective in improving outcomes than the traditional focus on individuals’ intent and actions.⁵³ So understood, the ACA’s call for tax-exempt hospitals to perform CHNAs that include public health perspectives can be seen as stimulating structural responses to racial and ethnic disparities in local communities.⁵⁴

Another important aspect of the strategies that hospitals are called to devise to respond to the health needs identified in their communities is that these strategies will be local in nature. As noted, the new Section 501(r) calls for hospitals to consider input from persons broadly representing the range of interests in the communities served.⁵⁵ This input should help the hospital identify and understand

50. *Id.* at 1787.

51. *See generally, e.g., id.*; Scott Burris, *From Health Care Law to the Social Determinants of Health: A Public Health Law Research Perspective*, 159 U. PA. L. REV. 1649 (2011) (discussing the relationship between social determinants of health and public health law research).

52. *See Burris, supra* note 51, at 1657-62 (discussing structural versus individual interventions to promote health). This idea is not entirely novel. Jessica Berg, writing prior to the passage of the ACA, advocated for an interpretation of the “community benefit” standard that would require hospitals to provide “population health care benefits.” *See Berg, supra* note 8, at 395-402.

53. *See generally* Samuel R. Bagenstos, *The Structural Turn and the Limits of Antidiscrimination Law*, 94 CAL. L. REV. 1 (2006) (describing both the power of and limits to a structural approach to employment discrimination law).

54. Along the same lines, Elizabeth Pendo has suggested that the health care reform law may provide “a new and complementary . . . systems reform approach that could benefit people with disabilities.” Pendo, *supra* note 3, at 1083.

55. 26 U.S.C. § 501(r)(3)(B) (2006).

the particular health needs experienced by the community that it serves.⁵⁶ Public health literature highlights the importance of local community input and engagement to implementing initiatives that seek to change the dynamics producing negative health outcomes.⁵⁷ Moreover, one recent study suggests that national data regarding health disparities may mask the role of particular social environments in explaining disparities and thus underscores the potential value of a local focus in developing policies to address disparities.⁵⁸ The local focus demanded by the CHNA requirement, if applied with an eye to identifying and understanding racial and ethnic disparities, may help us determine whether in fact we should say that “all disparities are local” (to borrow from a saying often attributed to former House Speaker Tip O’Neill).⁵⁹

A third benefit potentially flowing from the ACA’s imposition of the CHNA requirement on tax-exempt hospitals is the generation of data and knowledge that could prove informative and applicable beyond a hospital’s immediate community. Although the Act does not explicitly call for the collection and dissemination of data regarding tax-exempt hospitals’ efforts to address the health needs of their communities, it lays the foundation for such a process by calling for the inclusion of public health expertise.⁶⁰ A failure by hospitals and the public health experts, with whom they are supposed to work, to collect, analyze, and share data relating to hospitals’ strategies to address community needs would seem a terrible waste of an opportunity to better understand the complexities of how disparities are produced and persist. As a team of researchers from RAND recently concluded regarding the value of a public health focus in addressing disparities: “Approaching disparities through a public health framework can pro-

56. Of course, one possible point of contention is how broadly the term “community” should be understood for purposes of the CHNA requirement. See Berg, *supra* note 8, at 409 (noting possible different interpretations of “community”). In its preliminary guidance, the IRS indicated that the term should be interpreted to focus on the geographic community served by a particular hospital facility, rejecting the idea that a multi-hospital system might define the community from a system-wide perspective. See NOTICE 2011-52, *supra* note 37.

57. See generally NEIL BRACHT, HEALTH PROMOTION AT THE COMMUNITY LEVEL: NEW ADVANCES (2d ed. 1999) (discussing aspects of organizing community-wide health promotion).

58. See Thomas LaVeist et al., *Place, Not Race: Disparities Dissipate in Southwest Baltimore When Blacks and Whites Live Under Similar Conditions*, 30 HEALTH AFF. 1880, 1880 (2011).

59. See Martin Tolchin, *Thomas P. O’Neill Jr. Dies at 81; A Power in the House for Decades*, N.Y. TIMES, Jan. 6, 1994, at A1.

60. See STARR, *supra* note 47, at 178.

vide the foundation for developing more robust evidence to inform additional policies for improving access and reducing disparities.”⁶¹

In light of the fact that the ACA calls on hospitals—if they wish to maintain their federal tax-exempt status—to seek input from community stakeholders and public health experts in identifying and responding to the health needs existing in their communities, the new CHNA requirement seems to offer significant potential to become a valuable addition to the existing “toolkit” for addressing racial and ethnic disparities. If implemented with an eye to maximizing this value, the CHNA requirement could involve hospitals more directly in determining whether disparities exist in their communities and why some vulnerable groups suffer particular problems, and it could motivate hospitals to try to do something about the disparities and vulnerabilities they uncover. If realized, the benefits from this engagement and involvement by hospitals could prove a pretty good *quid pro quo* for the many billions of dollars in value that hospitals nationally receive by virtue of their tax exemption.⁶² Several factors exist, however, that could diminish the likelihood that these benefits will result, and the next section will briefly suggest some of these challenges.

V. BARRIERS TO USING THE CHNA AS A TOOL FOR ADDRESSING DISPARITIES

The previous section sketches out a vision of how the ACA’s new requirement for tax-exempt hospitals could provide a helpful complement to existing efforts to understand and address racial and ethnic disparities in health and health care. Several significant barriers, however, may prevent the CHNA requirement from being implemented in a way that would permit the realization of this vision. These include the primary role that the IRS can be expected to play in enforcing the new requirement and hospitals’ predictable reluctance to embrace a shift in their perspective to incorporate a population-focused, rather than patient-focused, understanding of community benefit.

Because the ACA’s new requirements for hospital tax exemption are incorporated into the Tax Code via the new Section 501(r), the IRS is the agency charged with enforcing the CHNA requirement and

61. Kathryn Pitkin Derose et al., *Understanding Disparities In Health Care Access—and Reducing Them—Through a Focus on Public Health*, 30 HEALTH AFF. 1844 (2011).

62. See *supra* note 16.

providing regulatory guidance to hospitals subject to the new law.⁶³ As noted above, the IRS and the Treasury Department in July 2011 issued a Notice and Request for Comments on the CHNA requirement.⁶⁴ That document, which addressed a variety of technical questions about hospitals' obligations under Section 501(r), provided few specifics about how hospitals should solicit and incorporate input from community members or public health experts or about the kinds of needs—for example, disparities—that hospitals might now be called upon to address.⁶⁵

The IRS's failure in the Notice to consider how the ACA's policy goals, which include addressing health disparities across populations,⁶⁶ might be advanced via the new tax-exemption rules for hospitals is not surprising. For decades, the IRS has indirectly made health policy through its enforcement (or lack of enforcement) of the community benefit standard, without professing to bring to bear any particular expertise in the field of health policy.⁶⁷ If the IRS follows this pattern, it seems unlikely that any regulatory guidance it provides with respect to compliance with Section 501(r) will incorporate any emphasis on disparities.

And without meaningful prodding by the IRS, most hospitals may be unlikely to do more than the bare minimum identified as needed to satisfy the new requirement, particularly when it comes to the possibility of widening their focus to include not only individual patients but population-level health needs. The administrative staff of hospitals does not typically include individuals with public health expertise, and hospital leadership may have no desire and little incentive to partner with public health experts or community members any more than necessary in conducting the mandated CHNA.⁶⁸ Given the

63. Section 9007(a)(7) of the ACA, which creates the new section 501(r) in the Internal Revenue Code and its CHNA requirement grants "the Secretary" regulatory authority with respect to the provisions of section 9007(a). Later references in section 9007 are to "the Secretary of the Treasury." PPACA, Pub. L. No. 111-148 § 9007(c), 124 Stat. 119 (2010).

64. *See supra* note 37.

65. *Id.*

66. *See supra* note 2.

67. *Cf.* Lucinda E. Jesson, *Creating Health Policy Through the Tax Code*, in *BEYOND EFFICIENCY* (forthcoming 2012), available at <http://ssrn.com/abstract=1695673>; *see also* John D. Colombo, *The Failure of Community Benefit*, 15 *HEALTH MATRIX* 29, 59 (2005) ("The one thing that virtually everyone who writes or thinks about tax exemption for health care providers agrees on is that current tax exemption policies make taxing authorities unwitting (and often uninformed) major players in health care policy.").

68. *Cf.* Berg, *supra* note 8, at 407 ("[U]sing the [hospital's] existing governing board to oversee community benefit is not adequate.").

many pressures to which non-profit hospitals today are subject, this response can be expected and is not necessarily blameworthy. A real risk exists, however, that many hospitals will not reflect on how the CHNA might provide an opportunity to develop a new level of relationship with their communities, but will instead view the CHNA requirement simply as a new hoop to jump through with the least possible effort expended.⁶⁹

VI. SO SHOULD WE GIVE UP ON THIS IDEA AS “PIE IN THE SKY”?

Adopting this more cynical perspective, it may seem that any hopes that the new CHNA requirement might be implemented in a way that meaningfully advances our collective understanding of, and response to, racial and ethnic disparities are entirely in vain. The barriers to that implementation this Essay has identified are quite daunting, and there are probably more barriers not yet identified. That said, the potential value that the CHNA requirement offers with respect to addressing disparities should not be lightly discarded on grounds of impracticality, particularly when we consider the scale of the problem of disparities. A 2009 report by a researcher at the Urban Institute estimated that disparities among African Americans, Hispanics, and non-Hispanic whites with respect to preventable health conditions cost the Medicare and Medicaid programs \$17 billion.⁷⁰ This estimate highlights the scale and seriousness of the problem of disparities not just from a moral perspective, but from an economic perspective as well. Given a problem of this scale and intractability, it seems ill advised to ignore a potentially valuable new tool—even one that it may be challenging to apply.

69. A comment made by an audience member at a lecture that I attended regarding hospitals' community benefit obligations under the ACA reinforced this perception. The audience member, who identified himself as working within a hospital system, stated that this hospital system had turned the question of how to comply with the CHNA requirement over to the system's marketing department. This approach is consistent with how many hospitals have touted their “community benefit” efforts as part of their marketing initiatives.

70. TIMOTHY WAIDMANN, ESTIMATING THE COST OF RACIAL AND ETHNIC DISPARITIES 1 (2009), available at http://www.urban.org/uploadedpdf/411962_health_disparities.pdf. This study examined estimates of excess costs flowing from selected disease disparities (specifically, disparities in diabetes, hypertension, stroke, and renal disease) and disparities in general health status (based on self-reporting of health status as either fair or poor). *Id.* The excess costs were examined by payer, and the author estimated that the health disparities resulted in excess costs of more than \$15 billion to the Medicare program and more than \$2 billion to the Medicaid program in 2009. *Id.*

What steps might enhance the CHNA requirement's potential for addressing disparities and thus keep that requirement from becoming simply a new—and potentially meaningless—hoop for hospitals to jump through? This Essay will conclude by offering a few ideas regarding responses to this question, in hopes of stimulating further thinking and action.

First, policy expertise regarding public health and health disparities should be brought to bear on the regulatory implementation of the CHNA requirement. Doing so would require the IRS to consult with other federal agencies as it develops a regulatory framework, but—while unusual—that is not without precedent. In fact, the Departments of Treasury, Labor, and Health and Human Services already have been working in concert to develop regulations and other administrative guidance with respect to other provisions of the ACA.⁷¹ Even without congressional direction, the Treasury Department could seek to consult with Health and Human Services (particularly its Public Health Service) or the National Institute on Minority Health and Health Disparities as, over time, it provides further regulatory guidance to tax-exempt hospitals on compliance with the CHNA requirement.

Second, as noted above, while hospitals will face the CHNA requirement as a matter of federal law for the first time in 2012, hospitals in some states have been required for some years to perform community needs assessment by state law.⁷² According to a report by the Catholic Health Association, of the dozen states legally requiring hospitals to engage in community health needs assessments, five states require hospitals to give priority to public health needs in their assessments and three call for a focus on vulnerable populations.⁷³ Examining the experience in those states, with respect to both hospitals' efforts to comply with these requirements and state regulators' approaches to enforcement, may provide insights on how the challenges identified above might be met and suggest useful models that could be replicated. This work is already underway. For example, the Hilltop Institute, a research center at the University of Maryland Baltimore County, is producing a series of issue briefs on topics relating to the

71. *See, e.g.*, Summary of Benefits and Coverage and the Uniform Glossary, 76 Fed. Reg. 52,442 (Aug. 22, 2011) (to be codified at 26 C.F.R. pts. 54, 602) (notice issued by Departments of the Treasury, Labor, and Health and Human Services noting that written comments submitted to one Department will be shared with the other Departments).

72. *See* CATHOLIC HEALTH ASS'N, *supra* note 35.

73. *Id.*

implementation of the federal CHNA requirement, including one examining state innovations in community benefit policy.⁷⁴

Moreover, while market pressures may cause some hospital leaders to gravitate towards an approach to compliance that avoids as much as possible the hospital's commitment of further effort and resources, the market is also likely to produce resources for hospitals that seek to take advantage of the opportunity to partner with their communities. Depending on how vigorously and thoughtfully the IRS signals it will enforce the CHNA requirement, consultants may be able to fill hospitals' expertise gap by guiding hospitals' outreach to community members and public health experts in assessing and responding to community needs. Similarly, academic medical centers may be able to take advantage of public health expertise within their own universities to develop a more integrated, and disparities-sensitive, approach to fulfilling the CHNA requirement.

CONCLUSION

This Essay's purpose has been to highlight briefly how a provision of the ACA establishing new requirements for tax-exempt hospitals might be employed as a tool in addressing the persistent problem of racial and ethnic disparities in health status and health care. Hospitals' new obligation to conduct and respond to community health needs assessments that take into account community and public health input could potentially become a potent mechanism for identifying and addressing disparities in local communities. While significant obstacles to realizing this potential exist, this Essay seeks to set the stage for further consideration and action regarding how to maximize the effect of the CHNA requirement in addressing disparities and the needs of vulnerable communities.

74. HILLTOP INSTITUTE, <http://www.hilltopinstitute.org/index.cfm> (last visited Mar. 23, 2012). A copy of the April 2011 issue brief titled "Hospital Community Benefits after the ACA: Building on State Experience" can be found at http://www.hilltopinstitute.org/publication_view.cfm?pubID=289&st=tbl_Publications. The Hilltop Institute's work in this area is being supported by the Robert Wood Johnson Foundation and the Kresge Foundation. *Id.*

Less Talk More Action: Accelerating Innovative Strategies to Eliminate Racial and Ethnic Health Disparities

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INTRODUCTION

The purpose of this Article is to provide the historical context essential for understanding the crisis of persistent racial and ethnic health disparities in the United States. We begin with a description of the National Negro Health Movement, pioneered by Booker T. Washington. This almost forgotten and much neglected historical milestone is the foundation for contemporary minority health, launched in 1985 with the Secretary’s Task Force Report on Black and Minority Health, commissioned by Margaret Heckler, Secretary of the Department of Health and Human Services (DHHS) (1983-1985) under President Ronald Reagan.¹ We move on to characterize the evolution of African American and minority health into four generations of disparities research over the past two decades, and conclude with descriptions of promising and innovative interventions enhanced by passage of the Patient Protection and Affordable Care Act (ACA) of 2010.

I. FROM NEGRO HEALTH IMPROVEMENT TO HEALTH EQUITY: AN HISTORICAL PERSPECTIVE

Disparities research aimed at achieving health equity has its origins with Booker T. Washington’s² launch of Negro Health Improvement Week in 1915.³ Over the next three decades, this humble attempt to bring modern public health to impoverished black commu-

1. SANDRA CROUSE QUINN & STEPHEN B. THOMAS, THE NATIONAL NEGRO HEALTH WEEK, 1915 TO 1951: A DESCRIPTIVE ACCOUNT, *MINORITY HEALTH TODAY* 44 (Mar./Apr. 2001). See generally MARGARET M. HECKLER, REPORT OF THE SECRETARY’S TASK FORCE ON BLACK AND MINORITY HEALTH: VOLUME 1, EXECUTIVE SUMMARY (1985) (“[T]he Department of Health and Human Services (DHHS) has consolidated minority health issues into one report [for the first time].”).

2. Caption for photo: In 1915, Booker T. Washington, founder of Tuskegee Institute, viewed the poor health status of blacks as an obstacle to economic progress and issued a call to action.

3. QUINN & THOMAS, *supra* note 1, at 44.

nities would grow into a national movement.⁴ In 1914, after noting that “45 percent of all deaths among Negroes are preventable,”⁵ Booker T. Washington gathered a group of African American medical, educational, religious, business, and other organizations to advocate for social justice through the launch of Health Improvement Week in April 1915.⁶ The movement combined health and sanitation focused activities with nightly sermons, rallies, speeches, and efforts to involve local health officials in improving minority health.⁷ By the 1930s, it was such an overwhelming success that it was incorporated into the U.S. Public Health Services to form the centerpiece of the new Office of Negro Health Works and became a national effort renamed National Negro Health Week.⁸ The movement continued until 1951, when it became National Public Health Week.⁹

During its remarkable thirty-five year existence, National Negro Health Week resulted in immeasurable impacts on African Americans beyond the improvement in health, sanitation, training, and employment of African American health officials, by providing them an opportunity to develop community organizing skills and public speaking skills through bringing national attention to the issue of health disparities between African Americans and whites.¹⁰ This community-born campaign merged health promotion with health care and social and political advocacy to improve the health of African Americans.¹¹ Under the leadership of Dr. Roscoe Brown, it grew from its community roots of churches, schools, local health departments, fraternal societies, and other local groups; it gained the support of physicians and the sustainability was made possible through the U.S. Public Health Service.¹² However, it never lost the common touch and held onto its

4. See generally DANA R. CHANDLER & CHERYL FERGUSEN, *GUIDE TO THE RECORDS OF THE NATIONAL NEGRO HEALTH* (2009) (outlining the evolution of the National Negro Health Week to the yearround National Negro Health Movement).

5. Phoebe Ann Pollitt, *From National Negro Health Week to National Public Health Week*, 21 J. COMMUNITY HEALTH 401, 402 (1996).

6. QUINN & THOMAS, *supra* note 1, at 44-45.

7. CHANDLER & FERGUSEN, *supra* note 4.

8. See QUINN & THOMAS, *supra* note 1, at 48.

9. Pollitt, *supra* note 5, at 406. (“In 1950, reflecting an increasing spirit of racial cooperation in the country, the work of the Negro Division of the U.S. Public Health Service was blended with the programs intended for white citizens and National Negro Health Week became National Public Health Week.”) (internal quotations omitted).

10. See generally QUINN & THOMAS, *supra* note 1 (describing the National Negro Health Week and public health issues in the black community).

11. *Id.*

12. Pollitt, *supra* note 5, at 405.

community-based approach by retaining the freedom to tailor the campaign to meet the needs of individual communities.¹³

Thirty-four years after the closing of the Office of Negro Health Works, Margaret Heckler, Secretary of U.S. Department of Health and Human Services, released the *Secretary's Task Force Report on Black and Minority Health* that documented excess deaths for minorities from seven causes (cancer, cardiovascular disease, chemical dependency, diabetes, homicide, unintentional injuries, and infant mortality) and highlighted significant health gaps between minorities and whites.¹⁴ Also included in the report were recommendations on how to address these disparities, many of which remain relevant today.¹⁵ With this report, Heckler captured the imagination of the nation, generating demand and bipartisan support for the establishment of the Office on Minority Health.¹⁶ This also set the stage for the creation and development of other minority health offices within government departments including, but not limited to, the National Institutes of Health's (NIH) Office on Minority Health Programs established in 1990, the Centers for Disease Control and Prevention's (CDC) Office of the Associate Director of Minority Health established in 1988 and the Agency for Healthcare Research and Quality's Senior Advisor in Minority Health to name a few.¹⁷ These new offices and administrative positions launched targeted programs designed to bring focused attention to the elimination of racial and ethnic health disparities, such as the following U.S. Department of Health and Human Services' (DHHS) programs: Health Resources and Services Administration's (HRSA) Bureau of Primary Health Care's 100% Access and 0 Disparities Campaign, DHHS's Closing of the Health Gap: Take a Loved One to the Doctor Day, the DHHS's Council on Health Disparities and roadmap document Healthy People.¹⁸

Minority health efforts across multiple federal agencies were coalesced with passage of the ACA, and ushered in a new era of federal provisions designed to close the gap:

13. See generally CHANDLER & FERGUSEN, *supra* note 4 (detailing a history of the National Negro Health Week campaign).

14. HECKLER, *supra* note 1, at 5.

15. *Id.* at 9-45.

16. See Stephen B. Thomas et al., *Historical and Current Policy Efforts to Eliminate Racial and Ethnic Health Disparities in the United States: Future Opportunities for Public Health Education Research*, 7 HEALTH PROMOTION PRAC. 324, 326 (2006).

17. *Id.*

18. *Id.* at 327.

Among these provisions there are specific requirements that relate to the: (a) reauthorization of the Office of Minority Health to the Office of the Secretary and authorization of appropriations for carrying out the duties of the Office of Minority Health through 2016; (b) establishment of individual offices of minority health within the Agency for Healthcare Research and Quality (AHRQ), Centers for Disease Control and Prevention (CDC), Centers for Medicare & Medicaid Services (CMS), Food and Drug Administration (FDA), Health Resources and Services Administration (HRSA), and Substance Abuse and Mental Health Services Administration (SAMHSA); (c) elevation of the National Center on Minority Health and Health Disparities to an institute within the National Institutes of Health; and, (d) reauthorization of the Indian Health Care Improvement Act.¹⁹

While not an exhaustive list of all the departments and initiatives committed to the elimination of health disparities, the new provisions represent an unprecedented expansion and coordination of federal agencies tackling this problem in the U.S.²⁰

In this article, we describe the evidence of health disparities and examine what we know about the causes of these disparities. We then describe two federal programs, Healthy People 2020 and the ACA, that contain specific provisions and objectives aimed at combating health disparities and provide tools and guidance for how to tackle unequal health and health care. Finally, we discuss two innovative community-level programs (Health Advocates In-Reach and Research (HAIR) the Family History Initiative) that have shown promise in the education about and treatment of minorities' health issues as examples of how neighborhood-based programs are critical components necessary to achieve the nation's goals of eliminating health disparities and improving the health of all Americans.

II. FIRST GENERATION DISPARITIES RESEARCH: THE EVIDENCE

Evidence of racial and ethnic health disparities would be easy to ignore were they not so well documented. The statistics on the dispro-

19. U.S. DEP'T OF HEALTH & HUMAN SERVS., REPORT ON MINORITY HEALTH ACTIVITIES, at vi (2011).

20. Though beyond the scope of this Article, major efforts were also launched at the state level, leading to the March 10, 2005 establishment of the National Association of State Offices of Minority Health. See Thomas, *supra* note 16, at 326. See generally NAT'L ASS'N OF STATE OFFICES OF MINORITY HEALTH, <http://nasomh.virtualforum.com/> (last visited Mar. 20, 2012).

portionate numbers of African Americans that are affected by many diseases in the U.S. paint a grim picture of the continued disparities in health between minorities and non-minorities. On average, African Americans live shorter lives and suffer more from many chronic diseases than whites, including cancer, diabetes, heart disease, HIV/AIDS, stroke, and infant mortality.²¹ For example, according to the 2010 National Center for Health Statistics *Health, United States* report, in 2007, African American men were 1.3 times and 1.4 times, respectively, more likely to be diagnosed with lung and prostate cancer, twice as likely to be diagnosed with stomach cancer, and more likely to die from prostate cancer than whites.²² African American women were 10% less likely to have been diagnosed with breast cancer, and yet were nearly 40% more likely to die from the disease than white women.²³ African Americans are twice as likely to have diabetes, and are 2.2 times more likely to die from the disease.²⁴ A recent study found that the lifetime risk of cardiovascular disease was directly related to the risk-factor burden earlier in life and noted that African Americans have a higher prevalence of adverse risk factors, and thus a higher lifetime risk of cardiovascular disease.²⁵ In fact, African American men are 30% more likely to die from heart disease and are 1.5 times more likely to have high blood pressure as compared to white men.²⁶ African American women are 60% more likely than white women to be obese.²⁷ African Americans suffer more strokes than whites, and are both more likely to die from strokes and to suffer

21. See generally CTR. FOR DISEASE CONTROL & PREVENTION, HEALTH DISPARITIES AND INEQUALITIES REPORT—UNITED STATES (2011) (illustrating health disparities in the African American community).

22. CTR. FOR DISEASE CONTROL AND PREVENTION, HEALTH, UNITED STATES, 2010: WITH SPECIAL FEATURE ON DEATH AND DYING 204-07 (2011).

23. *Cancer and African Americans*, U.S. DEPARTMENT HEALTH & HUMAN SERVICES OFF. MINORITY HEALTH, <http://minorityhealth.hhs.gov/templates/content.aspx?lvl=2&lvlID=51&ID=2826> (last modified Sept. 2, 2011, 2:14 PM).

24. *Diabetes and African Americans*, U.S. DEPARTMENT HEALTH & HUMAN SERVICES OFF. MINORITY HEALTH, <http://minorityhealth.hhs.gov/templates/content.aspx?lvl=2&lvlID=51&ID=3017> (last modified Sept. 14, 2010, 3:35 PM).

25. See Jarett D. Berry et al., *Lifetime Risks of Cardiovascular Disease*, 366 NEW ENG. J. MED. 321, 324 (2012).

26. *Heart Disease and African Americans*, U.S. DEPARTMENT HEALTH & HUMAN SERVICES OFF. MINORITY HEALTH, <http://minorityhealth.hhs.gov/templates/content.aspx?lvl=2&lvlID=51&ID=3018> (last modified Mar. 6, 2012, 9:24 AM).

27. *Obesity and African Americans*, U.S. DEPARTMENT HEALTH & HUMAN SERVICES OFF. MINORITY HEALTH, <http://minorityhealth.hhs.gov/templates/content.aspx?lvl=3&lvlID=537&ID=6456> (last modified Jan. 25, 2011, 4:19 PM).

from disabilities following strokes than whites.²⁸ In 2008, African Americans accounted for 48% of the HIV/AIDS cases in the U.S., though they made up only 13% of the U.S. populations, and death rates from HIV/AIDS are similarly higher for African Americans than whites.²⁹ African American infants are over twice as likely to die as white infants, and four times as likely to die from causes related to low birth weight.³⁰ Unfortunately, the list of disparities is long, and the evidence suggests that little progress has been made to reduce the disproportionate numbers of minorities suffering from these diseases. Though there is evidence that quality of care is improving overall for Americans, few (less than 20%) health disparities between minorities and whites showed evidence of narrowing according to National Healthcare Disparities Report of 2010.³¹

III. SECOND GENERATION DISPARITIES RESEARCH: THE REASONS WHY

The existence of health disparities has been extensively documented now, but the reasons for these disparities are not completely understood. In many studies socioeconomic status (SES) has been linked to health status and outcomes, with those of low SES being worse off in terms of health than those people of higher SES.³² The SES factors that determine health status are complex and likely inter-related in ways that are not yet fully defined. In some simple ways, we can easily identify this relationship. For example, people with lower SES may reside in neighborhoods that are populated by high numbers

28. *Stroke and African Americans*, U.S. DEPARTMENT HEALTH & HUMAN SERVICES OFF. MINORITY HEALTH, <http://minorityhealth.hhs.gov/templates/content.aspx?lvl=3&lvlID=10&ID=3022> (last modified Mar. 13, 2012, 3:20 PM).

29. *HIV/AIDS and African Americans*, U.S. DEPARTMENT HEALTH & HUMAN SERVICES OFF. MINORITY HEALTH, <http://minorityhealth.hhs.gov/templates/content.aspx?lvl=3&lvlID=7&ID=3019> (last modified Dec. 8, 2011, 11:54 AM).

30. *Infant Mortality and African Americans*, U.S. DEPARTMENT HEALTH & HUMAN SERVICES OFF. MINORITY HEALTH, <http://minorityhealth.hhs.gov/templates/content.aspx?lvl=3&lvlID=8&ID=3021> (last modified July 22, 2011, 3:17 PM).

31. U.S. DEP'T OF HEALTH & HUMAN SERVS., 2010 NATIONAL HEALTHCARE DISPARITIES REPORT 7 (2010).

32. See generally Nancy E. Adler et al., *Socioeconomic Status and Health: The Challenge of the Gradient*, 49 AM. PSYCHOL. 15 (1994) (examining of the graded association between SES and health); Aaron Antonovsky, *Social Class, Life Expectancy and Overall Mortality*, 45 MILBANK Q. 31 (1976) (examining the relationship between class and life expectancy); Raymond Illsley & Deborah Baker, *Contextual Variations in the Meaning of Health Inequality*, 32 SOC. SCI. MED. 359 (1991) (examining the contextual determinants of health, beyond class-based analysis).

of fast food restaurants.³³ Fast food consumption has been linked to the prevalence of rising obesity in children because of the high-calorie, inexpensive food options.³⁴ Trans-fats, which are associated with fried foods and have been linked to numerous poor health measures, have recently been shown to have decreased in blood levels in white adults since the FDA instituted regulations requiring food labels to declare the trans-fat content.³⁵ Unfortunately, this study only contains data on white adults, so that while showing that FDA regulations may be effective for promoting healthy behaviors, it prohibits the generalizability of the results because no minorities were involved.³⁶ As the costs of fresh fruits and vegetables are higher than the cost of low-nutrient, high-calorie foods, healthy food choices are limited for those of lower SES.³⁷ Additionally, unsafe neighborhoods, lack of green space, lack of time (due to extensive work schedules) make physical activity difficult—if not impossible—for people with lower SES.³⁸

However, though the link between SES and health does explain many of the differences in health status between minorities and whites, disparities in health persist even after adjusting for typical measures of SES such as income, education, insurance coverage, and poverty, suggesting that more complex socioeconomic or other factors must be involved.³⁹ One potential explanation for the persistence of health disparities between minorities and whites even at “equivalent” SES levels may lie in the racial segregation that still exists in the U.S.

33. See generally Jason P. Block et al., *Fast Food, Race/Ethnicity, and Income: A Geographic Analysis*, 27 AM. J. PREVENTIVE MED. 211 (2004) (examining the relationship between geographic distribution of fast food restaurants and neighborhood socio-demographics).

34. See generally Brennan Davis & Christopher Carpenter, *Proximity of Fast-Food Restaurants to Schools and Adolescent Obesity*, 99 AM. J. PUB. HEALTH 505 (2009) (arguing that there is a relationship between obesity in students and proximity of fast food restaurants to schools); Adam Drewnowski & Nicole Darmon, *Food Choices and Diet Costs: An Economic Analysis*, 135 J. NUTRITION 900 (2005); Adam Drewnowski & S. E. Specter, *Poverty and Obesity: The Role of Energy Density and Energy Costs*, 79 AM. J. CLINICAL NUTRITION 6 (2004).

35. See generally Hubert W. Vesper et al., *Levels of Plasma Trans-Fatty Acids in Non-Hispanic White Adults in the United States in 2000 and 2009*, 307 J. AM. MED. ASS'N 562 (2012) (showing changes in blood TFA levels in white adults between 2000 and 2009).

36. *Id.*

37. See generally Drewnowski & Darmon, *supra* note 34 (“An analysis of the relationships among diet quality, food prices, and diet costs is the main topic of this article.”).

38. David R. Williams & Chiquita Collins, *Racial Residential Segregation: A Fundamental Cause of Racial Disparities in Health*, 116 PUB. HEALTH REP. 404, 409 (2001).

39. See generally David R. Williams, *Race, Socioeconomic Status, and Health: The Added Effects of Racism and Discrimination*, 896 ANNALS N.Y. ACAD. SCI. 173 (1999) (describing how racism adversely affects health); Sharon B. Wyatt et al., *Racism and Cardiovascular Disease in African Americans*, 325 AM. J. MED. SCI. 315 (2003) (explaining that examination of the evidence on how racism may affect rates of CVD, description of disparities in CVD rates between blacks and whites).

and results in different home environments and risk exposures among racial groups. Williams and Collins note that residential segregation is linked to morbidity and mortality, and that there are particular characteristics of segregated neighborhoods that are separate from those of low income, white neighborhoods.⁴⁰ For example, LaVeist and Wallace found that there were more liquor stores per capita in low income and predominantly African American census tracts, and suggested significant associations between the presence of liquor stores and the risk of health related social problems.⁴¹ In addition, there are fewer supermarkets, more small groceries, and higher prices in minority communities, making access to healthy foods difficult.⁴²

Access to health care and health insurance are additional factors that contribute to health disparities in the United States. Families of lower SES, and minorities in particular, have been shown to have less comprehensive health care insurance plans and less access to health care, including lack of personal physicians, access to health screenings, or education about making healthy lifestyle choices.⁴³ In the U.S., primary care is at the base of the health care system, and studies indicate that access to a usual health care source increases the chance of receiving sufficient preventive care and other important health services.⁴⁴ However, data from the Agency for Healthcare Research and

40. Williams & Collins, *supra* note 38, at 409.

41. See generally Thomas A. LaVeist & John M. Wallace, Jr., *Health Risk and Inequitable Distribution of Liquor Stores in African American Neighborhood*, 51 SOC. SCI. MED. 613 (2000) (explaining that disproportionate number of liquor stores in black census tracts after controlling for SES, significant associations between presence of liquor stores and health-related problems).

42. See generally PHILIP R. KAUFMAN ET AL., U.S. DEP'T OF AGRIC., *DO THE POOR PAY MORE FOR FOOD? ITEM SELECTION AND PRICE DIFFERENCES AFFECT LOW-INCOME HOUSEHOLD FOOD COSTS* (1997); Chanjin Chung & Samuel L. Myers, *Do the Poor Pay More for Food? An Analysis of Grocery Store Availability and Food Price Disparities*, 33 J. CONSUMER AFF. 276 (1999) (providing an empirical analysis of food store access and food prices in inner city and suburban neighborhoods, fewer chain grocery stores in inner city neighborhoods contribute to higher food prices); Latetia V. Moore & Ana V. Diez Roux, *Associations of Neighborhood Characteristics with the Location and Type of Food Stores*, 96 AM. J. PUB. HEALTH 325 (2006) (describing associations between local food environment and neighborhood racial/ethnic and SES composition); Lisa M. Powell et al., *Food Store Availability and Neighborhood Characteristics in the United States*, 44 PREVENTIVE MED. 189 (2007) (analyzing food store availability and associations with neighborhood characteristics such as race, ethnicity, and SES).

43. See generally U.S. CENSUS BUREAU, *INCOME, POVERTY, AND HEALTH INSURANCE COVERAGE IN THE UNITED STATES: 2009* (2010) (providing data on income, poverty, and health insurance coverage); Julian Chun-Chung Chow et al., *Racial/Ethnic Disparities in the Use of Mental Health Services in Poverty Areas*, 93 AM. J. PUB. HEALTH 792 (2003) (describing how poverty is related to race and mental health service access); Kevin Fiscella et al., *Inequality in Quality: Addressing Socioeconomic, Racial, and Ethnic Disparities in Health Care*, 283 J. AM. MED. ASS'N 2579 (2000) (reviewing health care disparities).

44. See generally Susan Louise Ettner, *The Relationship Between Continuity of Care and the Health Behaviors of Patients: Does Having a Usual Physician Make a Difference?*, 37 MED. CARE

Quality show that Hispanics and African Americans are more likely than whites to lack a usual source of health care and to rely primarily on hospitals or clinics for their health care needs.⁴⁵

Beyond the availability of regular health care is the more complex and disturbing issue of racism in the health care system. After accounting for insurance status, income, age, and severity of condition, disparities in health care between minorities and whites still exist, and these disparities contribute to increased death rates for minorities from diseases such as cancer, heart disease, and diabetes.⁴⁶ In the National Research Council's publication *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, editors Smedley, Stith and Nelson highlight several studies that concluded that African Americans and Hispanics received lower quality care than whites.⁴⁷ For example, studies revealed that African Americans and Hispanics were less likely than whites to receive appropriate cardiac medication and undergo coronary artery bypass surgery, even at "equivalent" levels of SES.⁴⁸ Another study indicated that while income was not a factor determining quality of care for patients with congestive heart failure or pneumonia in a hospital setting, race did impact the quality of care received, with African American patients receiving lower quality care than white patients.⁴⁹ Additionally, Gornick et al. found race, independent of income, was associated with

547 (1999) (explaining that preventive care visits may affect health behaviors, such as substance abuse); Susan Louise Ettner, *The Timing of Preventive Services for Women and Children: The Effect of Having a Usual Source of Care*, 86 AM. J. PUB. HEALTH 1748 (1996) (stating that the usual source of medical care correlates with earlier rate of preventive services); Barbera Starfield et al., *Contribution of Primary Care to Health Systems and Health*, 83 MILBANK Q. 457 (2005) (explaining that primary care helps prevent illness and death).

45. KAREN SCOTT COLLINS ET AL., U.S. MINORITY HEALTH: A CHARTBOOK 77-79 (1999).

46. BRIAN MEDLEY, *UNEQUAL TREATMENT: CONFRONTING RACIAL AND ETHNIC DISPARITIES IN HEALTH CARE* 29-30 (2003).

47. *Id.*

48. See generally John Z. Ayanian, et al., *Racial Differences in the Use of Revascularization Procedures After Coronary Angiography*, JAMA (May 26, 1993), at 2642-46 (explaining that whites are more likely than blacks to receive revascularization procedures after coronary angiography); John G. Canto, et al., *Relation of Race and Sex to the Use of Reperfusion Therapy in Medicare Beneficiaries with Acute Myocardial Infarction*, 342 NEW ENG. J. MED. 1069 (2000) (explaining that blacks are less likely to receive reperfusion therapy than whites); Edward L. Hannan, et al., *Access to Coronary Artery Bypass Surgery by Race/Ethnicity and Gender Among Patients Who Are Appropriate for Surgery*, MED. CARE (Jan. 1999), at 68-77 (stating that African Americans and Hispanics are less likely to undergo coronary artery bypass graft surgery than white, non-Hispanic patients).

49. See generally John Z. Ayanian et al., *Quality of Care by Race and Gender for Congestive Heart Failure and Pneumonia*, MED. CARE (Dec. 1999), at 1260-69 (explaining that black CHF or pneumonia patients received lower quality care than whites).

lowered use of many health care services.⁵⁰ Penner et al. reported that interactions between African American patients and non-black physicians are usually less positive than same-race interactions.⁵¹ Given the shortage of African American physicians and other health professionals, this issue adds additional complexity to the problem.⁵² Greater efforts must be made to reduce racial bias during medical encounters. Success will require more than simply requiring cultural competence training; it must be inclusive of producing more self-reflective health professionals willing to acknowledge their bias and engage in a lifelong process of change.⁵³

The U.S. has made great strides in the determination of causes for health disparities between minorities and non-minorities. The existence of disparities is undisputed, and we know that SES alone does not account for all the disparities.⁵⁴ Institutional racism, residential segregation, racial prejudice among health professionals, and other factors also contribute to the continued disproportionate numbers of minority Americans suffering from preventable disease.⁵⁵ The U.S. has identified the elimination of health disparities as a national priority, and has created numerous federal, state and local initiatives designed to improve minority health to reduce and eliminate health disparities.⁵⁶ In the following section, we will focus on Healthy People 2020 and the ACA as two initiatives that, with different approaches, seek to accomplish the same goal of eliminating health disparities to achieve health equity for all.

50. See generally Marian E. Gornick et al., *Effects of Race and Income on Mortality and Use of Services among Medicare Beneficiaries*, NEW ENG. J. MED. (Sept. 12, 1996), at 791-99 (explaining that black Medicare recipients use fewer services than white Medicare recipients).

51. See generally Louis A. Penner et al., *Aversive Racism and Medical Interactions with Black Patients: A Field Study*, J. EXPERIMENTAL SOC. PSYCHOL. (Mar. 1, 2010), at 436-40 (investigating the role of explicit and implicit biases of non-black physicians and their interactions with black patients).

52. See, e.g., Ivora Hinton, et al., *The Educational Pipeline for Health Care Professionals Understanding the Source of Racial Differences*, J. HUM. RESOURCES (Dec. 21, 2010), at 116-17.

53. See generally Stephen B. Thomas et al., *Toward a Fourth Generation of Disparities Research to Achieve Health Equity*, ANN. REV. PUB. HEALTH (Apr. 2011), at 399-416 (explaining that professionals must address their own biases when interacting with minorities).

54. See above sections on health disparities and relationship between SES and disparities.

55. See generally David R. Williams & Chiquita Collins, *Racial Residential Segregation: A Fundamental Cause of Racial Disparities in Health*, 16 PUB. HEALTH REP. 404 (2001) (explaining how racial segregation in housing causes health disparities).

56. See above sections detailing some of the government programs designed to address and eliminate health disparities.

IV. THIRD GENERATION DISPARITIES RESEARCH:
PROVIDING SOLUTIONS

A. Healthy People 2020

The Healthy People Initiative sets science-based national health goals to improve the health of Americans in ten-year increments.⁵⁷ The Healthy People Initiative began in 1979, with the Surgeon General's report, *Healthy People: The Surgeon General's Report on Health Promotion and Disease Prevention*, which set forth goals to reduce preventable illness and death.⁵⁸ It did not identify health disparities between minorities and whites specifically.⁵⁹ In 2000, the Healthy People goals included the reduction of health disparities.⁶⁰ In Healthy People 2010, the two overarching goals were to increase the quality and years of healthy life and to eliminate health disparities.⁶¹ These goals were continued with the launch of Healthy People 2020, which identifies the achievement of health equity, the elimination of disparities, and improvement of health for all groups one of its overarching goals.⁶² Though some progress has been made to improve the health of Americans, including increased life expectancy and lowered mortality rates from heart disease and stroke, health disparities persist.⁶³

The Healthy People Initiative moves beyond simply identifying issues and setting goals by also providing tools and data to enable States, cities, communities, and individuals to achieve their objectives.⁶⁴ Using a framework termed MAP-IT, Healthy People offers guidance on how to mobilize partners, assess the needs of the community, implement a plan to reach goals, and track progress.⁶⁵ In addition, Healthy People, without explicit acknowledgement, builds on the

57. HEALTHY PEOPLE 2020, <http://www.healthypeople.gov/2020/about/default.aspx> (last visited Mar. 1, 2012).

58. See generally U.S. Dep't of Health, Educ. & Welfare, HEALTHY PEOPLE: THE SURGEON GENERAL'S REPORT ON HEALTH PROMOTION AND DISEASE PREVENTION 29-121 (1979) (detailing a national initiative identifying health risks and formulating detailed health goals).

59. See generally *id.* (detailing the first iteration of the Healthy People initiative).

60. U.S. DEP'T OF HEALTH & HUMAN SERVS., HEALTHY PEOPLE 2000 FINAL REVIEW 1 (2001).

61. U.S. DEP'T HEALTH HUMAN SERVS., HEALTHY PEOPLE 2010: UNDERSTANDING AND IMPROVING HEALTH 14 (2010).

62. HEALTHY PEOPLE, <http://www.healthypeople.gov/2020/about/default.aspx> (last visited Mar. 1, 2012).

63. See, e.g., *id.*

64. See Dep't of Health & Human Servs., *Implementing Healthy People 2020*, HEALTHY PEOPLE, <http://www.healthypeople.gov/2020/implementing/default.aspx> (last visited Feb. 14, 2012) [hereinafter *Implementing Healthy People 2002*].

65. *Id.*

lessons of the first Negro Health Week by remaining close to the community and allowing for the needs of individual communities to be tailored with the interventions designed to reach their goals.⁶⁶

The Healthy People project provides implementation examples on how to address health problems specific to individual communities and also offers guidance on how to identify community partners and stakeholders and how to secure funding.⁶⁷ They also highlight successful real-life implementations, such as the South Side Healthcare Collaborative (SSHC) in Chicago.⁶⁸ The SSHC is a group of more than 30 community health centers and local hospitals that help relieve the burden on overused emergency rooms by providing a network of primary care services to emergency room patients. Since 2009, this program has educated over 14,000 patients about the importance of having a primary doctor, and more than half of those patients have made follow-up appointments at SSHC clinics.⁶⁹

The Healthy People Initiative has many strengths that allow it to be a particularly promising government project for achieving health improvement and health equity in the United States. First, Healthy People objectives are science- and evidence-based, and the data behind the planning of the Healthy People goals is made available to the public via the internet.⁷⁰ Second, Healthy People sets measurable goals and features tracking and monitoring of the progress toward the goals.⁷¹ Third, it involves diverse users and allows its programs and objectives to be tailored to specific users and communities.⁷² And finally, it provides users with tools for securing funding and other support and offers instruction and examples of how to develop implementation plans.⁷³

66. *Id.*

67. *Id.*

68. Dep't of Health & Human Servs., *Who's Leading the Leading Health Indicators?*, HEALTHY PEOPLE, <http://www.healthypeople.gov/2020/LHI/whosleading.aspx> (last visited Feb. 14, 2012).

69. *Id.*

70. Dep't of Health & Human Servs., *About Healthy People*, HEALTHY PEOPLE, <http://healthypeople.gov/2020/about/default.aspx> (last visited Feb. 14, 2012).

71. *Implementing Healthy People 2020, supra* note 64.

72. *Id.*

73. *Id.*

B. The Affordable Care Act of 2010: The Civil Rights of Healthcare

In 2010, the Patient Protection and Affordable Care Act (ACA) was passed by Congress and signed into law by President Barack Obama. The ACA was created to reform our nation's healthcare system and improve the health of and health care for Americans. The ACA contains many provisions designed to improve health care for all Americans, such as expanded insurance coverage to reduce the number of uninsured Americans, increased Medicaid eligibility, more work-based insurance requirements, and elimination of exclusion due to pre-existing conditions.⁷⁴ In addition to these health care improvement initiatives, the ACA includes several provisions that are specifically meant to address health disparities and improve the health of racially and ethnically diverse populations.⁷⁵

One area in which health disparities will be addressed in the ACA is the ability to identify disparities and monitor efforts to reduce them.⁷⁶ To date, non-uniform data collection and reporting has limited efforts to develop evidence-based conclusions about health disparities.⁷⁷ Several provisions in the ACA specifically attempt to improve data collection and reporting by race and ethnicity, which will allow for evidence-based improvement initiatives and increased awareness and knowledge of the persistence of health disparities.⁷⁸

A second issue related to health disparities addressed by the ACA is the lack of diversity in the health care workforce.⁷⁹ Racial and ethnic minorities are far underrepresented in health care fields relative to their proportion in the U.S. population.⁸⁰ Several studies have reported that minorities are distrustful of non-minority physi-

74. See DENNIS P. ANDRULIS ET AL., JOINT CTR. FOR POLITICAL & ECON. STUDIES, PATIENT PROTECTION AND AFFORDABLE CARE ACT OF 2010: ADVANCING HEALTH EQUITY FOR RACIALLY AND ETHNICALLY DIVERSE POPULATIONS 40 (2010).

75. *Id.* at 8-9.

76. *Id.* at 2-3.

77. *Id.* at 2.

78. *Id.* at 2.

79. In 2004, Dr. Louis W. Sullivan et al., Former HHS Secretary (1989-1993) under President George H.W. Bush, released the *Sullivan Commission Report*. See generally LOUIS SULLIVAN, SULLIVAN COMMISSION REPORT, MISSING PERSONS: MINORITIES IN THE HEALTH PROFESSIONS (2004), available at http://depts.washington.edu/ccph/pdf_files/Sullivan_Report_ES.pdf (describing how the lack of minority health professionals is compounding the nation's persistent racial and ethnic health disparities).

80. *Id.* at 2; see also Jordan J. Cohen et al., *The Case for Diversity in the Health Care Workforce*, 21 HEALTH AFF. 90, 90-102 (2002), available at <http://content.healthaffairs.org/content/21/5/90.full.html> (stating that a more diverse health care workforce is necessary to ensure adequate health care for all populations).

cians and other health care providers⁸¹ and are more comfortable with health care providers of the same racial or ethnic group.⁸² Increasing the number of ethnic and racial minorities in the health care workforce may not only allow minorities to be more comfortable and thus seek out health care advice more frequently, but may also improve the communication between patients and their providers if there is linguistic matching. The ACA seeks to increase the diversity in the health care workforce through reauthorization and expansion of Title VII programs to include scholarships and grants to HBCUs and other institutions with strong track records of educating and serving diverse populations.⁸³ The ACA also provides financial support for the training of individuals as home care aides, the recruitment of community health workers, and to support Area Health Education Centers (AHECs) that target underserved populations.⁸⁴

A third area in which the ACA seeks to reduce health disparities is in promoting cultural competence⁸⁵ training and education.⁸⁶ As outlined above, minorities sometimes receive lower quality health care than whites, and this may be especially evident with people for whom English is not the primary language.⁸⁷ The ACA includes provisions for the development of cultural competence training in a variety of venues and for a number of different audiences, as well as

81. See, e.g., L. Ebony Boulware, et al., *Race and Trust in the Health Care System*, 11 PUB. HEALTH REP. 358 (2003) (explaining that patterns of trust in health care system differ by race); M. P. Doescher et al., *Racial and Ethnic Disparities in Perceptions of Physician Style and Trust*, 9(10) ARCHIVES FAMILY MED. 1156 (2000) (stating that minority patients reported less satisfaction and trust in their physicians than whites); Chanita H. Halbert et al., *Racial Differences in Trust in Health Care Providers*, 166 ARCHIVES INTERNAL MED. 896 (2006) (illustrating that African Americans are more likely than whites to have low levels of trust in health care providers).

82. See, e.g., Lisa A. Cooper, et al., *Patient-Centered Communication, Ratings of Care, and Concordance of Patient and Physician Race*, 138 ANNALS INTERNAL MED. 907, 907-15 (2003) (showing that race-concordant visits are longer and more positive); Thomas A. Laveist & Amani Nuru-Jeter, *Is Doctor-Patient Race Concordance Associated with Greater Satisfaction with Care?*, 43 J. HEALTH SOC. BEHAV. 296, 296-306 (2002) (stating that race concordance correlates with satisfaction).

83. ANDRULIS ET AL., *supra* note 74, at 3.

84. *Id.* at 3.

85. The Thomas article takes issue with cultural competence as the only measure of responsiveness to this provision. Thomas, *supra* note 53, at 399-416. The authors write that “[t]his focus on cultural competence contributes to the use of attendance at workshops as evidence of competence. Our concern is that the proliferation of cultural competence workshops and guides may create an artificial sense of efficacy with regard to engaging people of different racial and ethnic backgrounds.” *Id.* at 411. They go on to describe a complementary approach: “[cultural confidence as] a lifelong process based on the individual’s self-reflection about their personal biases and prejudices.” *Id.*

86. ANDRULIS ET AL., *supra* note 74, at 4-5.

87. HOLLY MEAD ET AL., *RACIAL AND ETHNIC DISPARITIES IN U.S. HEALTHCARE: A CHARTBOOK* 61-65 (2008).

promoting the Office of Minority Health (OMH) within the chain of command in the federal government.⁸⁸

Additionally, the ACA seeks to increase the resources available to conduct research into health disparities. The ACA promoted the National Center on Minority Health and Health Disparities to Institute status, giving it greater authority to carry out disparity research within the NIH.⁸⁹ The ACA also increased funding to Centers of Excellence involved with disparities research and also created an institute to examine differences in health care service between minorities and whites.⁹⁰

The inclusion of a prevention focus in the ACA also sets the stage for new actions to achieve health equity.⁹¹ Several initiatives addressed in the ACA are a national oral health campaign with emphasis on minority oral health; standardizing drug labeling to meet the literacy needs of low-literacy individuals; providing culturally appropriate literature and education; and, providing at-home support for maternal and child care.⁹² The ACA also promotes prevention initiatives focused on providing education to racial and ethnic minority adolescents on pregnancy and STDs, and specific provisions designed to address health care needs of American Indians and Alaska Natives, including prevention programs targeting substance abuse, diabetes, and suicide, which are health-related problems disproportionately affecting these populations.⁹³

Finally, the ACA seeks to address disparities by focusing on health insurance reform. Racial and ethnic minorities are more likely than whites to be uninsured or have low-coverage health insurance.⁹⁴ The ACA provides financial support for outreach efforts designed to educate low-income communities about available health insurance and to increase the enrollment within these communities in newly expanded insurance benefits.⁹⁵ The ACA requires that education materials be expressed in plain language, and in language appropriate to the community.⁹⁶

88. ANDRULIS ET AL., *supra* note 74, at 4.

89. *Id.* at 5.

90. *Id.*

91. *See generally* Thomas, *supra* note 53, at 399-416 (discussing various initiatives implemented to achieve health equity).

92. ANDRULIS ET AL., *supra* note 74, at 6.

93. *Id.* at 6.

94. *Id.*

95. *Id.* at 6-7.

96. *Id.*

The ACA brings attention to many of the health care needs of Americans in general, and minority Americans specifically, and highlights the need to eliminate health disparities.⁹⁷ In keeping with the basic method of community engagement to initiate health status change started by Washington's Negro Health Week in 1915, these current government initiatives, Healthy People and the ACA, both recognize the need to involve minority communities. The ACA recognizes the power of community involvement and emphasizes Community-Based Participatory Research (CBPR) as a way to achieve change.⁹⁸ The ACA also supports Community Transformation Grants that target neighborhood-level issues and identifies cultural competence as one of its aims to reduce and eliminate health disparities.⁹⁹ Though the ACA indicates that these community-based initiatives are an important part of the elimination of disparities, it does not provide specific guidance on how to accomplish these neighborhood-level activities.¹⁰⁰ Healthy People does provide some tools for engaging with communities including ideas to mobilize partners, assess the needs of the community, create a plan to meet objectives, and tracking progress.¹⁰¹ Below, we provide two examples of promising community engagement strategies to increase health knowledge, care and status for African Americans: the Health Advocates In-Reach and Research (HAIR) program and the Family History Initiative.

V. FOURTH GENERATION DISPARITIES RESEARCH:
LESS TALK MORE ACTION¹⁰²

A. Health Advocates In-Reach and Research

The Research HAIR program was inspired by the prominent role barbershops and beauty salons have in the lives of African Americans. One of the few historic professions that provided African Americans with the opportunity to become business owners, barbershops and

97. *Id.* at 1-7.

98. *Id.* at 13.

99. *Id.*

100. *See generally id.* (noting that community-based initiatives will help support healthy lifestyles, but listing no specific initiatives to do so).

101. *Implementing Healthy People 2002, supra* note 64.

102. The Thomas article elaborates on the generations of disparities research and emphasizes the power of the approach as both a descriptive and prescriptive framework. The first three generations were focused on: 1) identification of disparities; 2) reasons for disparities; 3) promising solutions; while the fourth generation is focused on action informed by critical race theory. The aim is to accelerate movement from health disparities to health equity. Thomas et al., *supra* note 53.

beauty salons have served as settings for community building and community organizing since the 1800s.¹⁰³ Today, these venues continue to function as more than a place to get a haircut or style, with barbers and stylists often serving as trusted confidants and the barber-shop or beauty salon serving as a “safe haven” in which to discuss politics, the economy, and relationship issues.¹⁰⁴ With many repeat customers and long-term relationships, barbers and stylists tend to be concerned about the health and well being of their community, and can be mobilized to promote health within the African American community.¹⁰⁵

Historically, barbershop and salon interventions have focused on such health issues as cancer, hypertension, diabetes, kidney disease, stroke, and cardiovascular disease, and have targeted health behaviors such as diet, physical activity, and smoking.¹⁰⁶ Although the aforementioned illnesses and factors of disease are important health issues researchers often select the focus of these interventions with little input from the community.¹⁰⁷ Involving the community in the decision-making process may increase the feeling of community ownership and sustainability of the program. Several barbershop interventions have been shown to have positive impacts on health, such as that by Victor and colleagues who noted increased control of hypertension (HTN) in intervention barbershops, as compared to control the rate in non-intervention barbershops.¹⁰⁸

The idea for HAIR was developed in 2001, when the Department of Health and Human Services launched a national public awareness campaign to address racial and ethnic health disparities leading many African American communities hosting “Take a Loved One to the

103. See, e.g., DOUGLAS WALTER BRISTOL, JR., *KNIGHTS OF THE RAZOR: BLACK BARBERS IN SLAVERY AND FREEDOM* (2009); MELISSA VICTORIA HARRIS-LACEWELL, *BARBERSHOPS, BIBLES, AND BET: EVERYDAY TALK AND BLACK POLITICAL THOUGHT* (2004).

104. COMMUNITY-BASED PARTICIPATORY RESEARCH FOR HEALTH: FROM PROCESS TO OUTCOMES 339 (Meredith Minkler & Nina Wallerstein eds., 2d ed. 2008) [hereinafter COMMUNITY-BASED RESEARCH].

105. See, e.g., BRISTOL, *supra* note 103; Paul L. Hess et al., *Barbershops as Hypertension Detection, Referral, and Follow-Up Centers for Black Men*, 49 *HYPERTENSION* 1040 (2007); Latasha T. Johnson et al., *Beauty Salon Health Intervention Increases Fruit and Vegetable Consumption in African-American Women*, 110 *J. ACAD. NUTRITION & DIETETICS* 941 (2010); Laura A. Linnan, Karen M. Emmons & David B. Abrams, *Beauty and the Beast: Results of the Rhode Island Smokefree Shop Initiative*, 92 *AM. J. PUB. HEALTH* 27, 27-28 (2002).

106. COMMUNITY-BASED RESEARCH, *supra* note 104, at 341.

107. *Id.*

108. Ronald G. Victor et al., *Effectiveness of a Barber-Based Intervention for Improving Hypertension Control in Black Men*, 171 *ARCHIVES INTERNAL MED.* 342 (2011) (stating that barber-shop intervention increased HTN control in patrons).

Doctor Day.” In many African American communities, and specifically in the black neighborhoods of Pittsburgh, many residents did not have a doctor to go to.¹⁰⁹ Building on the idea of utilizing barber-shops as venues for health education and change, the senior author, Dr. Stephen B. Thomas¹¹⁰ launched “Take a Health Professional to the People Day” and partnered with a network of local black barber-shops and salons in Pittsburgh and mobilized medical professionals and public health educators to provide clinical screenings and health risk assessments to people who otherwise did not have easy or readily available access to these lifesaving services.¹¹¹

Gaining the trust and support of the barbers was the first step in developing these partnerships, and there was initial suspicion of University researchers and what they wanted to do in the community.¹¹² We dedicated many resources, including a full-time staff member trained in community-based participatory methods, to educate the barbers about our purpose and train them to become lay health advocates.¹¹³ Also, care was taken to work around their schedules and preferences to ensure minimal disruption to their ability to serve their clientele.¹¹⁴ As time was taken and trust was built, the barbers and stylists became invested in and excited about the project, and what started with three barbershops and ten health professionals in 2001 grew to ten barbershops and beauty salons and over 200 health professionals in 2008, and became the year-round community engaged program, HAIR.¹¹⁵ In 2008, throughout the HAIR barber-shop and salon network, health professionals (including physicians, nurses, and dentists) conducted 700 blood pressure screens, 150 depression screens, and numerous echocardiograms and prostate exams (PSA blood test and Rectal Digital Exams).¹¹⁶

In addition to bringing health education and medical screenings to community members, the barber-shops’ role expanded to include the building of relationships with health sciences schools that had a commitment to address health disparities, but lacked the authentic

109. COMMUNITY-BASED RESEARCH, *supra* note 104, at 341-42.

110. At the time, Dr. Thomas was serving as Director of the Center for Minority Health, and the Inaugural Philip Hallen Professor of Community Health and Social Justice in the Graduate School of Public Health at the University of Pittsburgh.

111. COMMUNITY-BASED RESEARCH, *supra* note 104, at 342.

112. *Id.* at 342-43.

113. *Id.* at 343.

114. *Id.*

115. *Id.* at 342.

116. *Id.* at 343-44.

mechanism to ethically engage the community.¹¹⁷ Through the building of these relationships, HAIR became the architecture upon which the barbershops began to serve as venues for pharmacy and dental students to practice their skills, as clinical rotations for nursing students, and locations to recruit eligible individuals into clinical trials research.¹¹⁸ The HAIR network of barbershops also participated with the Mayo Clinic's Center for Translational Science Activities (CTSA) and the Pittsburgh Research Center's formal "Urban Immersion" course in 2007.¹¹⁹ Physician scientists from the CTSA would work with the health professionals who were placed in the barbershops, to help the physicians develop their "cultural confidence."¹²⁰ Through all these efforts, the community members benefited from receiving valuable medical screening and public health education to which they might otherwise not have access, while the physicians and health care professionals learned how to authentically engage with and understand the health care needs of these communities.¹²¹

Gilbert provides the urban context that anchored the HAIR network barbers and their customers in an extensive network consisting of the Pittsburgh Research Center, the Kingsley Association, the National Broadcasting Company (NBC) local affiliate WPXI-TV, other media partners, and the Robert Wood Johnson Foundation and other local foundations.¹²² Together, this network established and promoted the Healthy Black Family Project, a community-based intervention designed to provide no cost health promotion and disease prevention services for people at risk for type II diabetes and HTN

117. *Id.* at 345.

118. *Id.*

119. *Id.* at 345-46; see also *Taking Healthcare to the People: Mayo Clinic, Univ. of Pittsburgh Collaborate to Reach Patients Where They Live and Work*, MAYO CLINIC: CTR. FOR TRANSLATIONAL SCI. ACTIVITIES (Oct. 10, 2007), <http://www.mayo.edu/ctsa/news/news-stories/taking-healthcare-to-the-people-mayo-clinic-univ-of-pittsburgh-collaborate-to-reach-patients-where-they-live-and-work>.

120. Thomas et al., *supra* note 53, at 399.

Cultural confidence is a lifelong process based on the individual's self-reflection about their personal biases and prejudices. We define a culturally confident person as someone who is flexible and humble enough to admit ignorance and is willing to be uncomfortable addressing complex racialized issues. This new approach is guided by race consciousness, the social construct of race, intersectionality, critical approaches, and disciplinary self-critique, which demand continual discussion and reflection about race and racism.

Id. at 411-12.

121. COMMUNITY-BASED RESEARCH, *supra* note 104, at 346.

122. See generally Keon L. Gilbert et al., *The Urban Context: A Place to Eliminate Health Disparities and Build Organizational Capacity*, 39 J. PREVENTION & INTERVENTION CMTY. 77 (2010) (exploring the process of building capacity to address health disparities in urban neighborhoods).

identified in the barbershops.¹²³ With media coverage showing the barbershops as places to receive health education and medical care in the midst of neighborhoods beset by high crime rates, public health professionals were drawn to these locations to learn about the fundamental needs of daily living and how to serve the African American community.¹²⁴ The general public learned that chronic disease is a factor of neighborhood deprivation, racial residential segregation, and poverty, in addition to personal lifestyle behaviors and access to medical care, and thus, these broader social determinants of health were identified as targets for public policy interventions as well as the traditional medical and public health approach of prevention, treatment, and disease management.¹²⁵

B. Family Health History Initiative

A second successful example of the impact community based campaigns can have on the health of its members can be seen in the Family Health History Initiative (FHH). This project, also led by the senior author, was conducted in the greater Pittsburgh area between May 2004 and June 2008, in a variety of settings throughout the city, including neighborhoods, churches, retirement centers, community health fairs and events, barbershops, beauty salons, and community centers.¹²⁶ In these different settings, trusted by the community, African Americans were invited to complete family health history interviews with Master's level genetic counseling students.¹²⁷ The goals of the FHH project were to provide participants with disease risk assessments based on their family history, and to ask participants if they would like to have their family history information entered into a database that would allow them to be invited to participate in relevant research, including clinical trials.¹²⁸

The graduate students met with each participant individually for thirty to sixty minutes and asked detailed information about the age, health status, health history, and age and cause of death of family

123. COMMUNITY-BASED RESEARCH, *supra* note 104, at 344.

124. *Id.*

125. *Id.*

126. See generally Kristen J. Vogel et al., *The Use of Family Health Histories to Address Health Disparities in an African American Community*, 8 HEALTH PROMOTION PRAC. 350 (2007) (addressing the University of Pittsburgh's Center for Minority Health's Family Health History initiative).

127. *Id.* at 4.

128. *Id.*

members of each participant.¹²⁹ In the development of the pedigree, the graduate students also asked directed questions about cancer, heart disease, and diabetes.¹³⁰ After completing the family health history, the graduate student offered each participant a general risk assessment with a focus on any specific diseases for which the participant might be at increased risk.¹³¹ The student would also provide behavior modification information about how to decrease their risk for certain diseases, such as improved diet, increased physical activity, age-appropriate health screening, and smoking cessation.¹³² Participants were encouraged to share the information with their families and health care providers.¹³³

The individuals who completed the family health history were also invited to enroll in the Minority Research Recruitment Database (MRRD). This database would allow participants who met inclusion criteria for different clinical trials to be contacted and invited to participate in a research study.¹³⁴ From its inception in 2004 through July 2007 approximately 606 family health histories were completed.¹³⁵ Of these approximately 404 (77.5%) agreed to enroll in the MRRD.¹³⁶ Beyond the research nature of the project, there was a wonderful human element, and many of the participants were thrilled to share their family stories with someone who would listen. Many community members who participated in the FHH project expressed satisfaction with the process, with statements such as: “The family health project was very informative and brought to light more about my family history and my chances of developing health problems. You are doing a great thing for our community.” and “This was an enjoyable experience. It will encourage me to have some specific information gathering conversations with family members.”¹³⁷

The framework upon which the FHH initiative is based is the health belief model (HBM), which proposes that individuals will take better care of and control over their health if they understand their risk levels and serious consequences associated with certain diseases

129. *Id.*

130. *Id.*

131. *Id.* at 4.

132. *Id.*

133. *Id.*

134. *Id.* at 4-5.

135. Stephen B. Thomas & Sandra Crouse Quinn, *Poverty Elimination of Urban Health Disparities: Challenge and Opportunity*, 1136 ANNALS N.Y. ACAD. SCI. 111, 122 (2008).

136. *Id.*

137. Vogel et al., *supra* note 126, at 6.

and are knowledgeable about measures they can take to improve or prevent or manage the condition.¹³⁸ The goal of the FHH was to raise awareness of disease susceptibility and to provide accessible intervention strategies to hopefully increase risk-reduction behaviors.¹³⁹

One study related to the FHH specifically examined how it impacted individuals' perceptions of their risk for breast, colon, and prostate cancers and found that the numbers of individuals who had an accurate risk perception for these disease increased after the FHH.¹⁴⁰ This shows that use of FHH may be an important tool in raising the awareness of African Americans' susceptibility to certain diseases based on their family history. Awareness of risk is one of the first steps necessary to bring about behavioral changes associated with lowering that risk. Combined with additional resources, such as expanded preventive care provisions in the ACA or partnerships with local organizations promoting Healthy People 2020, the FHH Initiative can be a powerful tool for improving the health of African Americans and other minority groups.

CONCLUSION

This Article brings to light the long history of community-based interventions that began with Booker T. Washington's Health Improvement Week in 1915 and continues today. Washington's initiative set the stage and provided valuable lessons about how to successfully engage with community members, church groups, business owners, and local officials and leaders to advocate for health improvement as a matter of social justice. This local-grown movement was so successful and gained such momentum that it captured the attention of the U.S. Public Health Services, and set the foundation for many health reforms we take for granted today. The contemporary minority health movement began with the Secretary's Task Force report in 1985 and continues today. With the formal establishment of minority health centers within many government departments, national attention was brought to the issue of health disparities, and illustrated the need for effective and innovative solutions to achieve health equity. In this ar-

138. *Id.* at 3.

139. *Id.*

140. See generally Vinaya S. Murthy et al., *Using a Family History Intervention to Improve Cancer Risk Perception in a Black Community*, 20 J. GENETIC COUNSELING 639 (2011) (studying the influence of a family health history intervention on risk perceptions for breast, colon, and prostate cancers among African Americans in Pittsburgh, PA).

ticle, we highlighted two prominent national efforts that identify the elimination of health disparities as central to their aims, the ACA and the Healthy People Initiative.

The passage of the ACA contains many provisions specifically meant to address the health of minority Americans. That minority Americans are disproportionately affected by many preventable diseases represents a social injustice to these populations, and the U.S. government has recognized shortcomings in our current healthcare system that contribute to these disparities, such as the high cost or unavailability of health insurance, inadequate data collection and management to fully understand health disparities, the lack of a diverse healthcare workforce, among others. The ACA calls for national reform to our healthcare system to address these issues. Beyond the provisions set forth in the ACA, and Healthy People 2020 also seeks health equity for Americans, and identifies the elimination of health disparities as one of its overarching goals. The ACA provides the policy mandate and Healthy People 2020 provides tools and guidance for developing neighborhood level interventions and offers ideas on how to identify and build trusting relationships with community partners essential for eliminating racial and ethnic health disparities.

Both the ACA and Healthy People 2020 build off of Booker T. Washington's Negro Health Movement framework by recognizing the need for a culturally tailored approach and community level programs to address health disparities. Additionally, both move beyond first generation to fourth generation research with specific policy mandates designed to move toward health equity. The ACA includes provisions designed to increase cultural competence by providing resources for training and educational programs and addressing the needs specific to racial and ethnic minority populations. The Healthy People 2020 Initiative also takes a tailored approach, and provides tips and tools for designing culturally appropriate and evidence based programs. Thus, the ACA contains the legal framework and government support for the elimination of health disparities while the Healthy People 2020 offers tools and guidance to achieve the ultimate goal of health equity. Moreover, both of these efforts recognize the importance of a community-engaged approach. We can see the success of community engagement practices since Washington's Negro Health Week and in the numerous community-based programs that exist today. In this Article, we highlighted only two efforts, HAIR and the Family Health His-

tory Initiative, as illustrative examples of specific ways community level programs can bring about improved education and health to minorities.

The resources made available by the ACA are essential to the goal of eliminating health disparities. And yet in February 2012, the U.S. Supreme Court accepted the petition for a writ of certiorari to examine the constitutionality of the ACA.¹⁴¹ As we await the outcome of their deliberations, it will be important for both legal and health scholars to understand the historical context for minority health improvement efforts and realize that the opportunity is to recognize health disparities as *an issue of justice* because specific groups were subjected to systematic racial discrimination and denied the basic benefits of society,¹⁴² a violation of the social contract.¹⁴³

141. *Patient Protection and Affordable Care Act Cases*, SUPREME COURT OF THE UNITED STATES: DOCKET, <http://www.supremecourt.gov/docket/PPAACA.aspx> (last visited Mar. 22, 2012).

142. See generally *THE SOCIAL CONTRACT FROM HOBBS TO RAWLS* (David Boucher & Paul Kelly eds., 1994) (explaining the societal relationship between individuals and government).

143. In April, Health and Human Services Secretary Sebelius stated “. . . Healthcare inequalities have been one of the most persistent forms of injustice, . . . [Now] is not the time to turn back.” David Morgan, *Sebelius Seeks Civil Rights Support for U.S. Healthcare Law* (Apr. 12, 2012), REUTERS WASHINGTON BUREAU, <http://www.reuters.com/article/2012/04/12/us-usa-health-care-rights-idUSBRE83B10820120412>.

Abortion, Contraception and the ACA: The Realignment of Women's Health

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INTRODUCTION

Abortion and contraception have become the two most highly contested health care services in the ongoing debate over the Patient Protection and Affordable Care Act (ACA).¹ During the enactment process, those opposed to abortion and those opposed to the ACA used the process to simultaneously oppose the ACA and to expand funding restrictions on abortion. More recently, in response to Department of Health and Human Services (HHS) rules requiring coverage of prescription contraception as part of women’s preventive care, religious conservatives responded with claims that the rules violate religious freedom.²

Initial interpretations cast these conflicts as extensions of the abortion wars that have pervaded national politics since the 1970s. That explanation is correct, but incomplete. While the conflict and outcomes over abortion, contraception, and the ACA may not have been inevitable, they did follow logically from dominant threads formed during the preceding decades of health policy. This Article situates the debate over abortion, contraception, and the ACA within that broader landscape.

The discussion that follows is an effort to surface what we may be on the verge of losing – a whole body, experience-based understanding of women’s health that is predicate to gender equality and civic participation. The women’s liberation movement has centered around access to fertility control services since the 1960s.³ The women’s health

1. Patient Protection and Affordable Care Act, Pub. L. No. 111-148, 124 Stat. 119 (2010).
2. See *infra* text accompanying notes 250-56.
3. See Rita Rubin, *The Pill Turns 50: Improved Birth Control Didn’t Start the Sexual Revolution, but It Left an Enduring Imprint on Women’s Rights – and Our Culture*, USA TODAY, May 7, 2010, at A1 (discussing the pill in the context of women’s rights); Gloria Steinem, *Margaret Sanger*, TIME (Apr. 13, 1998), <http://www.time.com/time/magazine/article/0,9171,988152,00.html> (discussing how Margaret Sanger’s efforts to legalize birth control spurred the women’s liberation movement).

movement, founded in the late 1960s, linked a broader understanding of women's health with self-determination and equality. However, backlash against civil rights and social justice have challenged that link.

The challenges to women's health and rights have taken many forms. This Article notes that the abortion wars have drawn a line between reproductive and sexual health, on the one hand, and women's health, on the other. The analysis probes the discourses within women's health that maintain or, in some cases, have the potential to erase that line. Notably, the federal government's efforts to promote health disparities research has played a role.⁴ The ostensibly apolitical framing of health disparities helped separate women's health from its experience-based, civil rights foundations.⁵ As a result, the federal approach to health disparities may have made women's health more vulnerable to challenge.⁶

This Article also considers the effects of the ACA's exclusion of abortion and inclusion of contraception on the understanding of women's health. Normatively, the segregation and isolation of abortion narrows the scope of women's health. Materially, the ACA increases barriers to abortion access for women most at risk of unintended pregnancy.⁷ This effect will certainly exacerbate social, economic, and health disparities for low-income women.⁸ The August 2011 HHS rules provide coverage for all Food and Drug Administration (FDA)-approved prescription contraceptives without cost-sharing. In terms of results, this constitutes a victory for women's health and women's rights advocates. Yet, coverage of contraception as preventive care, in conjunction with the broad ban on abortion coverage, also signals a political shift. In effect, the ACA describes contraception as abortion prevention. That description moves contraception from the civil rights framing of women's health established by the Women's Health Movement in the 1960s and 1970s, to a narrower framing that aligns with the agendas of religious conservatives and neoliberals.

While ACA promises to decrease the number of uninsured and reduce health disparities by gender, race and wealth, it does so by sacrificing materially and politically vital health services. The results

4. *See infra* Part II.B.

5. *See id.*

6. *See id.*

7. *See infra* Part III.B.

8. *See id.*

reflect recent trends in wealth distribution in the United States. The population band of those less able to access abortion and determine the course of their lives will expand, and the gap between the tiers in system of health services and rights will grow.

Part I sets out the historical and discursive parameters for defining women's health. It examines the political significance of women's health as a policy approach and civil rights issue, as well as uses of women's reproductive capacity to impose social control. Part II identifies some of the challengers to the rights-based understanding of women's health. The discussion also traces the policy threads that the ACA incorporates. These include the abortion wars, the federal government's approach to health disparities work and its evolution, and the shift to market competition in health care delivery and financing. Part III traces those threads forward into the brokering and content of the ACA, focusing on abortion and contraception coverage issues under the ACA, and the implications for women's health, self-determination and equality.

I. WOMEN'S HEALTH

The Women's Health Movement of the 1960s and 1970s provides a touchstone for understanding the political and material significance of women's health. Women's health advocates defined women's health within the broader women's rights movement.⁹ Women's health advocates challenged patriarchy in the form of paternalistic, male-centric health care delivery.¹⁰ It simultaneously asserted the broader goals of self-determination, gender equality, and civic participation.¹¹ Competing understandings of women's health emerged from the imposition of reproductive technology use, including contraception and sterilization, in ways which situated women as vehicles for social control. "Population control" concerns have justified campaigns and coercion aimed at selected populations from the 1960s.¹² More recently, efforts to address health disparities have also undermined the links between women's health and civil rights.

9. *See infra* Part II.A.

10. *See id.*

11. *See id.*

12. *See* Angela Davis, *Racism, Birth Control, and Reproductive Rights*, in *FROM ABORTION TO REPRODUCTIVE FREEDOM: TRANSFORMING A MOVEMENT* 15, 20-25 (Marlene Gerber Fried ed., 1990) [hereinafter *FROM ABORTION TO REPRODUCTIVE FREEDOM*] (tracing the ways that race and class bias have informed family planning campaigns, eugenics, and sterilization abuse).

A. The Women's Health Movement

The founding story of the Women's Health Movement of the 1960s and 1970s starts with a series of kitchen table conversations in 1969.¹³ Those conversations among women, for women, about women's bodies, fomented a woman-driven challenge to medical authority.¹⁴ More specifically, women's health activists sought access to knowledge about women's bodies and women's health.¹⁵ They challenged medical paternalism and the ways in which it shaped health care delivery and allocated decision-making to doctors.¹⁶

The first results of the kitchen table conversations included the December 1970 print run of 5,000 copies of *Women and Their Bodies*¹⁷ and wide-ranging health advocacy efforts.¹⁸ Women researched and wrote *Women and Their Bodies* as a handbook about women's bodies that situated women's health in a "radically new political and social context."¹⁹ In 1973, the book was retitled, *Our Bodies, Ourselves*, with a print run of 350,000.²⁰ Now, the book is both iconic and one of the most widely used authorities on women's health and sexuality.²¹

The advocacy efforts were myriad. Advocacy efforts included challenges to paternalism in the doctor-patient relationship, the safety of the pill and Diethylstilbestrol ("DES"), overuse of the hysterectomy.

13. SANDRA MORGEN, INTO OUR OWN HANDS: THE WOMEN'S HEALTH MOVEMENT IN THE UNITED STATES, 1969-1990, at 3-4 (2002). For an account of women's health movements in the global setting, see MEREDETH TURSHEN, WOMEN'S HEALTH MOVEMENTS: A GLOBAL FORCE FOR CHANGE (2007).

14. See MORGEN, *supra* note 13, at 4.

15. See generally SHERYL BURT RUZEK, THE WOMEN'S HEALTH MOVEMENT: FEMINIST ALTERNATIVES TO MEDICAL CONTROL (1978) (discussing the rise of the women's health movement in America).

16. *Id.* at 33.

17. BOSTON WOMEN'S HEALTH COLLECTIVE, WOMEN AND THEIR BODIES: A COURSE (1970) [hereinafter BOSTON WOMEN'S HEALTH], available at <http://www.ourbodiesourselves.org/uploads/pdf/OBOS1970.pdf>.

18. See *History of Our Bodies Ourselves and the Boston Women's Health Book Collective*, OUR BODIES OURSELVES [hereinafter *History of Our Bodies Ourselves*], <http://www.ourbodiesourselves.org> (last visited Mar. 2, 2012).

19. *Id.* at 18. One of the opening sections in *Women and their Bodies* situates paternalism in medicine vis à vis capitalism, in a section called, "Women, Medicine and Capitalism." BOSTON WOMEN'S HEALTH, *supra* note 17, at 6.

20. MORGEN, *supra* note 13, at 5.

21. Gina Maranto, *Turning 40, Going Global*, BIOPOLITICAL TIMES BLOG (Sept. 28, 2011), <http://www.geneticsandsociety.org/article.php?id=5871>. Since 1973, 4.5 million copies in twenty-six languages have sold. *Id.* The most recent edition was published in 2011. See *Our Bodies, Ourselves 2011 Edition*, OUR BODIES OURSELVES, <http://www.ourbodiesourselves.org> (last visited Mar. 2, 2012) [hereinafter *Our Bodies, Ourselves 2011 Edition*] (explaining the contents and focus of the revised 2011 Edition of *Our Bodies, Ourselves*).

tomy and radical mastectomy, childbirth practices, abuse of authority for sterilization procedures, medical control over gynecology practices,²² and profit-driven health care.²³ Advocates established self-help clinics,²⁴ midwifery training,²⁵ and of course, they fought for access to safe abortion and contraception.²⁶

Generally, two themes characterized these efforts. Women's health advocates challenged physician control over decision-making.²⁷ They protested the assumption that the harms these procedures or technologies caused were acceptable. In doing so, women's health advocates pushed for health services, procedures and technologies based on both scientific evidence and women's own experiences and needs.²⁸

The women's health movement also contested the ways in which medicine and society more generally defined women and women's roles by their capacity to reproduce. In the 1970s, health studies expert Sheryl Burt Ruzek wrote, "[W]omen do more than 'enter' the health system through their reproductive organs."²⁹ The women's health movement used a gender lens on medicine that exposed traditional health care's focus on women's reproductive capacity. The movement's agenda included non-reproductive issues such as paternalism in routine care,³⁰ breast cancer treatment,³¹ and profit-driven medicine.³² Thus, the women's health movement defined women's

22. See RUZEK, *supra* note 15, at 33-59.

23. MORGEN, *supra* note 13, at 74.

24. *Id.* at 72-74; see also Jane, *Just Call "Jane"*, in FROM ABORTION TO REPRODUCTIVE FREEDOM, *supra* note 12, at 93-100 (describing the growth of the feminist movement and public abortions).

25. See RUZEK, *supra* note 15, at 59.

26. MORGEN, *supra* note 13, at 32-39.

27. RUZEK, *supra* note 15, at 33.

28. *Id.* at 36-44. See generally SEIZING OUR BODIES: THE POLITICS OF WOMEN'S HEALTH (Claudia Dreifus ed., 1977) [hereinafter SEIZING OUR BODIES] (discussing the past and current conditions of the women's health movement).

29. RUZEK, *supra* note 15, at 11.

30. *Id.*, at 32-33; see CAROLE S. WEISMAN, WOMEN'S HEALTH CARE: ACTIVIST TRADITIONS AND INSTITUTIONAL CHANGE 72 (1998); Kay Weiss, *What Medical Students Learn About Women*, in SEIZING OUR BODIES, *supra* note 28, at 212.

31. ROSE KUSHNER, BREAST CANCER: A PERSONAL HISTORY AND INVESTIGATIVE REPORT (1975); Carole S. Weisman, *Breast Cancer Policymaking*, in BREAST CANCER: SOCIETY SHAPES AN EPIDEMIC 213, 217 (Anne S. Kasper & Susan J. Ferguson eds., 2000).

32. See RUZEK, *supra* note 15, at 143; see also Carol A. Brown, *Women Workers in the Health Service Industry*, in SEIZING OUR BODIES, *supra* note 28, at 235-37 ("Health care is a costly but essential commodity . . ."). For a brief assessment of the movement's successes and failures, see TURSHEN, *supra* note 13, at 2-4.

health in terms of the whole body and the lived experience of women.³³

B. *Autonomy and Equality*

The women's health movement and its whole body, the experience-based definition of women's health, formed within a civil rights framework. It arose out of the women's rights movement.³⁴ In fact, women attending the first national women's liberation conference in Boston convened the kitchen table conversations.³⁵ As activist-scholar Angela Davis stated:

It was not a coincidence that women's consciousness of their reproductive rights was born within the organized movement for women's political equality. Indeed, if women remained forever burdened by incessant childbirths and frequent miscarriages, they would hardly be able to exercise the political rights they might win. Moreover, women's new dreams of pursuing careers and other paths of self-development outside marriage and motherhood could only be realized if they could limit and plan their pregnancies.³⁶

Abortion access became an important link between the broader women's rights movement and the women's health movement. One of the core women's rights organizations, the National Organization for Women (NOW) placed legalized abortion on its agenda in 1967, two years before the Boston conference.³⁷ The nascent women's health movement formed an obvious point of convergence between advocacy for abortion access and second wave feminism.³⁸ This convergence placed both legalized abortion and women-controlled health clinics that provided a full range of health services, including abortion, on the list of women's health movement goals.³⁹

33. CHRISTINA LEE, *WOMEN'S HEALTH: PSYCHOLOGICAL AND SOCIAL PERSPECTIVES* 1 (Christine Eiser & Jan Wallander eds., 1998). One women's health scholar, in terms that echo those of the women's health movement, describes a woman-centered perspective on health as "one which starts from a perception that women's perspectives, women's subjectivity, are as legitimate as are men's." *Id.* "Women's health," from this perspective, is much more than obstetrics and gynecology." *Id.* Professor Lee also calls for exploring "the ways in which social myths and stereotypes about appropriate or 'natural' behavior for women impact on their well-being." *Id.* at 2.

34. *See* MORGEN, *supra* note 13, at 3-5.

35. *Id.* at 17.

36. Davis, *supra* note 12, at 18.

37. WEISMAN, *supra* note 30, at 70.

38. *See* MORGEN, *supra* note 13, at 70.

39. *See id.*

Women's health advocates not only worked for abortion access as a civil right, but also framed women's health in civil rights terms. Advocates claimed that what unified women was their "shared experience of a lack of control over their bodies and their health care."⁴⁰ Women's health activists linked not only reproductive rights, but also health, more broadly, to the goals of self-determination and civic participation. The women's health movement made it clear that self-determination over one's own body and health care is a predicate to gender equality and to social, economic, and democratic participation.⁴¹

C. Shifts in "Women's Health"

The women's health movement did not originate or monopolize the definition of women's health. Shifts in the framing and content of women's health have reflected shifts in political discourse over the status of women. Shifts in the scope of women's health often result from trends formed in the abortion wars.⁴² More specifically, the extent to which women's health is understood to refer only to abortion or only to reproductive health and the weight given to societal interests in woman's reproductive health indicate the relative strength of anti-abortion and pro-choice discourse at various times.

1. Women's Health as Reproductive Health

The definition of "women's health" has and remains contested. A conflation between women's health and its subset, women's reproductive health, has been the biggest challenger to the fuller definition that the women's health movement set out.⁴³ As discussed, women's health advocates defined women's health in opposition to biological essentialism and the ways in which it shaped medical practices.⁴⁴ The abortion wars also have played a major role in centering the narrower understanding of women's health.⁴⁵ The virulence of the decades-long political battle over the moral and legal character of abortion has highlighted that particular procedure, that particular biological capac-

40. WEISMAN, *supra* note 30, at 72.

41. *See id.*

42. *See* MORGEN, *supra* note 13, at 181.

43. *See* LEE, *supra* note 33, at 1.

44. *See supra* notes 29-33 and accompanying text.

45. TURSHEN, *supra* note 13, at 156.

ity (pregnancy), and that particular corporeal site (the female body) to the near-exclusion of the rest of women's bodies and women's lives.⁴⁶

2. Reproductive Health: Rights Versus Social Control

Reproductive health itself has acquired different meanings. As discussed, reproductive rights, women's health, and women's rights movements linked reproductive health and reproductive rights, thus situating reproductive health in a civil rights framework.⁴⁷ In contrast, social problems identified during periods of heightened social anxiety sometimes call for reproductive control. For example, population control campaigns in the early 20th Century and again in the 1960s and early-1970s⁴⁸ framed women's reproductive health in utilitarian terms. Population control messaging described women's fertility and lack of family planning as a social problem.⁴⁹

Almost inevitably, historically-rooted narratives of subordination fuse with the social problem and form vectors of blame aimed at the out-group of the moment.⁵⁰ Thus, in the 1970s, the federal program implemented by the Maternal and Child Health and Mental Retardation Amendments expanded from providing prenatal care to distributing contraceptives to low-income women.⁵¹ The perceived hyperfertility and cycle of poverty in low-income communities, particularly low-income African American communities, made the reproductive capacity of women in those communities the primary target of population control efforts.⁵² In that light, population control advocates could call birth control "the bargain of the decade."⁵³ That message nar-

46. *Id.* ("[H]ealth economists and health planners designed programs for the reproductive years, neglecting childhood, adolescence, and old age.").

47. *See supra* text accompanying notes 34-41.

48. For a critical account of the 1960s' and 1970s' discourse on overpopulation, see BETSY HARTMANN, *REPRODUCTIVE RIGHTS AND WRONGS: THE GLOBAL POLITICS OF POPULATION CONTROL AND CONTRACEPTIVE CHOICE* 15-40 (1987).

49. RICKIE SOLINGER, *PREGNANCY AND POWER: A SHORT HISTORY OF REPRODUCTIVE POLITICS IN AMERICA* 164-65 (2005). The women's health movement has itself challenged population control policies aimed at women. *See* Claudia Garcia-Moreno & Amparo Claro, *Challenges from the Women's Health Movement: Women's Rights Versus Population Control*, in *POPULATION POLICIES RECONSIDERED: HEALTH, EMPOWERMENT, AND RIGHTS* 47-61 (Gita Sen, Adrienne Germain & Lincoln C. Chen eds., 1994).

50. *See, e.g.*, Gwendolyn Mink, *The Lady and the Tramp: Gender, Race, and the Origins of the American Welfare State*, in *WOMEN, THE STATE, AND WELFARE* 92-122 (Linda Gordon ed., 1990).

51. Jean Sharpe, *The Birth Controllers*, in *SEIZING OUR BODIES*, *supra* note 28, at 57, 69.

52. SOLINGER, *supra* note 49, at 168-69.

53. Sharpe, *supra* note 51, at 69 (quoting J. Mayone Stycos, population expert at Cornell University) (internal quotation marks omitted).

rowed the focus of reproductive health to poor women's reproductive capacity and simultaneously positioned poor women and women of color as a threat to society.

II. HEALTH DISPARITIES AND WOMEN'S HEALTH

From the 1970s, the abortion wars separated abortion discursively and often materially from the rest of women's health. The politics of abortion and of health care intertwined at times, with significant consequences for women.⁵⁴ For the most part, however, the politics of abortion and health care ran different courses into the first decade of the 21st Century.⁵⁵

A. The Abortion Wars⁵⁶

The abortion wars have pervaded U.S. politics in varying degrees from the 1960s to the present.⁵⁷ The political, legal, and cultural battle over a woman's right to decide is familiar and nearly impossible to ignore. The fervency and persistence of the battle has defined abortion as politically unique. This account simply identifies discursive threads that have and continue to shape both the abortion wars and women's health policy.

In 1973, the Supreme Court issued *Roe v. Wade*, its landmark decision invalidating the criminalization of abortion.⁵⁸ Many trace the abortion wars to earlier dates.⁵⁹ Nearly all agree, however, that *Roe v. Wade* ramped up the stakes for supporters and opponents of the right to decide.⁶⁰ From that time, the abortion wars became highly visible and influential.

Abortion opponents have offered two explanations that have proven enduring and effective. Opponents of abortion initially criticized *Roe v. Wade* primarily as a threat to family. More specifically,

54. Kathryn Kolbert & Andrea Miller, *Legal Strategies for Abortion Rights in the Twenty-First Century*, in *ABORTION WARS: A HALF CENTURY OF STRUGGLE, 1950-2000*, at 95, 107 (Rickie Solinger ed., 1998) [hereinafter *ABORTION WARS*]; Lisa C. Ikemoto, *When a Hospital Becomes Catholic*, 47 *MERCER L. REV.* 1087, 1087-88 (1996).

55. See *infra* notes 116-24 and accompanying text.

56. For accounts of the political battle over abortion using the term, "abortion wars," see *ABORTION WARS*, *supra* note 54; see also CAROLE JOFFE, *DISPATCHES FROM THE ABORTION WARS: THE COSTS OF FANATICISM TO DOCTORS, PATIENTS, AND THE REST OF US* 99-108 (2009); WILLIAM SALETAN, *BEARING RIGHT: HOW CONSERVATIVES WON THE ABORTION WAR* (2003).

57. *ABORTION WARS*, *supra* note 54, at 1.

58. *Roe v. Wade*, 410 U.S. 113, 164-66 (1973).

59. See, e.g., *ABORTION WARS*, *supra* note 54, at 5-6.

60. *Id.* at 6.

abortion opponents expressed fear that abortion would remove the deterrent of unintended pregnancy and undermine traditional norms governing sexuality and gender roles in family.⁶¹ At this time, women's rights and women's health advocates expressed views that directly challenged those of abortion opponents.⁶²

By the late 1970s, mainstream abortion opposition shifted to a pro-life stance.⁶³ This stance centered fetal personhood over traditional family values as abortion opponents' driving moral claim.⁶⁴ While this position assumes women's needs and women's rights should be subordinated to that of the fetus,⁶⁵ the pro-life stance less directly challenged the claim to gender equality than traditional family values did. It shifted the political gaze from gender discrimination to fetal personhood. Liberal pro-choice advocates have staunchly continued the battle for access to abortion as fundamental to women's health and women's rights, but have had to simultaneously fight a moral symbol, the fetus.⁶⁶

From the late 1970s, abortion opponents have succeeded in making abortion less available in many, if not most parts of the country. The resulting restrictions impact low-income women the hardest. One

61. ROSALIND POLLACK PETCHESKY, *ABORTION AND WOMAN'S CHOICE: THE STATE, SEXUALITY, AND REPRODUCTIVE FREEDOM* 241-85 (1990).

62. See, e.g., Amy Kesselman, *Women Versus Connecticut: Conducting a Statewide Hearing on Abortion*, in *ABORTION WARS*, *supra* note 54, at 42, 49 ("In all the Women versus Connecticut literature in this early period, arguments for the legalization of abortion were embedded in a multi-faceted analysis of women's oppression and a critique of capitalism. 'We want control of our bodies,' . . . Women must not be forced into personal and economic dependence on men or on degrading jobs in order to assure adequate care for the children they bear.'")

63. Susan Frelich Appleton, *When Welfare Reforms Promote Abortion: "Personal Responsibility," "Family Values," and the Right to Choose*, 85 *Geo. L.J.* 155, 181-84 (1996) [hereinafter Frelich, *When Welfare Reforms Promote Abortion*].

64. *Id.*

65. See Susan Frelich Appleton, *Gender, Abortion, and Travel After Roe's End*, 51 *ST. LOUIS U. L.J.* 655, 660 (2007) [hereinafter Frelich, *Gender, Abortion, and Travel*]; Reva Siegel, *Reasoning from the Body: A Historical Perspective on Abortion Regulation and Questions of Equal Protection*, 44 *STAN. L. REV.* 261, 277 (1992).

66. See CYNTHIA R. DANIELS, *AT WOMEN'S EXPENSE: STATE POWER AND THE POLITICS OF FETAL RIGHTS* 9-29 (1993) (describing the emergence of "fetal rights"); SALETAN, *supra* note 56, at 37 (briefly recounting the 1983 efforts of pro-lifers "to focus attention on the humanity of the fetus"); see also Elizabeth Harman, *Creation Ethics: The Moral Status of Early Fetuses and the Ethics of Abortion*, 28 *PHIL. & PUB. AFF.* 310 (1999) (explaining the discussions regarding the moral status of the fetus); Albert Mohler, Jr., *The Strongest Argument Against Abortion - the Fetus*, ALBERTMOHLER.COM (Feb. 19, 2004), <http://www.albertmohler.com/2004/02/19/the-strongest-argument-against-abortion-the-fetus/> (stating that pro-life advocates must return the moral focus on the fetus); Westchester Coal. for Legal Abortion, *Legal Abortion: Arguments Pro & Con*, CHOICEMATTERS.ORG, <http://www.choicematters.org/articles/legal-abortion-arguments-pro-con/> (listing pro-choice responses to pro-life assertions regarding the fetus and immorality of abortion).

of the earliest and most devastating laws, the Hyde Amendment,⁶⁷ took direct aim at women's health funding. It carved out abortion and de-funded that health service for women receiving Medicaid.⁶⁸ Other restrictions impose barriers that indirectly increase the cost of abortion. The Hyde Amendment represents the beginning of a long line of regulations that have, in effect, created and maintained a two-tiered system of women's reproductive health and women's rights.⁶⁹

B. Health Disparities

In the 1990s, health policy turned to health status disparities by gender, race, and ethnicity.⁷⁰ The fact that income and wealth stratifications contribute to health disparities was already well-established.⁷¹ Civil rights and community leaders had long noted health differences by race.⁷² Finally, at the 20th Century's end, mainstream policy discourse began to acknowledge that morbidity and mortality rates and other health indicators differed among U.S. populations by gender, race, and ethnicity. As a result, women's health and minority health emerged as public issues in national health policy discourse.

The federal government framed disparities concerns narrowly. The use of *disparities* and *equity*, rather than *discrimination* and *equality*, seemed to push health disparities away from a civil rights framework.⁷³ The language suggested that the existence of health disparities do not necessarily implicate discrimination, structural sub-

67. Pub. L. No. 94-439, 90 Stat. 1418, § 209 (1976); *Harris v. McRae*, 448 U.S. 297, 330 (1980).

68. *Public Funding for Abortion: Medicaid and the Hyde Amendment*, NAT'L ABORTION FED'N (2006), http://www.prochoice.org/pubs_research/publications/downloads/about_abortion/public_funding.pdf [hereinafter *Public Funding for Abortion*].

69. For an account of the "two Americas of reproductive health," see JOFFE, *supra* note 56, at 99-113.

70. Sidney D. Watson, *Foreword to Health Law Symposium*, 48 ST. LOUIS U. L.J. 1, 2-5 (2003).

71. U.S. DEP'T OF HEALTH & HUMAN SERVS., SECRETARY'S TASK FORCE ON BLACK & MINORITY HEALTH 75 (1985) [hereinafter TASK FORCE ON BLACK & MINORITY HEALTH] (discussing income strata and stating that "lack of income and education must be recognized as risk factors for disease and death in Blacks"); Jonathan S. Feinstein, *The Relationship Between Socio-economic Status and Health: A Review of the Literature*, 71 MILBANK Q. 279, 279 (1993).

72. See W.E.B. DU BOIS, *THE HEALTH AND PHYSIQUE OF THE NEGRO AMERICAN* (1906) (reporting on a social study of Negro American health problems); DAVID BARTON SMITH, *HEALTH CARE DIVIDED: RACE AND HEALING A NATION* 37-57 (1999) (discussing views of MLK Jr.); Vanessa Northington Gamble & Deborah Stone, *U.S. Policy on Health Inequities: The Interplay of Politics and Research*, 31 J. HEALTH POL. POL'Y & L. 93, 99-108 (2006).

73. See Gamble & Stone, *supra* note 72, at 96.

ordination, or social and bureaucratic practices based on biased norms as causal factors.⁷⁴

This ostensibly apolitical approach echoed that of the Task Force reports that initiated the federal government's role in health disparities work.⁷⁵ In 1985, two federal task forces issued reports that ignited the federal government's involvement in health disparities work.⁷⁶ The Secretary's Task Force on Black and Minority Health issued a ten-volume report that documented health disparities between the health status of Blacks and African Americans, Native Americans, Hispanics, and Asian and Pacific Islanders, as compared to whites.⁷⁷ The Public Health Service Task Force on Women's Health Issues issued a two-volume report that identified health issues particular to women.⁷⁸ While both reports acknowledged the role of social and economic environment and social norms in health status, both reports focused on "information strategies—improving education, research, data, and communication among agencies—but were silent on the question of politics and political will, as if knowledge deficiencies were the only cause of disparities."⁷⁹

Within the federal government, HHS has taken the lead. In 1994, HHS improved health data collection methods to enable correlation between health data and race and ethnicity data.⁸⁰ HHS has made that data available to health researchers. Health law scholar Sidney Watson observed, this data "prompted a flood of empirical research exploring racial and ethnic disparities in care. Between 1996 and 2002, more than one hundred such studies were reported in the medical literature."⁸¹ Despite the fact that "[t]he studies overwhelmingly conclude that racial and ethnic minorities receive different—and

74. See INST. OF MED. OF THE NAT'L ACADS., *UNEQUAL TREATMENT: CONFRONTING RACIAL AND ETHNIC DISPARITIES IN HEALTH CARE* 160-79 (Brian D. Smedley et al. eds., 2003).

75. See Gamble & Stone, *supra* note 72, at 105.

76. TASK FORCE ON BLACK AND MINORITY HEALTH, *supra* note 71. See generally TASK FORCE ON WOMEN'S HEALTH ISSUES, 100 REPORT OF THE PUBLIC HEALTH SERVICE TASK FORCE ON WOMEN'S HEALTH ISSUES (1985) [hereinafter TASK FORCE ON WOMEN'S HEALTH ISSUES] (discussing women's health issues with the intersection of sociological changes in the U.S.).

77. See generally TASK FORCE ON BLACK AND MINORITY HEALTH, *supra* note 71 (analyzing the knowledge of the significant health factors that affect the health status of blacks, Hispanics, Asian/Pacific Islanders, and Native Americans).

78. See TASK FORCE ON WOMEN'S HEALTH ISSUES, *supra* note 76.

79. Gamble & Stone, *supra* note 72, at 105.

80. See Bruce C. Vladeck, *From the Health Care Financing Administration: Race and Ethnicity Data Collections*, 272 JAMA 761, 761 (1994).

81. Watson, *supra* note 70, at 4.

less-treatment than do white Americans,”⁸² the federal government’s approach has remained significantly information-driven. A major portion of health disparities work has focused on identifying health indicators and documenting the statistical existence, scope, and details of health status and health outcomes among particular populations.⁸³

Health disparities work initially formed within the sphere of biomedicine.⁸⁴ It made its earliest impacts on biomedical research. The discretely tailored research methodologies that biomedicine uses may help explain the narrowness of the federal disparities approach. At the same time, defining health issues on a population basis falls within the parameters of public health. The production of health indicators data on a population basis enables epidemiological analysis and other public health strategies.

Federal public health policy, expressed most clearly in the Healthy People initiatives,⁸⁵ has called for a wider embrace of public health’s emphasis on access, education, and prevention than that of the 1980s.⁸⁶ The Healthy People initiatives started with a 1979 report by the Surgeon General.⁸⁷ Since then, the initiative has issued a new report at the start of each decade.⁸⁸ Each report is intended to set the agenda for federal health policy for the decade to come. The reports are aimed at public health entities, including states and local government. The initiative’s emphasis is expressed in the report titles, which all refer to promoting health and/or disease prevention.⁸⁹

82. *Id.*

83. See Gamble & Stone, *supra* note 72, at 108-11 (critically evaluating the preeminence of the information approach in federal health disparities work); see, e.g., U.S. DEP’T OF HEALTH & HUMAN SERVS., HHS ACTION PLAN TO REDUCE RACIAL AND ETHNIC HEALTH DISPARITIES: A NATION FREE OF DISPARITIES IN HEALTH AND HEALTH CARE 12-14 (2011) [hereinafter ACTION PLAN TO REDUCE RACIAL AND ETHNIC HEALTH DISPARITIES], available at http://www.minorityhealth.hhs.gov/npa/files/Plans/HHS/HHS_Plan_complete.pdf (describing the “Overarching Secretarial Priorities” primarily in terms of information gathering and assessment).

84. See Watson, *supra* note 70, at 4-5; *infra* notes 85-93 and accompanying text.

85. See U.S. Dep’t of Health & Human Servs., *History and Development of Healthy People*, HEALTHYPEOPLE.GOV, <http://www.healthypeople.gov/2020/about/history.aspx> (last visited Mar. 2, 2012) [hereinafter *History and Development of Healthy People*].

86. *Id.*; see also U.S. OFFICE OF POPULATION AFFAIRS, REPRODUCTIVE HEALTH AND HEALTHY PEOPLE 2020, at 4-6 (2010) (setting out educational and community-based programs as key strategies in improving reproductive health outcomes).

87. *History and Development of Healthy People*, *supra* note 85.

88. *Id.*

89. See U.S. DEP’T OF HEALTH, EDUC., & WELFARE, PUB. NO. 79-55071, HEALTHY PEOPLE: THE SURGEON GENERAL’S REPORT ON HEALTH PROMOTION AND DISEASE PREVENTION (1979); U.S. DEP’T OF HEALTH & HUMAN SERVS., HEALTHY PEOPLE: PROMOTING HEALTH/PREVENTING DISEASE: OBJECTIVES FOR THE NATION (1980) [hereinafter PROMOTING HEALTH/PREVENTING DISEASE]; U.S. DEP’T OF HEALTH & HUMAN SERVS., PUB. NO. 91-50213, HEALTHY PEOPLE 2000: NATIONAL HEALTH PROMOTION AND DISEASE PREVENTION OBJEC-

The Healthy People agendas for national health include objectives and frameworks for implementation. The 1985 Task Force report on women's health used the 1990 Healthy People report to identify target objectives with special salience to women's health.⁹⁰ The agendas set out objectives and strategies from a public health perspective. Highlighted strategies include improving access to health services, increasing the availability of health data to public health entities, and expanding means of preventive care, including education.⁹¹ Federal policy on health disparities and federal public health policy converged significantly in their respective emphases on data and education.

C. Health Care in the Market

In the late 20th Century, market mechanisms began to structure the ways in which health care services were delivered and financed.⁹² During that period, neoliberal precepts significantly re-shaped dominant explanations for allocation of health care resources, access to, and quality of care.⁹³ In the 1980s, managed care emerged as the perceived fix for rapidly increasing health care costs.⁹⁴ In the 1990s, managed care became the dominant model for third-party financing.⁹⁵ Privatization expanded into publicly insured services.⁹⁶ And the neoliberal understanding of personal responsibility began to compete with the traditional liberal notion of professional and patient autonomy.

The neoliberal concept of personal responsibility produced several impacts on health policy that probably exacerbated health disparities. The concept operates as a criticism of government interventions in social and economic life. Its most obvious impact was on Congress' debate over whether to reauthorize Aid to Families with Dependent

TIVES (2000); U.S. Dep't of Health and Human Servs. *Healthy People 2010: Understanding and Improving Health* (2000).

90. TASK FORCE ON WOMEN'S HEALTH ISSUES, *supra* note 76, at 74.

91. PROMOTING HEALTH/PREVENTING DISEASE, *supra* note 89.

92. Rand E. Rosenblatt, *The Four Ages of Health Law*, 14 HEALTH MATRIX 155, 175-90 (2004).

93. Sue L.T. McGregor, *Neoliberalism and Health Care*, 25 INT'L J. CONSUMER STUD. 82, 82-89 (2001).

94. DAVID DRANOVE, *CODE RED: AN ECONOMIST EXPLAINS HOW TO REVIVE THE HEALTHCARE SYSTEM WITHOUT DESTROYING IT* 83-84 (2008).

95. *Id.*

96. See Sidney D. Watson, *Commercialization of Medicaid*, 45 ST. LOUIS U. L.J. 53, 63 (2001).

Children in 1996.⁹⁷ The law that substantially reduced the government's role in assisting low-income women and children included the phrase *personal responsibility* in its title.⁹⁸ The law de-linked the resulting form of welfare, Temporary Assistance for Needy Families, from Medicaid.⁹⁹ Personal responsibility also became the prevailing explanation for why employers as well as government should not be responsible for providing health benefits.¹⁰⁰

Personal responsibility affected health disparities work as well. The concept of personal responsibility bolstered explanations for disparities in disease incidence and mortality rates that pointed to “lifestyle.”¹⁰¹ In neoliberal terms, “lifestyle” is matter of personal choice, and resulting health consequences are attributable wholly to those choices.¹⁰² The lifestyle explanation undercut efforts to examine the role of social inequalities in producing health disparities. Finally, market thinking and the norm of personal responsibility affected the understanding of choice itself. For many, including policy makers, a consumerist notion—free market individualism replaced the liberal autonomy-based understanding of choice.¹⁰³

97. See PAUL STARR, *REMEDY AND REACTION: THE PECULIAR AMERICAN STRUGGLE OVER HEALTH CARE REFORM* 135-36 (2011).

98. Personal Responsibility and Work Opportunity Reconciliation Act of 1996, Pub. L. No. 104-193, 110 Stat. 2105.

99. STARR, *supra* note 97, at 136.

100. See generally TIMOTHY STOLTZFUS JOST, *DISSENTLEMENT? THE THREATS FACING OUR PUBLIC HEALTH-CARE PROGRAMS AND A RIGHTS-BASED RESPONSE* 185-86 (2003) (describing conservative criticisms of tax subsidies that incentivize use of employment-based insurance that in turn limits employee choice among health plans, creates job-lock, and dampens wages).

101. See Elizabeth Fee & Nancy Krieger, *Understanding AIDS: Historical Interpretations and the Limits of Biomedical Individualism*, 83 AM. J. PUB. HEALTH 1477, 1481 (1993). In relevant part:

The biomedical model is also premised on the ideology of individualism. Adopting the notion of the abstract individual from liberal political and economic theory, it considers individuals “free” to “choose” health behaviors. It treats people as consumers who make free choices in the marketplace of products and behaviors, and it generally ignores the role of industry, agribusiness, and government in structuring the array of risk factors that individuals are supposed to avoid.

Id.

102. *Id.*

103. See generally Scott Burris, *The Invisibility of Public Health: Population-Level Measures in a Politics of Market Individualism*, 87 AM. J. PUB. HEALTH 1607, 1607-08 (1997); Barry R. Furrow, *Access to Health Care and Political Ideology: Wouldn't You Really Rather Have a Pony?*, 29 W. NEW ENG. L. REV. 405, 415, 418-19 (2007) (arguing for reform of the American health care system).

D. The Configuration of “Women of Color” in Health Policy

Most health disparities work, including that of women’s health advocates and HHS, has treated race/ethnicity and gender as separate tracks. In this iteration of women’s health advocacy, gender equity became the goal.¹⁰⁴ That is, women sought health equity with men. Women’s health advocates “argued that women were entitled to an equitable share of health resources and to health care based on research on *women*, and they sought redress for what they perceived as years of neglect of women’s health problems in research and in health care institutions.”¹⁰⁵

Minority health policy work on health disparities has largely focused on race and ethnicity to the exclusion of gender. Early research revealed how research agendas and health care resources prioritized the needs of white males and simultaneously neglected the needs of communities of color.¹⁰⁶ At the same time, minority health experts paid relatively little attention to gender disparities within minority populations and to the particular health needs of women of color.¹⁰⁷ Minority health advocates made demands similar to those of women’s health advocates.¹⁰⁸ And yet, the federal Office of Women’s Health and the Office of Minority Health rarely interacted.¹⁰⁹ In 1991, the Office of Research on Women’s Health set up a task force to assess then-current women’s health research and to identify opportunities and directions for future research.¹¹⁰ Critics of the resulting agenda pointed to the dearth of attention to women of color and older women.¹¹¹ Health disparities work on each track typically overlooked the health needs of women of color.¹¹²

Despite the parallel track approach, government efforts to document and define the scope of health disparities produced data showing

104. WEISMAN, *supra* note 30, at 78-79.

105. *Id.*

106. TASK FORCE ON BLACK & MINORITY HEALTH, *supra* note 71, at 84-85.

107. Lisa C. Ikemoto, *In the Shadow of Race: Women of Color in Health Disparities Policy*, 39 U.C. DAVIS L. REV. 1023, 1040-42 (2006) [hereinafter Ikemoto, *In the Shadow of Race*].

108. TASK FORCE ON BLACK & MINORITY HEALTH, *supra* note 71, at 84-85.

109. U.S. COMM’N ON CIVIL RIGHTS, *THE HEALTH CARE CHALLENGE: ACKNOWLEDGING DISPARITY, CONFRONTING DISCRIMINATION, AND ENSURING EQUALITY* 120 (1999); Gamble & Stone, *supra* note 72, at 112-13.

110. Nancy Fugate Woods, *The U.S. Women’s Health Research Agenda for the Twenty-First Century*, 25 SIGNS 1269, 1270 (2000).

111. *Id.*

112. See Lisa C. Ikemoto, *The Fuzzy Logic of Race and Gender in the Mismeasure of Asian American Women’s Health Needs*, 65 U. CIN. L. REV. 799, 799 (1997); Ikemoto, *In the Shadow of Race*, *supra* note 107, at 1025.

significant disparities among women by race and ethnicity.¹¹³ The data, along with mostly non-governmental research, policy, and advocacy efforts to push the disparities analysis to address the role of racial inequality, configured a new category in health disparities work.¹¹⁴ In 1994, the National Institute of Health (NIH) issued the NIH Guidelines on the Inclusion of Women and Minorities as Subjects in Clinical Research.¹¹⁵ This prompted discussion that acknowledged disparities among women by race and ethnicity.¹¹⁶ And in 1999, the Office of Research on Women's Health issued an agenda that explicitly acknowledged the gap in research on differences among racial/ethnic populations of women.¹¹⁷ The Office on Women's Health, within HHS, ultimately set out a program with women of color projects.¹¹⁸ In the late 1990s, women's health became a more racially inclusive category and programmatic approach. Women of color are now taken into account in federal health disparities research and policy.¹¹⁹

During this same period, the reproductive rights movement also underwent a shift. As many have observed, white middle-class women have largely driven and populated the mainstream reproductive rights movement.¹²⁰ While women of color have participated in mainstream organizations such as The National Organization for Women, Planned Parenthood, and the National Abortion Rights Action League, women of color also founded women of color-led organizations whose agendas and approaches expressed their own experiences and priorities.¹²¹ These included the National Black Women's Health Project (now Black Women's Health Imperative),¹²² Organizacion

113. See Ikemoto, *In the Shadow of Race*, *supra* note 107, at 1044-46.

114. *Id.* at 1044.

115. *NIH Policy and Guidelines on the Inclusion of Women and Minorities as Subjects in Clinical Research*, U.S. DEP'T OF HEALTH & HUMAN SERVS. (Oct. 2001), http://grants.nih.gov/grants/funding/women_min/guidelines_amended_10_2001.htm.

116. See Woods, *supra* note 110, at 1270.

117. 2 U.S. DEP'T OF HEALTH & HUMAN SERVS. PUB. NO. 99-4386, NAT'L INSTS. OF HEALTH, *AGENDA FOR RESEARCH ON WOMEN'S HEALTH FOR THE 21ST CENTURY: A REPORT OF THE TASK FORCE ON THE NIH WOMEN'S HEALTH RESEARCH AGENDA FOR THE 21ST CENTURY* 38-39 (1999).

118. See *Minority Women's Health*, WOMENSHEALTH.GOV (May 18, 2010), <http://www.womenshealth.gov/minority-health/government-in-action/index.cfm>.

119. See Ikemoto, *In the Shadow of Race*, *supra* note 107, at 1045.

120. MORGEN, *supra* note 13, at 41-69.

121. See Jael Silliman et al., *UNDIVIDED RIGHTS: WOMEN OF COLOR ORGANIZE FOR REPRODUCTIVE JUSTICE* 175 (2004).

122. See *Our Story*, BLACK WOMEN'S HEALTH IMPERATIVE, <http://www.blackwomenshealth.org/about-us/our-story/> (last visited Mar. 4, 2012).

Nacional de la Salud de la Muher Latina,¹²³ and Asian and Pacific Islanders for Reproductive Choice (now Asian Communities for Reproductive Justice).¹²⁴ In the 1990s, the reproductive rights movement underwent at least two significant changes. Mainstream organizations began to make more effective commitments to use race conscious analyses, agendas, and membership outreach.¹²⁵

In addition, key women of color organizations aligned with an emerging progressive social justice movement. Organizations such as Asian Communities for Reproductive Justice,¹²⁶ SisterSong,¹²⁷ and Latina Institute for Reproductive Health¹²⁸ developed and implemented a reproductive justice framework, intending to complement existing reproductive rights and reproductive health projects.¹²⁹ The reproductive justice movement's shift from services and legal rights to challenging existing social structures and cultural norms that maintain inequalities has had its greatest impacts at the community-level.¹³⁰ At the same time, its commitment to coalition building¹³¹ has also enabled it to influence the mainstream movement.

E. Reproductive Health Disparities

1. The Disparities Account of Women's Reproductive Health

Not surprisingly, the disparities account of reproductive health features data. The data shows significant differences among populations of women in a wide range of reproductive health indicators. For

123. See *Outreach*, NAT'L LATINA HEALTH ORG., <http://www.latinahealth.org/milestones.html> (last visited Mar. 4, 2012).

124. See SILLIMAN ET AL., *supra* note 121, at 189.

125. *Id.* at 35-37.

126. See *EMERJ: Building a National Movement for Strong Families*, ASIAN COMMUNITIES FOR REPROD. JUST., <http://reproductivejustice.org/emerj> (last visited Mar. 4, 2012).

127. See *Our Story*, SISTERSONG, http://www.sistersong.net/index.php?option=com_content&view=article&id=25&Itemid=66 (last visited Mar. 4, 2012) [hereinafter SISTERSONG, *Our Story*].

128. See *About NLIRH*, NAT'L LATINA INST. FOR REPROD. HEALTH, <http://latinainstitute.org/about> (last visited Mar. 4, 2012).

129. See, e.g., ASIAN COMMUNITIES FOR REPROD. JUST., *A NEW VISION FOR ADVANCING OUR MOVEMENT FOR REPRODUCTIVE HEALTH, REPRODUCTIVE RIGHTS AND REPRODUCTIVE JUSTICE 2* (2005) [hereinafter *A NEW VISION*], available at <http://reproductivejustice.org/assets/docs/ACRJ-A-New-Vision.pdf>.

130. See SILLIMAN ET AL., *supra* note 121, at 289-90.

131. See EMERJ, *The EMERJ REPRODUCTIVE JUSTICE LENS TOOLKIT 1-8* (2008), available at <http://reproductivejustice.org/assets/docs/ACRJ-RJ-Lens-Toolkit.pdf>; MARIA NAKAE & MOIRA BOWMAN, *INTERSECTIONS AT THE GRASSROOTS: INSIGHTS FROM ORGANIZING FOR REPRODUCTIVE JUSTICE, YOUTH LEADERSHIP, AND IMMIGRANT & REFUGEE RIGHTS 1* (2008), available at <http://reproductivejustice.org/assets/docs/ACRJ-MS2-Intersections-at-the-Grassroots.pdf>; SISTERSONG, *Our Story*, *supra* note 127.

example, the overall rate of unintended pregnancy in the U.S. increased slightly between 2001 and 2006.¹³² During that period, unintended pregnancy rates decreased among higher-income women,¹³³ but increased among particular subgroups, including: women aged twenty to twenty-four;¹³⁴ black women; poor women; women without higher education; and women cohabiting with men.¹³⁵ Women of color are disproportionately represented among women with unintended pregnancies—“black women are three times as likely as white women to experience an unintended pregnancy; Hispanic women are twice as likely.”¹³⁶ Not surprisingly, “[t]he disparities in unintended pregnancy rates result mainly from similar disparities in access to and effective use of contraceptives.”¹³⁷ Although, other factors clearly contribute to unintended pregnancy disparities.¹³⁸

Data indicates that the national abortion rate has declined since the early 1980s;¹³⁹ yet, abortion rates among women of color have remained high.¹⁴⁰ As a result, “[a]bortion has accordingly become increasingly important for poor and minority women’s reproductive autonomy even as it recedes in importance for affluent whites.”¹⁴¹ Publicly funded clinics, including Title X clinics have provided access to health information, contraceptives, and abortion, thus helping “millions of women avoid unintended pregnancies and the births, abortions, or miscarriages that inevitably would follow.”¹⁴² But public funding restrictions on abortion impact women who are young, poor, and/or of color the hardest.¹⁴³

132. Lawrence B. Finer & Mia R. Zolna, *Unintended Pregnancy in the United States: Incidence and Disparities, 2006*, 84 *CONTRACEPTION* 478, 480 (2011).

133. *Id.*

134. *Id.*

135. *Id.*

136. Susan A. Cohen, *Abortion and Women of Color: The Bigger Picture*, 11 *GUTTMACHER POL’Y REV.* 2, 3 (2008) [hereinafter Cohen, *Abortion and Women of Color*].

137. *Id.*

138. *Id.* at 4; Heather D. Boonstra, *The Impact of Government Programs on Reproductive Health Disparities: Three Case Studies*, 11 *GUTTMACHER POL’Y REV.* 6, 8 (2008) [hereinafter Boonstra, *Reproductive Health Disparities*]; Catherine Cubbin et al., *Socioeconomic and Racial/Ethnic Disparities in Unintended Pregnancy Among Postpartum Women in California*, 6 *MATERNAL & CHILD HEALTH J.* 237, 238 (2002).

139. Cohen, *Abortion and Women of Color*, *supra* note 136, at 2; Gilda Sedgh et al., *Induced Abortion: Incidence and Trends Worldwide From 1995 to 2008*, 379 *LANCET* 625, 629 (2012).

140. Cohen, *Abortion and Women of Color*, *supra* note 136, at 3.

141. NAOMI CAHN & JUNE CARBONE, *RED FAMILIES V. BLUE FAMILIES: LEGAL POLARIZATION AND THE CREATION OF CULTURE* 104 (2010)

142. Boonstra, *Reproductive Health Disparities*, *supra* note 138, at 8.

143. *Id.* at 11.

2. The Political Effects of the Informational Approach

The narrow, informational approach has produced valuable information. And yet, this ostensibly apolitical approach has significant political consequences. First, the emphasis on documentation, research, and data decontextualizes the information. While much of disparities work has adopted the whole body approach to women's health, as well as a lifespan approach to reproductive health, research often omits the experience-based understanding of women's health. Since disparities work began, women's health advocates have pointed out "that unless research questions were grounded in an understanding of the nature of women's lives they were not likely to generate knowledge for women."¹⁴⁴ This approach, then, undercuts the political vitality of women's health knowledge for the empowerment of women.

The informational approach also medicalizes women's health.¹⁴⁵ Research and documentation has focused heavily on traditional biomedical health indicators; the focus is intra-body. Biomedical research identifies, frames, and locates cause and effect primarily at the organism level.¹⁴⁶ That cabins the expertise needed to address the issues in biomedicine medical and scientific experts and simultaneously designates biomedicine as the authority on the unacknowledged, but undeniable social problems.¹⁴⁷ As a result, data produced for health research and medicine, and not for women, strengthens the authority of biomedicine to define and determine what matters in women's health, including reproductive health. In other words, the disparities approach allocates authority to the experts and institutions that women's health advocates challenged in the 1960s and 1970s.

The informational approach echoed federal public health policy. In addition, both medicalization and the informational approach to education and prevention focus on the individual as the relevant entity. Both medicalization and public health designate institutional authorities as fit to define the problem and the content of education that will remedy that problem. Thus, the informational approach to health

144. Woods, *supra* note 110, at 1271.

145. See Adele E. Clarke et al., *Biomedicalization: A Theoretical and Substantive Introduction*, in *BIOMEDICALIZATION: TECHNOSCIENCE, HEALTH, AND ILLNESS IN THE U.S.* 1, 20-22 (Adele E. Clarke et al. eds., 2010) (providing a summary of scholarship on medicalization theory); Peter Conrad, *Medicalization and Social Control*, 18 *ANN. REV. SOC.* 209 (1992) (expanding the theory beyond physicians to include other health-related and social institutions).

146. See Adele E. Clarke et al., *supra* note 145, at 47, 54.

147. Conrad, *supra* note 145, at 223-24.

disparities naturalizes top-down education and prevention as the means of reducing reproductive health disparities.

The ostensibly apolitical account of health that the informational approach produces removes health status from the lives women live. Resulting health policy, with its emphasis on top-down education and prevention, casts off women's health from its moorings in autonomy and gender equality.¹⁴⁸ In this setting, reproductive health disparities data begged for explanation. The ostensible apoliticism of the informational approach positioned women's health in an apparently open space, making it more vulnerable to capture. The strongest contenders blamed women with higher rates of unintended pregnancy, lower rates of contraceptive use, and higher rates of abortion.¹⁴⁹ The contenders include both neoliberal explanations that point to faulty lifestyle choices and conservative religious explanations that point to immoral lifestyle choices.

F. Update on the Abortion Wars

Recently, abortion opposition has widened its net, in at least two ways. The reach of the pro-life discourse has widened to include claims of embryo personhood.¹⁵⁰ Embryo personhood asserts the moral status of in vitro embryos. On that basis, some have objected to human embryonic stem cell research, which necessitates destruction of in vitro blastocysts.

Some have also challenged in vitro fertilization used in fertility clinics.¹⁵¹ In addition, recent strategies return abortion opposition to its patriarchal roots, but offer new threads. Abortion opponents have medicalized the claimed need to protect women.¹⁵² Opponents justify

148. See Woods, *supra* note 110, at 1272 (explaining that while the 1994 *NIH Guidelines on the Inclusion of Women and Minorities as Subjects in Clinical Research* included chapters focusing on sex and gender differences and on racial, ethnic, and cultural diversity. "Whether the material in this section of the report can be integrated into the work recommended in the scientific chapters will depend on the willingness of scientists to expand their frames of reference beyond the biomedical view." *Id.*

149. See CAHN & CARBONE, *supra* note 141, at 1-2, 77-105 (2010) (using the concepts of "blue families" and "red families" to examine cultural patterns or "moral demographics" with respect to views on contraception and abortion use).

150. See Lynn M. Morgan, "Properly Disposed of": A History of Embryo Disposal and the Changing Claims on Fetal Remains, 21 *MED. ANTHROPOLOGY* 247, 267 (2002).

151. See Erik Parens, *On the Ethics and Politics of Embryonic Stem Cell Research*, in *THE HUMAN EMBRYONIC STEM CELL DEBATE: SCIENCE, ETHICS, AND PUBLIC POLICY* 37, 38 (Suzanne Holland et al. eds., 2001).

152. See Chinué Turner Richardson & Elizabeth Nash, *Misinformed Consent: The Medical Accuracy of State-Developed Abortion Counseling Materials*, 9 *GUTTMACHER POL'Y REV.* 6, 6-7

statutes that require women who request abortions to undergo ultrasounds or that mandate doctors to give women unnecessary information as necessary to protect women from making a poor decision.¹⁵³ These laws also force the patient and doctor into a relationship that harks back to pre-women's health movement days. Abortion opponents' proffered need to protect women is silently accompanied by a claim that women are not to be trusted, with their own bodies, their own decisions, or the fetal others they may conceive.¹⁵⁴

Within the abortion wars, abortion occupies two starkly different positions *vis a vis* women's health. To abortion opponents, abortion is unique. The procedure is separate from the category of women's health that deserves attention. Within this view, women's health equity may be desirable, but women's health has little to do with self-determination and gender equality.¹⁵⁵ To pro-choice advocates, abortion rights and access are crucial to achieving self-determination and equality by and for women. From this perspective, including abortion in the range of necessary women's health services is critical.

G. Synthesis

Women's health advocates forged a link between women's health, self-determination, and equality that has since been challenged on a number of fronts. First and most obviously, abortion opponents' unrelenting efforts to subtract the right to decide and eliminate abortion services has threatened both the scope of women's health and rights and the goal of maximizing health to enable women's civil participation.

Challenges have also emerged within the general sphere of health and health care. Federal public health policy set out goals and strategies associated with traditional liberalism.¹⁵⁶ The Healthy People initiatives encouraged greater government participation in increasing access to health care, educating the public, and providing more preventive care. Health disparities work formed under the auspices of biomedicine, but its focus on population health dovetailed with public

(2006); Reva B. Siegel, *The Right's Reasons: Constitutional Conflict and the Spread of Woman-Protective Antiabortion Argument*, 57 DUKE L.J. 1641,1686 (2008).

153. Reva B. Siegel, *Dignity and the Politics of Protection: Abortion Restrictions Under Casey/Carhart*, 117 YALE L.J. 1694, 1699-1700 (2008).

154. SOLINGER, *supra* note 49, at 168-69, 222-23.

155. *Id.* at 230.

156. *See supra* notes 81-83 and accompanying text.

health strategies.¹⁵⁷ Ironically, the federal government's ostensibly apolitical approach to health disparities stripped women's health of some of its strengths, leaving the door open to an understanding of women's health that is not by or for women.¹⁵⁸ In this space, neoliberal precepts twinned with anti-abortion discourse to form a neologism, which uses individual choice as the primary explanation for health status, but freights choices regarding sexuality and fertility with mistrust.¹⁵⁹ That mistrust, in turn, is used to justify restricting choice to impose social control of women.

Since the 1990s, a period characterized by extreme hostility to women's health, at least two discourses have emerged that echo themes from the women's health movement. One is the politically moderate to liberal health disparities discourse.¹⁶⁰ The governmental approach to health disparities has remained cautiously sanitized.¹⁶¹ However, health policy scholarship, community-based organizations, and civil rights organizations have pursued disparities problems as rooted in inequality.¹⁶² Many who have worked to address health disparities supported health care reform as an opportunity to reduce disparities.¹⁶³ Reproductive rights and justice work forms the second discourse.¹⁶⁴ This work has largely paralleled and rarely overlapped with health disparities work. In 2009 and 2010, the political fight over health care reform placed health care access and the issue of whether health and women's health, in particular, includes access to services proven necessary by the life experience of women in the United States.

III. THE ACA AND WOMEN'S HEALTH

In early 2010, abortion opponents in Congress used women and women's health as a wedge issue.¹⁶⁵ The ACA passed and will expand health care access and improve health care quality for millions of per-

157. See *supra* notes 93-102 and accompanying text.

158. See *infra* notes 158-68 and accompanying text.

159. See *infra* notes 169-75 and accompanying text.

160. See *supra* notes 96-102 and accompanying text.

161. See *supra* notes 91-92 and accompanying text.

162. See, e.g., Gamble & Stone, *supra* note 72, at 99-100, 103.

163. See, e.g., JILL QUADAGNO, ONE NATION, UNINSURED: WHY THE U.S. HAS NO NATIONAL HEALTH INSURANCE 5-6 (2005).

164. See *supra* notes 132-43 and accompanying text.

165. Susan A. Cohen, *Insurance Coverage of Abortion: The Battle to Date and the Battle to Come*, 13 GUTTMACHER POL'Y REV. 2, 6 (2010) [hereinafter Cohen, *Insurance Coverage of Abortion*].

sons.¹⁶⁶ But the wedge strategy worked. As a matter of federal health law and policy, abortion and the women who choose it barely exist. In 2011, choice opponents took aim at contraception funding under the ACA.¹⁶⁷ In a major victory for women's health, HHS issued rules that mandate contraception coverage without cost sharing.¹⁶⁸ However, the normative implications of that victory are less certain.

A. Expanding Access

Generally, the ACA will provide access to health care for more people.¹⁶⁹ The ACA's major provisions expand the availability of health insurance, particularly for low-income and uninsured persons.¹⁷⁰ The highest rates of women living in poverty and women without insurance in well over a decade were recorded in 2010.¹⁷¹ Nearly one in five women between the ages of eighteen and sixty-four were uninsured in that year.¹⁷² The numbers for 2011 are not in yet. But long established patterns make it easy to predict that whether the numbers go up or down, women and persons of color will remain disproportionately poor and uninsured.¹⁷³ The ACA contains provisions on the types of services to be covered and the quality of care that will also reduce health disparities.¹⁷⁴

166. The Henry J. Kaiser Family Found., *Mapping the Effects of the ACA's Health Insurance Coverage Expansions*, HEALTH REFORM SOURCE, <http://healthreform.kff.org/Coverage-Expansion-Map.aspx> (last visited Mar. 4, 2012).

167. See *infra* notes 290-92 and accompanying text.

168. See *infra* notes 280-81 and accompanying text.

169. See Patient Protection and Affordable Care Act of 2010 § 1303(a)(2)(A), 42 U.S.C. § 18023 (2006) (prohibiting the use of federal funds for abortion coverage).

170. *Id.*

171. NWLC *Analysis of New Census Data Shows Record Numbers of Women in Poverty, Without Health Insurance*, NAT'L WOMEN'S L. CENTER (Sept. 13, 2011) <http://www.nwlc.org/press-release/nwlc-analysis-new-census-data-shows-record-numbers-women-poverty-without-health-insura> [hereinafter *NWLC Analysis*].

172. *Id.*

173. See MATTHEW BUETTGENS & MARK A. HALL, WHO WILL BE UNINSURED AFTER HEALTH INSURANCE REFORM? 1 (Mar. 2011), available at <http://www.rwjf.org/files/research/71998.pdf>.

174. In a 2011 report, HHS identified a number of ACA provisions that address health disparities. These include a provision for data collection on race, ethnicity, primary language, disability status, and gender; an \$11 billion investment in Community Health Centers; Health Professional Opportunity Grants to provide healthcare training to low-income workers; funding for maternal, infant, and early childhood visitation programs to "foster child development and improve prenatal and postnatal health outcomes"; and Community Transformation Grants to "reduce chronic disease rates, prevent the development of secondary conditions, and address health disparities." ACTION PLAN TO REDUCE RACIAL AND ETHNIC HEALTH DISPARITIES, *supra* note 83, at 39-41.

Many of the national women's health and rights organizations have staunchly supported the ACA.¹⁷⁵ In very important ways, the ACA reflects the advocates' hard work. Organizations such as the National Women's Law Center, Black Women's Health Imperative, Planned Parenthood, and the National Partnership for Women and Families¹⁷⁶ fought to pass the legislation and worked to ensure that it would address women's health needs.

Women's health and rights organizations now point to the ways in which the ACA will improve women's health.¹⁷⁷ The major provisions include the Medicaid expansion and the Health Insurance Exchanges.¹⁷⁸ These provisions, scheduled to become effective in 2014, will make public and private insurance available to a greater number of low- and moderate-income individuals and families.¹⁷⁹ The newly insured will include women, families with woman-headed households, low-income men, and families of color.¹⁸⁰ The ACA contains a non-discrimination section that extends existing federal civil rights laws to any health program or activity receiving federal financial assistance; any program or activity administered by an executive agency; or any entity established under Title I of the Act or its amendments.¹⁸¹ In effect, the ACA prohibits health care insurers, providers, and federally funded programs from discriminating on the basis of race, national origin, age, disability, or sex.¹⁸² In addition, the ACA bans both gender rating by insurers and discrimination based on pre-existing

175. Some organizations, including the National Latina Institute for Reproductive Health, expressed reservations about the final version of the ACA because it explicitly excludes many legally permanent residents, undocumented residents, and because of the abortion restrictions. See Nat'l Latina Inst. for Reprod. Health, *Statement on Health Care Reform*, <http://latina.institute.org/Statement-on-Health-Care-Reform> (last visited Mar. 4, 2012) [hereinafter Latina Inst., *Statement on Health Care Reform*].

176. For details on these organizations, see NAT'L WOMEN'S L. CENTER, <http://www.nwlc.org/> (last visited Apr. 4, 2012); BLACK WOMEN'S HEALTH IMPERATIVE, <http://www.blackwomenshealth.org/> (last visited Apr. 4, 2012); PLANNED PARENTHOOD, <http://www.plannedparenthood.org/> (last visited Apr. 4, 2012); NAT'L PARTNERSHIP FOR WOMEN & FAMILIES, <http://www.nationalpartnership.org/site/PageServer> (last visited Apr. 4, 2012).

177. See *infra* notes 217-18 and accompanying text.

178. Patient Protection and Affordable Care Act of 2010 § 2201, 42 U.S.C. §1396w-3 (2006).

179. NAT'L P'SHIP FOR WOMEN & FAMILIES, *THE AFFORDABLE CARE ACT: INCREASING ACCESS TO HEALTH CARE FOR LOWER-INCOME WOMEN & FAMILIES* (2011) [hereinafter *WOMEN & FAMILIES, THE AFFORDABLE CARE ACT*], available at http://www.nationalpartnership.org/site/DocServer/HCR_ACA_Anniversary_Fact_Sheet_Lower-Income_Women_FINAL_.pdf?docID=8401.

180. *Id.*; see also MATTHEW BUETTGENS ET AL., URBAN INST., *AMERICA UNDER THE AFFORDABLE CARE ACT* (2010), available at <http://www.urban.org/uploadedpdf/412267-america-under-aca.pdf> (discussing the demographics of newly insured people under the ACA).

181. See also Patient Protection and Affordable Care Act of 2010 § 1557.

182. See *id.*

conditions.¹⁸³ The gender-rating prohibition promises to make health insurance more affordable for more women.¹⁸⁴ The ban on health status discrimination will make it easier for victims of domestic violence to obtain health insurance.¹⁸⁵

With the extraordinary exception of abortion, the ACA will be implementing something like a whole body life-span approach to women's health. The ACA sets out "minimum essential benefits" for new health plans, as of 2014.¹⁸⁶ The ACA lists ten categories of benefits and stipulates that, in prescribing the minimum essential benefits, the Secretary must "take into account the health care needs of diverse segments of the population, including women, children, persons with disabilities, and other groups."¹⁸⁷ Advocates highlight the fact that the ten categories include maternity and newborn care, prescription drugs, mental health care, and preventive services.¹⁸⁸

B. Abortion

1. The ACA and Abortion

The standard format that advocacy organizations use to describe the ACA is telling. The opening is celebratory and asserts that the ACA will improve health care and access for women.¹⁸⁹ The text then describes the key ACA provisions that pertain to women, much like the discussion in subpart A does. A qualifying statement follows, accompanied by an explanation of the ways in which the ACA restricts abortion.

183. *Id.* § 1331(c)(2)(B).

184. DANIELLE GARRETT ET AL., TURNING TO FAIRNESS: INSURANCE DISCRIMINATION AGAINST WOMEN TODAY AND THE AFFORDABLE CARE ACT 14 (2012), available at http://www.nwlc.org/sites/default/files/pdfs/nwlc_2012_turningtofairness_report.pdf (discussing the ban on gender-rating under the ACA).

185. See, e.g., NARAL, HEALTH-CARE LAW HOLDS TREMENDOUS PROMISE FOR WOMEN'S REPRODUCTIVE-HEALTH CARE 4 (2011), available at <http://www.prochoiceamerica.org/media/fact-sheets/birth-control-healthy-pregnancies-affordable-care-act.pdf>; NAT'L WOMEN'S LAW CTR., THE PAST AND FUTURE IN WOMEN'S HEALTH: A TEN-YEAR REVIEW AND THE PROMISE OF THE AFFORDABLE CARE ACT AND OTHER FEDERAL INITIATIVES (2010), available at <http://hrc.nwlc.org/past-and-future>.

186. Patient Protection and Affordable Care Act of 2010 § 1302(b)(4)(C).

187. *Id.*

188. See, e.g., WOMEN & FAMILIES, THE AFFORDABLE CARE ACT, *supra* note 179, at 2-4.

189. See, e.g., NARAL, *supra* note 185; WOMEN & FAMILIES, THE AFFORDABLE CARE ACT, *supra* note 179, at 1.

The crux of the legislative fight over abortion and the ACA was private insurance coverage.¹⁹⁰ The ACA restricts private insurance coverage of abortion. First, the ACA explicitly excludes abortion from the list of required benefits that private insurers participating in the Health Insurance Exchanges must cover.¹⁹¹ In addition, the ACA leaves state insurance mandates and restrictions intact.¹⁹² That is, the ACA will not preempt state laws that require abortion coverage or state laws that prohibit abortion coverage. Third, insurers participating in the exchanges that include abortion coverage cannot use federal subsidy money to pay for abortion coverage.¹⁹³ The ACA requires these insurers to collect two payments from purchasers of plans with abortion coverage.¹⁹⁴ Some predict and, perhaps, some hope that administrative burdens of complying with the subsidy ban will encourage insurers to drop abortion coverage. In effect, these rules supersede insurers' actuarial and marketing-based coverage decisions with a particular moral judgment.

While most of the ACA's provisions will become effective in 2014, at least one abortion restriction is already in place. ACA regulations, issued in 2010, ban abortion coverage in the temporary high-risk pools.¹⁹⁵ Many women in the high-risk pools have conditions that pregnancy would aggravate. Yet, the restriction contains exceptions only where pregnancy results from rape or incest or would endanger the woman's life.¹⁹⁶ This exception matches the current Hyde Amendment exception.¹⁹⁷ And like the Hyde Amendment exception, it simply excludes a woman's health.

190. For a brief, but coherent account of the legislative history of the ACA, see *History of the Passage of the March 2010 Health Care Reform Laws*, PROCON.ORG, <http://healthcarereform.procon.org/view.resource.php?resourceID=003712> (last updated Feb. 23, 2011).

191. Patient Protection and Affordable Care Act of 2010 § 1303(a)(1)(A) (stating that insurance plans may voluntarily cover abortion services).

192. *Id.* § 1303(b)(1) (stating that the ACA does not preempt state laws regarding abortion coverage).

193. *Id.* § 1303(a)(2)(A) (prohibiting the use of federal funds for abortion coverage).

194. *Id.* § 1303(a)(2)(B) (requiring segregation of federal funds from other funds providing abortion coverage).

195. Press Release, U.S. Dep't of Health & Human Servs., Statement of HHS Spokeswoman Jenny Backus on the Pre-Existing Condition Insurance Policy Plan (July 14, 2010), available at <http://www.hhs.gov/news/press/2010pres/07/20100714d.html> [hereinafter Backus Press Release]; Phil Galewitz, *High-Risk Health Insurance Pool Rules Bar Abortions, Limit Patient Costs*, KAISER HEALTH NEWS (July 29, 2010), <http://www.kaiserhealthnews.org/Stories/2010/July/29/high-risk-health-insurance-pools.aspx>.

196. Backus Press Release, *supra* note 195.

197. Consolidated Appropriations Act 2010, Pub. L. No. 111-117, 123 Stat. 3034 (2009).

Abortion, Contraception and the ACA

The ACA both maintains and expands legal protection for providers and entities that refuse to explain, provide or cover the full range of medically necessary women's health services.¹⁹⁸ Existing laws include the Church Amendments,¹⁹⁹ the Public Health Service Act § 245,²⁰⁰ and the Weldon Amendment.²⁰¹ Collectively, these laws create extensive cover for providers and health care entities that refuse to perform or assist in abortion and sterilization procedures;²⁰² refuse to undergo training or arrange for training to perform abortions;²⁰³ and refuse to pay for, provide coverage of, or refer patients for abortions.²⁰⁴ The ACA expands existing legal cover for refusals by prohibiting health plans participating in the Health Insurance Exchanges from "discriminat[ing] against any individual health care provider or health care facility because of its unwillingness to provide, pay for, cover, or refer for abortion. . . ." ²⁰⁵ These laws restrict abortion by exempting providers and facilities from the basic principles of informed consent, and by licensing doctors to unilaterally remove abortion from the vocabulary and list of permissible medical topics to be discussed between doctor and patient.

2. The ACA Amplified

Shortly after Congress enacted the ACA, the National Latina Institute for Reproductive Health issued a statement that captures the synergistic effects of increased access to insurance and expanded abortion restrictions on women and communities of color.

[T]his battle was fought on the bodies of women and immigrant women. In the eleventh hour, President Barack Obama caved to the demands of a handful of anti-choice Democrats by agreeing to use the lives of women as trade. He will use his pen to add weight to the already cumbersome abortion restrictions in the health care bill. Latinas, immigrants, and women of color are deeply affected by any language restricting abortion access—because women of color and

198. See *Overview of Federal Statutory Health Provider Conscience Protections*, U.S. DEPT OF HEALTH & HUMAN SERVS., <http://www.hhs.gov/ocr/civilrights/faq/providerconsciencefaq.html> [hereinafter HHS, *Overview of Protections*].

199. 42 U.S.C. § 300a-7 (2006).

200. 42 U.S.C. § 238n (2006).

201. Consolidated Appropriations Act 2010, Pub. L. No. 111-117, 123 Stat. 3034 (2009).

202. § 300a-7(b)(1); see also HHS, *Overview of Protections*, *supra* note 198.

203. § 238n(a); see also HHS, *Overview of Protections*, *supra* note 198.

204. Consolidated Appropriations Act 2010 § 508(d)(1) (does not comport with other citations of the act); see also HHS, *Overview of Protections*, *supra* note 198.

205. See Patient Protection and Affordable Care Act of 2010, Pub. L. No. 111-148, § 1303(b)(2)(A), 124 Stat. 119, 169; see also HHS, *Overview of Protections*, *supra* note 198.

immigrants are disproportionately poor, and they are less likely to be able to pay for reproductive health care out-of-pocket, which puts them at risk for seeking an alternative, unsafe abortion methods. While health reform might lead to more Latinas being covered, it leaves out a significant portion of the population. By excluding and stigmatizing immigrants and women who need abortions, we are pushing them to the shadows of our health care system and placing unfair burdens on the already-strained system of community health care centers and emergency rooms. Over half of all immigrants are women, and fifty-three percent of all immigrants are from Latin America; though just recently signed by the President, this law is already outdated.²⁰⁶

The statement highlights both material and normative effects of the ACA. The statement speaks most directly about the ACA's impacts on Latinas. In fact, the effects will be felt more widely by all women, but, as the statement illustrates, with a disparate impact on women of color and immigrant women.²⁰⁷

The ACA abortion restrictions are amplified by the laws that precede it and the laws it has spawned. As noted, the Hyde Amendment has, from 1976, prohibited the use of federal Medicaid dollars to pay for abortion, except in cases where the pregnancy resulted from rape, incest, or will endanger the woman's life.²⁰⁸ Abortion is the only medical procedure banned from federal Medicaid funding.²⁰⁹ The law does permit states to fund abortion under Medicaid with state funds. Five states provide state Medicaid funding in cases where pregnancy will impair the woman's physical health and/or because of fetal anomaly, in addition to the narrow federal exceptions.²¹⁰ Seventeen states provide state Medicaid funding for abortions with narrow or no limitations.²¹¹ Hyde Amendment-like laws have restricted federal and state funding for other groups who receive insurance through the gov-

206. Latina Inst., *Statement on Health Care Reform*, *supra* note 175.

207. *See id.* (noting that women of color and immigrants are disproportionately poor and because of this, they are less likely to be able to pay for reproductive health care out-of-pocket).

208. *See Public Funding for Abortion*, *supra* note 68. The scope of the Hyde Amendment exception has varied over time. *Id.* Note, too, that South Dakota allows use of Medicaid funding only where pregnancy endangers the woman's life, which is narrower than, and therefore in violation of, the Hyde Amendment. *Id.*

209. Nat'l Network of Abortion Funds, *What is the Hyde Amendment?*, FUNDABORTION-NOW.ORG, <http://www.fundabortionnow.org/learn/hyde> (last visited Mar. 20, 2012) ("[Abortion] is the only medical procedure that has ever been banned from Medicaid.")

210. GUTTMACHER INST., STATE FUNDING OF ABORTION UNDER MEDICAID, STATE POLICIES IN BRIEF 2 (2012).

211. *Id.* at 1.

ernment.²¹² The ACA leaves those laws intact. In fact, an executive order established an enforcement mechanism for the existing federal ban on use of federal money for abortion.²¹³ The ACA provisions described above extend the Hyde principle into the Health Insurance Exchanges, where private insurers will offer plans.

The ACA has also spawned state laws that will prevent private insurers from offering plans with abortion coverage.²¹⁴ Abortion opponents took the ACA's promise to leave state coverage laws intact as an invitation to enact additional abortion coverage restrictions.²¹⁵ As of March 2012, fifteen states have laws that prohibit insurers from offering abortion coverage in the state Health Insurance Exchanges.²¹⁶ Eight states restrict insurance coverage of abortion in all private plans, regardless of whether the plans are offered in the exchanges.²¹⁷ The number of state coverage restrictions has increased substantially in less than two years.²¹⁸ In 2010, shortly after President Obama signed the ACA, four states had laws banning private insurers from covering abortion.²¹⁹ The pace is not slowing. Two of the laws aimed at plans in the insurance exchanges were enacted in the last quarter of 2011.²²⁰ Many of those laws contain extraordinarily narrow and specific exceptions for coverage.²²¹ Most of the exceptions are narrower than the current Hyde Amendment exception for pregnancies resulting from rape or incest or that would endanger the woman's life.

212. See, e.g., GUTTMACHER INST., RESTRICTING INSURANCE COVERAGE OF ABORTION, STATE POLICIES IN BRIEF 1 (2012) [hereinafter GUTTMACHER, RESTRICTING INSURANCE] ("15 states restrict abortion coverage in plans for public employees.").

213. Exec. Order No. 13,535, 75 Fed. Reg. 15,599 (Mar. 24, 2010).

214. In addition, the number of state and federal bills aimed at further restricting abortion have increased since the ACA was passed. These bills range widely, but include additional funding restrictions such as those intended to expand restrictions on private insurance and those aimed at Title X clinics, many of which are run by Planned Parenthood. GUTTMACHER, RESTRICTING INSURANCE, *supra* note 212.

215. NARAL, *supra* note 185, at 6.

216. GUTTMACHER, RESTRICTING INSURANCE, *supra* note 212, at 1.

217. *Id.*

218. In 2011, state laws containing abortion restrictions increased at a record rate. See Guttmacher Institute, *States Enact Record Number of Abortion Restrictions in 2011*, GUTTMACHER.ORG (Jan. 5, 2011), <http://www.guttmacher.org/media/inthenews/2012/01/05/endofyear.html>.

219. *Access to Abortion Coverage and Health Reform*, FOCUS ON HEALTH CARE REFORM (Kaiser Family Found., Washington, D.C.), Nov. 2010, at 2, available at <http://www.kff.org/healthreform/upload/8021.pdf>.

220. See GUTTMACHER INST., STATE POLICIES IN BRIEF: RESTRICTING INSURANCE COVERAGE OF ABORTION (Oct. 1, 2011 and Jan. 1, 2011) (on file with author).

221. See GUTTMACHER, RESTRICTING INSURANCE, *supra* note 212, at 1.

These laws amplify the ACA in three ways. They take the ACA restriction on the use of federal subsidy money a step further and directly restrict abortion coverage in the exchanges.²²² Second, they expand the pre-ACA body of state law restricting abortion coverage.²²³ Third, they trend toward using narrower exceptions that have the effect of widening the laws' restrictive effect.²²⁴ The ACA and its amplifiers implement restrictions that will obstruct women in need of abortions and narrow the right to decide. Because most of these laws target financing, they will hit women with low and moderate incomes the hardest.

3. Isolation and Privatization

In the standard account of the ACA that many women's health and rights organizations offer, the qualifying statements that follow the celebratory text are no doubt freighted with advocates' anger and grief.²²⁵ But many organizations have remained staunch in their support of the ACA. In early January 2012, sixty-one organizations filed an amicus brief to support the law's minimum coverage requirement against constitutional challenge in *United States Department of Health and Human Services v. State of Florida*.²²⁶ That position reflects a sense of hard-won pragmatism that, perhaps, regards the ACA's abortion restrictions as a battle lost in a long-running war.

The battle loss was big. The line drawn by the abortion wars between abortion and other aspects of women's health and lives has become a boundary policed by the federal government. As a matter of national health policy, abortion services have been severed and isolated from women's health. Hopefully, that overdramatizes the problem. It is true, however, that federal law now abjures women who seek abortions, doctors who provide the full range of women's health services, and insurers who cover them. At the same time, federal law shelters providers, facilities, and insurers who refuse to enable women to obtain abortion services and exercise their right to choose. In support of a recently enacted Ohio law that would ban abortion coverage

222. The proposed Stupak-Pitts Amendment to the ACA would have banned private plan coverage of abortion in the exchanges. The existing restrictions came from the Nelson Amendment. Cohen, *Insurance Coverage of Abortion*, *supra* note 165, at 3.

223. *See supra* notes 213-18 and accompanying text.

224. *See supra* note 218 and accompanying text.

225. *See, e.g.*, NARAL, *supra* note 185, at 5-7.

226. Brief for The Nat'l Women's Law Ctr., et al. as Amicus Curiae Supporting Petitioners, *Dep't of Health & Human Servs. v. Florida*, 132 S. Ct. 604 (2011) (No.11-398).

in the state's insurance exchange, the Ohio Right to Life Executive Director stated, "While we can all agree that people should have access to healthcare, we reject the notion that abortion is healthcare because the only measure of 'success' of an abortion procedure is the death of an innocent child."²²⁷ Federal health law and policy now mirror that statement.

As a result, the scope of women's health is narrower. The narrowing has two aspects; both are potentially devastating. Women's health, as defined by federal policy, now omits a procedure that an estimated three in ten women will have by the age of 45.²²⁸ Federal law only allows coverage in cases that fall within a narrow band of continuously contested exceptions.²²⁹ In addition, women's health has lost the key link to the rights of self-determination and equality. The director's statement deploys fetal personhood to explain his definition of health care. But the ACA's abortion restrictions target gender equality by preventing women from making decisions about their own health and their roles in life, because they are women. Most immediately, the restrictions will force more women to forego early abortion procedures while they scramble for funds, to undertake the increased mortality and health risks of later abortions, or to become mothers against their will.²³⁰

Normatively, the ACA shoves abortion into the sphere of wholly privatized health care in most states.²³¹ Since the Hyde Amendment, low-income women who are Medicaid enrollees in states with state Hyde Amendments have had to use their food and rent money, borrow, and wait for their next paychecks to pay for abortions.²³² The

227. Mary Wisniewski, *Ohio Law Bans Funding Abortions in Insurance Exchanges*, REUTERS (Dec. 21, 2011, 4:47 PM), www.reuters.com/article/2011/12/21/us-abortion-states-ohio-idUSTRE7BK1Y720111221.

228. R.K. Jones & M.L. Kavanaugh, *Changes in Abortion Rates Between 2000 and 2008 and Lifetime Incidence of Abortion*, 117 *OBSTETRICS & GYNECOLOGY* 1358, 1358 (2011); GUTTMACHER INST., *FACTS ON INDUCED ABORTION IN THE UNITED STATES, STATE POLICIES IN BRIEF 1* (2011), available at http://www.guttmacher.org/pubs/fb_induced_abortion.pdf.

229. See *infra* note 256 and accompanying text.

230. Christine Dehlendorf & Tracy Weitz, *Access to Abortion Services: A Neglected Health Disparity*, 22 *J. HEALTH CARE FOR POOR & UNDERSERVED* 415, 417 (2011).

231. GUTTMACHER INST., *STATE FUNDING OF ABORTION UNDER MEDICAID, STATE POLICIES IN BRIEF* (2012), available at http://www.guttmacher.org/statecenter/spibs/spib_SFAM.pdf (stating that thirty-two states and the District of Columbia fund abortion under Medicaid, only in cases of life endangerment, rape, and incest; one state funds abortion under Medicaid only in cases of life endangerment).

232. Boonstra, *Reproductive Health Disparities*, *supra* note 138, at 9; Heather D. Boonstra, *The Heart of the Matter: Public Funding of Abortion for Poor Women in the United States*, 10 *GUTTMACHER POL'Y REV.* 12, 12-14 (2007).

ACA abortion restrictions impose public regulation on private insurers to extend the requirement that women use wholly private means to access abortion.²³³ In this context, wholly private refers to employment-based insurance (except in the states that prohibit all insurers from covering abortion), individual insurance purchased outside the insurance exchanges (except in states that prohibit all insurers from covering abortion), and personal money.²³⁴ Thus, the ACA transforms abortion's framework from privacy to privatization.

C. Contraception

1. Contraceptive Coverage Without Cost-Sharing

The ACA requires benefit plans to cover essential health benefits.²³⁵ As mentioned, the law sets out ten categories of benefits, including preventive services, and authorizes HHS to issue regulations that specify which preventive services insurers will have to cover. The Secretary charged the Institute of Medicine (IOM) "to conduct a review of effective preventive services to ensure women's health and well-being."²³⁶ The IOM committee that provided the review performed its task during the first half of 2011.²³⁷ The committee issued its report in July 2011.²³⁸ HHS issued an interim final rule specifying the content of women's preventive services on August 1, 2011.²³⁹ That rule specifies that FDA-approved contraceptives will be covered in new plans without cost-sharing.²⁴⁰

The ACA's inclusion of coverage for preventive care services owes much to health disparities work. Disparities data helped document the need for disease and risk prevention.²⁴¹ Prevention has long

233. See *supra* notes 220-23 and accompanying text.

234. See *id.*

235. NARAL, *supra* note 185, at 6.

236. INST. OF MEDICINE, COMM. ON PREVENTIVE SERVS. FOR WOMEN, CLINICAL PREVENTIVE SERVICES FOR WOMEN: CLOSING THE GAPS 1 (2011) [hereinafter IOM, CLOSING THE GAPS], available at <http://www.iom.edu/Reports.aspx?page=4>.

237. *Id.* at 6.

238. See IOM, CLOSING THE GAPS, *supra* note 236, at 1.

239. Group Health Plans and Health Insurance Issuers Relating to Coverage of Preventive Services Under the Patient Protection and Affordable Care Act, 76 Fed. Reg. 46621-01 (Aug. 3, 2011) (to be codified at 45 C.F.R. pt. 147) (interim final regulations effective August 1, 2011).

240. *Id.*

241. See U.S. Dep't of Health & Human Servs., *Affordable Care Act Rules on Expanding Access to Preventive Services for Women*, HEALTHCARE.GOV (Aug. 1, 2011) [hereinafter *Affordable Care Act Rules*], available at <http://www.healthcare.gov/news/factsheets/2011/08/womens-prevention08012011a.pdf> ("Yet chronic diseases – which are responsible for 7 out of 10 deaths . . . often are preventable.").

been established as a public health goal and strategy. In fact, in its review process, the IOM committee used the Healthy People 2010 report as a guideline for assessing and prioritizing women's preventive health care services.²⁴² HHS made direct reference to disparities work in the press release it issued on August 1, 2011 to announce the rules. The heading of the document's concluding paragraph states, "These Guidelines Mean Fewer Health Disparities."²⁴³

Both data and politics may have made unintended pregnancy a likely candidate for prevention under the ACA. As the IOM report observes, unintended pregnancy rates are significantly higher in the U.S. than in other developed countries.²⁴⁴ The report also cites to disparities data on unintended pregnancy: "[U]nintended pregnancy is more likely among women who are aged 18 to 24 years and unmarried, who have a low income, who are not high school graduates, and who are members of a racial or ethnic minority group."²⁴⁵ In addition, in his 2008 campaign, President Obama responded to questions about his stance on abortion by emphasizing the need to find common ground—preventing the need for abortion.²⁴⁶ A survey conducted in 2010 shows that over two-thirds of voters support insurance coverage for abortion.²⁴⁷ These facts indicated that including contraception coverage as a service to prevent unintended pregnancy would be non-controversial.

2. Controversy

Of the seven items that new health plans must cover without cost-sharing, the rule requiring coverage of all FDA-approved contraceptive methods received the most attention, praise, and criticism. Before the rules were actually issued, the United States Conference of

242. Adam Sonfield, *Contraception: An Integral Component of Preventive Care for Women*, 13 GUTTMACHER POL'Y REV. 1 (2010), available at <http://www.guttmacher.org/pubs/gpr/13/2/gpr130202.html>; IOM, CLOSING THE GAPS, *supra* note 236, at 1.

243. *Affordable Care Act Rules*, *supra* note 241.

244. IOM, CLOSING THE GAPS, *supra* note 236, at 102.

245. *Id.*

246. E.J. Dionne, *The Final Debate: A Breakthrough for Abortion Reduction*, WASH. POST (Oct. 16, 2008), http://voices.washingtonpost.com/postpartisan/2008/10/the_final_debate_a_breakthrough.html (quoting President Obama on the issue of abortion, who stated that the country should focus on preventing unintended pregnancies).

247. Press Release, Planned Parenthood Fed'n of America, See Survey: Nearly Three in Four Voters in America Support Fully Covering Prescription Birth Control (Oct. 12, 2010) (on file with author).

Catholic Bishops objected to the proposal.²⁴⁸ After the rules were issued, Republicans in Congress challenged the contraception coverage rule as a violation of religious freedom and proposed a bill to further broaden federal refusal laws.²⁴⁹ In late January 2012, the Obama administration declined to broaden the exemption for contraceptive coverage, but did give some church-affiliated employers a one-year implementation delay.²⁵⁰ During the same period, five of the presidential candidates for the Republican nomination signed a declaration that life begins at fertilization,²⁵¹ a premise that if enforced at law, could prohibit some forms of contraception. One of the candidates, Rick Santorum, has publicly stated his opposition to *Griswold v. Connecticut* and his belief that states should be able to ban contraceptive use.²⁵² In late 2011, in what might have been an attempt to assuage religious conservatives, Secretary of Health and Human Services, Kathleen Sebelius, denied a request to lift an age restriction for over-the-counter access to emergency contraception for women and girls under the age of seventeen.²⁵³ HHS's decision countered the FDA's decision, based on unanimous scientific recommendations for approval.²⁵⁴

Despite this furor, the ACA rule requiring new plans to cover contraception without cost-sharing is a major victory for women and women's health. As the IOM Report states, while "[c]ontraceptive coverage has become standard practice for most private insurance and federally funded insurance programs,"²⁵⁵ "[th]e elimination of cost sharing for contraception therefore could greatly increase its use, in-

248. News Release, United States Conference of Catholic Bishops, Bishops' Pro-Life Chair Strongly Opposes Recommended Mandate for Birth Control, Sterilization in Private Health Plans (July 19, 2011).

249. Robert Pear, *U.S. Denies Exemption Sought by Church on Coverage for Contraceptives*, N.Y. TIMES, Jan. 21, 2012, at A17; Jennifer Steinhauer, *Birth Control Is Covered, and G.O.P. Vows a Fight*, N.Y. TIMES, Feb. 8, 2012, at A12.

250. *Id.*

251. Keith Ashley, *Personhood Republican Presidential Candidate Pledge*, PERSONHOOD USA BLOG (Dec. 15, 2011, 10:46 PM), <http://www.personhoodusa.com/blog/personhood-republican-presidential-candidate-pledge>.

252. Laura Chapin, *Rick Santorum Even Opposes Birth Control*, U.S. NEWS (Jan. 6, 2012), <http://www.usnews.com/opinion/blogs/laura-chapin/2012/01/06/rick-santorum-even-opposes-birth-control> (stating that Santorum opposes *Griswold v. Connecticut*).

253. News Release, U.S. Dep't of Health & Human Servs., Statement by U.S. Department of Health and Human Services Secretary Kathleen Sebelius (Dec. 7, 2011), available at <http://www.hhs.gov/news/press/2011pres/12/20111207a.html>.

254. See Reprod. Health Techs. Project, *HHS Overrules FDA Scientists on Lifting Plan B Age Restriction; Women's Health Advocates Outraged* (Dec. 7, 2011), <http://www.rhpt.org/documents/PlanBOne-StepApplicationDENIEDPressRelease.pdf>.

255. IOM, CLOSING THE GAPS, *supra* note 236, at 108.

cluding use of the more effective and longer-acting methods, especially among poor and low-income women most at risk for unintended pregnancy.”²⁵⁶ Among women’s health advocates, contraceptive coverage is understood as a means of self-determination. Expanding access to contraceptives will enable women to reduce the health risks they and their children experience from unintended pregnancy.²⁵⁷ Fertility control, enabled by contraceptive use, expands women’s ability to choose and shape their life courses, and thus achieve part of what women’s health advocates in the 1960s and 1970s fought for so vigorously.

3. Threats

Health disparities work helped place contraceptive access among the priority health prevention needs. Health disparities work described that need in stripped down data-based health terms, thus leaving space for other understandings of contraceptive coverage. In combination with the severance and isolation of abortion, the meaning of contraceptive coverage slips from contraceptive access as reproductive liberty to contraceptive use as abortion prevention. Political moderation and the stated desire to find common ground on abortion bolster that framing. Neoliberalism aligns with that reading by casting access as choice and insisting that lifestyle or flawed choice explain unintended pregnancy.

The threat from the right expands the claim of personhood to the in vitro fertilized egg and simultaneously seeks to narrow the scope of acceptable sexuality. The three framings—contraception as abortion prevention, contraception failure by choice, and contraception as threat to family—meet on common ground. Each steps back from efforts to achieve autonomy and equality for women. In addition, a mistrust of women unites the neoliberal and religious conservative framings.

D. Reclaiming Women’s Health

In 1976, the Hyde Amendment proved that federal law can constrict constitutionally protected choice and perpetuate inequality on the very site of those rights—women’s bodies. In 2010, Congress en-

256. *Id.* at 109.

257. *Id.* at 103.

acted the ACA and simultaneously gave and took away.²⁵⁸ Once again, the effects will be felt most harshly by women, and most particularly by women who have low- to moderate-incomes, women of color, and immigrant women.²⁵⁹ Moderation might have informed a decision that will expand contraceptive access. But moderation did not help protect access to abortion.

Reclaiming women's health as a whole body, experience-based understanding might start by returning to the fight for self-determination and equality for and by women. It is not that advocates have ever forsaken the civil rights framing. We have, however, focused heavily on protecting abortion within the right of privacy. We have to find new ways to insist, in the face of competing ideologies, on the linkage between reproductive choice and equality. Justice Ginsberg's dissent in *Gonzales v. Carhart* provides a stark reminder of the need for insistence.²⁶⁰ Advocates and scholars who have pushed to examine the role of racism and other forms of subordination in the formation of health disparities provide another source of inspiration.²⁶¹ Liberal public health perspectives suggest we insist not only on access, but on reducing barriers formed by social determinants—inequality in education and literacy, income, employment, and of course, insurance coverage.²⁶² Progressive reproductive justice activists provide analytical tools that enable the reframing of issues in ways that highlight connections, strengths, and move the work to coalition and community.²⁶³

258. See *supra* Part III.A-C.

259. George J. Annas & Wendy K. Mariner, *Women and Children Last – The Predictable Effects of Proposed Federal Funding Cuts*, 364 *NEW ENG. J. MED.* 1590 (2011), available at <http://www.nejm.org/doi/full/10.1056/NEJMp1102915>; see Latina Inst., *Statement on Health Care Reform*, *supra* note 175.

260. *Gonzales v. Carhart*, 550 U.S. 124, 172 (2007) (Ginsberg, J., dissenting) (“Thus, legal challenges to undue restrictions on abortion procedures do not seek to vindicate some generalized notion of privacy; rather, they center on a woman’s autonomy to determine her life’s course, and thus to enjoy equal citizenship stature.”).

261. See, e.g., Michelle van Ryn & Jane Burke, *The Effect of Patient Race and Socio-Economic Status on Physician’s Perceptions of Patients*, 50 *SOC. SCI. & MED.* 813, 814 (2000); Kevin A. Schulman et al., *The Effect of Race and Sex on Physicians’ Recommendations for Cardiac Catheterization*, 340 *NEW ENG. J. MED.* 618 (1999); Davis R. Williams & Chiquita Collins, *Racial Residential Segregation: A Fundamental Cause of Racial Disparities in Health*, 116 *PUB. HEALTH REP.* 404 (2001); David R. Williams & Michelle Sternthal, *Understanding Racial-Ethnic Disparities in Health: Sociological Contributions*, 51 *J. HEALTH & SOC. BEHAVIOR* S15 (2010), available at http://hsb.sagepub.com/content/51/1_suppl/S15.full.pdfhtml.

262. See, e.g., Boonstra, *Reproductive Health Disparities*, *supra* note 138, at 11.

263. See, e.g., A NEW VISION, *supra* note 129, at 2.

CONCLUSION

The ACA became a forum for ideological contests over abortion, contraception, and the vision of women's health advocates. That vision emerged torn and battered. Federal health policy now isolates and privatizes abortion. It segregates the women who need and the physicians who provide abortion services. The ACA's promise to require contraceptive coverage without cost-sharing is, at this time, a victory for women's health and women's rights. But the threats to women's health and its linkage to self-determination and equality persist. The most obvious threat arises from twinned neoliberal and conservative religious anti-woman discourses. Perhaps the strength to insist on a whole body, experience-based understanding of women's health lies in ideologies of social justice, formed outside the institutional power bases.

Medicaid Access, Rate Setting and Payment Suits: How the Obama Administration Is Undermining Its Own Health Reform Goals

BRIETTA R. CLARK*

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INTRODUCTION

President Obama has recognized Medicaid as a critical component of ensuring health care access and thus made Medicaid expan-

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sion one part of the Affordable Care Act passed in 2010.¹ Creation of the Medicaid program in 1965 has been one of the most important tools for saving lives and helping to fight health disparities due to income gaps and race discrimination.² Today Medicaid continues to provide needed health care to our sickest and most vulnerable groups—extending the life of those with chronic conditions, and promoting better health for children, pregnant women, seniors and people with disabilities who otherwise might not be able to access care.³ While not perfect, it is a critical part of the health care safety net, which is why advocates have been arguing for its expansion for years.

While many laud the recent Medicaid expansion, they are also cautiously optimistic. Health care access for Medicaid beneficiaries depends on providers willing to treat them, yet many providers are severely restricting the number of Medicaid patients they see or are dropping out of the Medicaid program altogether, and the most common reason given is low reimbursement.⁴ Hospitals with emergency rooms have fewer options to avoid this problem because they have a duty to screen and stabilize anyone who comes to the emergency room, regardless of insurance status or ability to pay; however, these hospitals may try to limit acceptance of Medicaid patients for non-emergency services or look for other ways to cut expenses such as

1. See Patient Protection and Affordable Care Act, Pub. L. No. 111-148, § 2001, 124 Stat. 119, 271 (2010); 42 U.S.C. § 1396a(k) (2011) (effective beginning 2014) [hereinafter Affordable Care Act].

2. See generally Karen Davis et al., *Health Care for Black Americans: The Public Sector Role*, in HEALTH POLICIES AND BLACK AMERICANS 213, 213-23 (David P. Willis ed., 1989) [hereinafter HEALTH POLICIES AND BLACK AMERICANS] (describing the improvement in health care access for poor and ethnic minority groups attributable to Medicaid); DAVID BARTON SMITH, HEALTH CARE DIVIDED: RACE AND HEALING A NATION 200-11 (1999) (describing how Medicare and Medicaid narrowed gaps in access and improved health outcomes for the poor and Blacks, but noting that racial disparities persist); Sidney D. Watson, *Race, Ethnicity and Quality of Care: Inequality and Incentives*, 27 AM. J. L. MED. 203, 203 (2001) [hereinafter Watson, *Inequality and Incentives*] (noting that enactment of Medicare and Medicaid is credited with helping to transform the U.S. health care system by encouraging access for those otherwise excluded from private insurance).

3. See HENRY J. KAISER FAMILY FOUND., KAISER HEALTH TRACKING POLL 3 (2011) [hereinafter KAISER HEALTH TRACKING POLL], available at <http://www.kff.org/kaiserpolls/upload/8190-F.pdf> (describing the results of a public poll on the importance of Medicaid); LEIGHTON KU & CHRISTINE FERGUSON, GEORGE WASHINGTON UNIV. SCH. OF PUB. HEALTH & HEALTH SERVS., MEDICAID WORKS: A REVIEW OF HOW PUBLIC INSURANCE PROTECTS THE HEALTH AND FINANCES OF CHILDREN AND OTHER VULNERABLE POPULATIONS 13 (2011), available at <http://www.firstfocus.net/sites/default/files/MedicaidWorks.pdf>.

4. See *infra* Part III.

cutting services, relocating to more affluent communities, or closing, especially in the case of public hospitals.⁵

Thus, existing threats to Medicaid access can be traced to state payment cuts, freezes, or changes in rate-setting methodology that dramatically reduce provider reimbursement, and shift greater financial risk onto health care providers. Payment rate cuts and freezes, in turn, have resulted from state and local budgetary pressures in difficult economic times, as well as federal pressure to contain Medicaid spending.⁶ Indeed, Congress gave the states significant flexibility in rate setting in order to encourage them to experiment with different payment and health delivery models that would reduce cost and deliver care more efficiently. Nonetheless, there are constraints on this flexibility. Congress has made clear, through the Medicaid Act and other legislation, that rates must be adequate to achieve other program goals, such as ensuring timely and equal access to quality care.⁷ The Medicaid Act also creates certain procedural requirements that states must follow in order to help ensure compliance—submitting rates for federal approval and giving the public adequate notice and opportunity to comment. In other words, although states have great flexibility in shaping a health care delivery and payment system that is more efficient and economical, they must do so in ways that respect federal access and quality protections.

Since Medicaid's enactment, providers and beneficiaries have brought payment suits challenging state rate cuts and rate-setting methodology as violating these requirements.⁸ In some cases, states ignore clear procedural requirements, making cuts without any consideration of access and quality factors. In other instances, the claim is that a state's process is inadequate because it does not consider the information necessary to ensure compliance with federal access and quality requirements. The U.S. Department of Health and Human Services (HHS), through its Centers for Medicaid and Medicare Services (CMS), is charged with oversight of the state rate-setting pro-

5. See generally Brietta R. Clark, *Hospital Flight From Minority Communities: How Our Existing Civil Rights Framework Fosters Racial Inequality in Healthcare*, 9 DEPAUL J. HEALTH CARE L. 1023 (2005) (describing the problem of dwindling hospital resources in underserved communities).

6. See *infra* Parts I.C, II.B (describing the economic, political, and regulatory context in which Medicaid cuts are made).

7. See *infra* Part III (providing a discussion and analysis of legal constraints that affect states' flexibility in rate-setting).

8. See *infra* Parts II, III.

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cess. Until very recently, however, HHS has not exercised its rulemaking power to provide guidance to states, providers, or beneficiaries about the rate-setting process and criteria to be used to assess the sufficiency of rates, nor has CMS used its enforcement power to reject state rate cuts that violate federal law.⁹ This lack of explicit statutory or regulatory guidance has exacerbated concerns that states are abusing their flexibility to avoid complying with federal law and to implement cuts that jeopardize Medicaid access.¹⁰ This has made state processes and rates vulnerable to legal attack as arbitrary and inadequate.

The fate of Medicaid payment suits as a tool for protecting health care access and quality is uncertain for a number of reasons. First, the Supreme Court is currently considering providers' and beneficiaries' right to challenge state rate cuts in federal court and the level of review courts must apply to state cuts approved by the federal government.¹¹ Second, the recent Medicaid expansion means that many more people will be eligible for Medicaid and will need providers, further exacerbating access concerns. Finally, despite the Obama Administration's renewed focus on Medicaid access problems and payment suits, it is sending conflicting signals about its commitment to enforce federal access and quality protections.¹²

This Article explores the future of Medicaid access linked to payment disputes in light of this regulatory and jurisprudential uncertainty. Part I introduces the basic design of the Medicaid program and describes what is at stake in these payment suits. Section A explains the important health needs met through Medicaid coverage. Section B provides evidence that low reimbursement rates discourage pro-

9. *See infra* Part IV.

10. *See infra* Part III (discussing the gaps and ambiguity in the Medicaid Act). This problem was identified by those seeking Medicaid expansion as part of health reform. However, the Affordable Care Act only includes a very limited provision requiring parity between Medicaid and Medicare rates for physicians with a primary specialty designation of family medicine, general internal medicine, or pediatric medicine, and it only lasts for two years. *See* 42 U.S.C. §1396a(a)(13)(C) (2006).

11. *Douglas v. Indep. Living Ctr. of S. Cal., Inc.*, 132 S. Ct. 1204, 1207 (2012) (granting certiorari on the question of whether patients and providers can use the Supremacy Clause to challenge state Medicaid payment cuts that conflict with federal rate-setting requirements). Although the Supreme Court issued a decision in the case, it did not answer the question on which it granted certiorari; rather, it reframed the question more narrowly and remanded the case back to the Ninth Circuit for further briefing. *See id.* at 1207-08. The implications of the Court's decision on remand are explored in the Conclusion. *See infra* Conclusion. For ongoing updates and commentary on *Douglas* and Medicaid payment suits, see HEALTH CARE JUSTICE BLOG, www.healthcarejusticeblog.org (last visited Apr. 2, 2012).

12. *See infra* Part IV.

vider participation and thus undermine access and quality. Section C discusses the on-going threats to Medicaid reimbursement, and problems with the current cost justifications given by states for these cuts.

Part II explores the evolution of the law with respect to rate setting, as well as access and quality goals, under the Medicaid Act and other federal legislation. It provides important context for understanding how federal policy goals are constrained by legal mandates, how state flexibility is checked by federal oversight, and concerns about the role that courts have played in mediating these disputes. Part III looks more closely at the kind of state actions typically challenged in these suits, the degree of scrutiny courts apply to state rate setting, and how courts have balanced their respect for state flexibility to make policy against their obligation to enforce legal protections for access and quality. This Part helps to illustrate that while in some cases the underlying goals of cost and access may trigger legitimate and difficult policy questions that courts want to avoid, many payment suit cases reveal a different problem: states' abdication of their duties under federal law to consider the explicit statutorily required factors of access and quality, or to do any meaningful assessment of cost, access, and quality factors in rate setting. Such blatant disregard of the law results in cuts that are clearly illegal, as opposed to legal decisions based on difficult policy choices that may have unfortunate effects.

Part IV considers the role of federal regulators in these disputes, historically, as well as more recent regulatory activity undertaken by the Obama administration. The lack of federal regulatory guidance and administrative oversight in the rate review and approval process has created a regulatory void that enables states to abuse their flexibility to make arbitrary rate-reductions. When coupled with federal pressure on states to reduce spending, enabling turns to encouragement. Although the Obama administration has gone the furthest so far in providing guidance to the states for rate-setting, its proposed rules continue to give states a great deal of discretion to design the rate-setting process and reviews of Medicaid access. Moreover HHS's recent reviews of state proposals to cut rates cast serious doubt over whether HHS will really be more proactive in its enforcement role than past administrations. Finally, and perhaps most disturbing, the Obama administration recently sided with states in their fight to remove one of the most important and reliable forms of consumer protection Medicaid beneficiaries have – the ability to challenge state

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illegal cuts and plan changes in federal court. The Obama administration urged the elimination of judicial review of rate setting, even as it entertained federal funding cuts to Medicaid that would shift more cost to the states and thus increase the likelihood of illegal cuts.

The Article concludes by suggesting what these trends in state program administration and federal regulatory action mean for the future of payment suits enforcing Medicaid access and quality protections, especially in light of the current challenge at the Supreme Court level. The key to the promise of expanded access under Medicaid reform lies with federal regulators' commitment to enforcement of federal protections, but by this measure, the outlook is not very promising. Medicaid payment suits have provided a critical check on state illegality and the federal regulatory void that enables states to ignore federal law. Federal courts acknowledge the importance of deferring to state discretion and federal agency expertise to make policy decisions that require a balancing of cost, access, and quality goals—an essential part of the rate-setting process; but they have also taken seriously their obligation to prevent public law failures that could cause significant harm to Medicaid beneficiaries. The Medicaid expansion and recent regulatory activity by HHS reaffirm the important role that federal courts play in realizing the promise of reform.

PART I. ACCESS CRISIS AND LINK TO MEDICAID PROGRAM ADMINISTRATION

The Medicaid program is typically described as a joint federal-state partnership – funding is provided by both levels of government, while program administration is left primarily to the states.¹³ As a condition of federal funding, states are subject to certain minimum requirements or rules relating to eligibility, services covered, delivery of care, and rate setting.¹⁴ Nonetheless, Congress has given states significant flexibility in administering the Medicaid program, in part, to allow states to tailor the program to meet local health needs in light of local resources.¹⁵ For example, states can establish medical and finan-

13. A more accurate description of this partnership would include the health care providers—government run and private, institutions and professionals—who are Medicaid participants and essential actors in delivering health care to Medicaid beneficiaries.

14. *See infra* Parts II, III.

15. KU & FERGUSON, *supra* note 3, at 16; *see also* Medicaid Program: Methods for Assuring Access to Covered Medicaid Services, 76 Fed. Reg. 26,342 (proposed May 6, 2011) [hereinafter *Methods for Assuring Access*] (to be codified at 42 CFR pt. 447) (describing the continued

cial criteria for eligibility and coverage that go beyond the minimum federal requirements.¹⁶

In customizing the Medicaid program to its particular needs, states can also apply for waivers that excuse compliance with certain federal requirements as long as the state can show that its approach will not be more costly.¹⁷ States have used waivers to help them do things like expand eligibility, change delivery methods, alter benefits and cost sharing, and modify provider reimbursement.¹⁸ Indeed, states have been important innovators in health care delivery and fi-

flexibility afforded to states in the proposed rule); *infra* notes 256-58 and accompanying text (discussing this theme of state flexibility in greater detail).

16. Although certain services are required to be covered (such as inpatient and outpatient hospital care, laboratory tests, nursing facility services, home health, and physician and surgical dental services), the law gives states the option of covering additional services, such as private nursing, adult dental, and physical, occupational, and speech therapy. *See* 42 U.S.C. § 1396a(a)(10)(A), 1396d(a) (2006) (creating mandatory and optional categories of services to be provided under state plans for medical assistance); *see also* 42 C.F.R. § 440.210, 440.220 (2010) (defining required services); 42 C.F.R. § 440.225 (defining optional services). Similarly, while certain categories of individuals must be covered (such as children, pregnant women, and those with disabilities, who also meet federal income eligibility requirements), federal law also gives states the option to expand eligibility to other groups. *See* 42 U.S.C. § 1396a(a)(10)(A)(i) (mandatory eligibles); 42 U.S.C. § 1396a(a)(10)(A)(ii) (optional categories of eligibility). For example, states can cover the “medically needy”— individuals who do not automatically meet strict income eligibility requirements to be categorically eligible for Medicaid, but whose income and resources are insufficient to meet the costs of necessary medical and remedial care and services. 42 C.F.R. §§ 435.300 – 435.350 (Optional Coverage of the Medically Needy). Such persons may become eligible during a designated period if the individual’s out-of-pocket medical expenses are high enough to cause them to spend down to the eligibility level. *See* 42 C.F.R. §§ 435.800 – 435.845 (Specific Eligibility and Post-Eligibility Financial Requirements of the Medically Needy).

17. *See* HENRY J. KAISER FAMILY FOUND., FIVE KEY QUESTIONS AND ANSWERS ABOUT SECTION 1115 MEDICAID DEMONSTRATION WAIVERS: EXECUTIVE SUMMARY 1 (2011), *available at* <http://www.kff.org/medicaid/upload/8196.pdf> (“Currently, 30 states and the District of Columbia operate one or more comprehensive Section 1115 Medicaid waivers that involved an estimated \$54.6 billion in federal outlays in 2011. These waivers generally fall into several categories, including waivers to implement managed care, to expand coverage with limited benefits, to restructure federal financing, and to expand coverage to low income adults in preparation for the Medicaid expansion in 2014.”).

18. *See id.*; *see also* TIMOTHY STOLTZFUS JOST, DISENTITLEMENT? THE THREATS FACING OUR PUBLIC HEALTH-CARE PROGRAMS AND A RIGHTS-BASED RESPONSE 172 (2003) (describing innovations in Arizona, Tennessee, and Oregon that expanded coverage for the poor). Of course, this same flexibility allows states to cut optional programs or groups, later. *See* Vernon K. Smith et al., KAISER COMM’N ON MEDICAID & THE UNINSURED, MOVING AHEAD AMID FISCAL CHALLENGES: A LOOK AT MEDICAID SPENDING, COVERAGE AND POLICY TRENDS 7 (2011) [hereinafter MOVING AHEAD AMID FISCAL CHALLENGES], *available at* <http://www.kff.org/medicaid/upload/8248.pdf> (“Eighteen states in [fiscal years] 2011 and 2012 reported eliminating, reducing or restricting benefits. Elimination of, or limits on, dental, therapies, medical supplies and DME and personal care services were most frequently reported.”); Abby Goodnough, *Medicaid Cuts Are Part of a Larger Battle in Maine*, N.Y. TIMES, Dec. 24, 2011, at A11 (detailing the Governor’s proposed cuts optional benefits, including dental care and room and board at assisted living centers, as well as making 19 and 20 year olds and childless adults ineligible, which would reduce the Medicaid rolls by 65,000).

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nancing: experimenting with managed care, medical homes, hospital consolidations, and expansion of clinics and outpatient care.¹⁹ This kind of experimentation illustrates a thoughtful and deliberate use of state flexibility to achieve multiple goals: controlling health care costs and improving health care outcomes by improving health care access to the right kind of care.²⁰ Unfortunately, states do not always use flexibility in this way; at times, they make changes without considering access and quality goals, or act in ways that clearly undermine such goals.²¹

Despite variations across states and localities with respect to beneficiary access and provider reimbursement, there are nationwide trends in Medicaid administration and rate-setting that frustrate the core access and quality goals set out in federal law. This part offers some generalizations about the important health and financial benefits that Medicaid coverage can provide, as well as how low reimbursement leads to access barriers that keep many Medicaid beneficiaries from realizing these benefits.

A. Benefits of Medicaid Coverage

As originally enacted, Medicaid was designed to help certain groups for whom it was viewed as socially desirable and important, and for whom attaining insurance in the private market would be practically impossible.²² These groups included people unable to

19. See *KU & FERGUSON*, *supra* note 3, at 17.

20. See *id.* at 16; see also *Methods for Assuring Access*, *supra* note 15, at 26,343. President Obama and his administration have touted this as the basis for its approach in health reform: reducing cost and improve quality through improved access to preventive care and consistent management for chronic disease. See *The Right Care at the Right Time: Leveraging Innovation to Improve Health Care Quality for All Americans: Hearing Before the Senate Comm. on Finance*, 110th Cong. 57-69 (July 17, 2008) (statement of Peter R. Orszag, Director of Congressional Budget Office), available at <http://finance.senate.gov/imo/media/doc/071708potest1.pdf>; Katherine Brandon, *The President on Health Care: "We are Going to Get this Done"*, WHITE HOUSE BLOG (July 17, 2009, 5:42 PM EDT), <http://www.whitehouse.gov/blog/The-President-on-Health-Care-We-are-Going-to-Get-this-Done>.

21. See *infra* Part III (focusing on this problem in the rate-setting context). However, other state abuses of flexibility have been identified. See *JOST*, *supra* note 18, at 172-73 (“[T]he few states that have shown leadership in expanding coverage are far outweighed by those that have limited eligibility expansions and tried to manipulate the Medicaid system to maximize federal expenditures for minimal state effort.”). *Jost* also noted that, according to a 2001 Families USA poll, two-thirds of the states did not cover all parents of families with dependent children with incomes below the poverty, even though they had this option. *Id.* at 173.

22. See *JOST*, *supra* note 18, at 11-17 (discussing the barriers presented by the private health insurance system, such as the exclusion of high risk (actual or perceived) individuals, and affordability linked to employment-based group health insurance plans, which make entitlements for the elderly, disabled, and very poor necessary); *SMITH*, *supra* note 2, at 141; Sara Rosenbaum,

work due to disability, pregnant women, and children – and only the poorest among these groups.²³ Many people referred to these mandatory eligible groups as the “deserving poor” because of the importance of health care for their continued well-being, as well as the fact that they were the least likely to be able to get insurance on their own due to circumstances assumed to be out of their control.²⁴ People disabled by illness could not access health insurance through their employer, and were often priced out or refused insurance in the individual market due to fears of high cost. The reality of the employment and insurance market made clear that women were also often excluded for reasons beyond their control, and concerns of child and fetal health were powerful motives for extending coverage to children and pregnant women.

Around the same time that Medicaid was created, the Civil Rights Act, prohibiting race discrimination by recipients of federal funding, was also enacted.²⁵ The federal government’s indirect subsidization of health care facilities through the Medicaid and Medicare programs gave the federal government significant power to fight overt discrimination by hospitals, however race discrimination and disparities in health care took new forms. Some providers used insurance status or ability to pay as a pretext for refusals, or they segregated care on the basis of race.²⁶ In other cases, ability to pay was not a

Medicaid at Forty: Revisiting Structure and Meaning in a Post-Deficit Reduction Act Era, 9 J. HEALTH CARE L. & POL’Y 5, 7 (2006).

23. See generally BARRY FURROW ET. AL., HEALTH LAW: CASES, MATERIALS AND PROBLEMS 821-24 (6th ed. 2008) (providing an overview of Medicaid eligibility). The Henry J. Kaiser Family Foundation also provides a nice overview of Medicaid and the Children’s Health Insurance Program (CHIP). See generally HENRY J. KAISER FAMILY FOUND., *Medicaid/CHIP*, <http://www.kff.org/medicaid/index.cfm> (last visited Apr. 2, 2012).

24. ROBERT STEVENS & ROSEMARY STEVENS, WELFARE MEDICINE IN AMERICA: A CASE STUDY OF MEDICAID 6-7 (1974) (describing the special assistance programs created during the early twentieth century to help “deserving” individuals and noting that this formed the framework on which Medicaid was designed); see also LAURIE KAYE ABRAHAM, MAMA MIGHT BE BETTER OFF DEAD: THE FAILURE OF HEALTH CARE IN URBAN AMERICA 44-59 (1993) (critiquing the unfairness underlying this kind of line drawing and describing the deleterious effects on the many hardworking uninsured individuals excluded from Medicaid).

25. See *Simkins v. Moses H. Cone Mem’l Hosp.*, 323 F.2d 959, 960-61 (4th Cir. 1963). See generally SMITH, *supra* note 2, at 91-94 (providing an account of the circumstances surrounding *Simkins* from the point of view of the people involved).

26. See SMITH, *supra* note 2, at 168-69; Vernellia R. Randall, *Racist Health Care: Reforming an Unjust Health Care System to Meet the Needs of African-Americans*, 3 HEALTH MATRIX 127, 148-49 (1993) (requiring pre-admission deposits that effectively excluded Medicaid patients and the uninsured, but applying the requirement selectively to minorities only). In other cases, hospitals constructed private rooms or wings of hospitals to separate the privately insured and affluent patients from those who were indigent or received Medicaid. See, e.g., ABRAHAM, *supra* note 24, at 118.

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pretext, but nonetheless had significant discriminatory effects because of the reality that racial minorities were disproportionately uninsured as they were still denied equal access to education and employment.²⁷ For covered groups, Medicaid was an important, though not perfect, step in overcoming access barriers due to income gaps and discrimination.²⁸

Initially, Medicaid helped save lives by facilitating access to care for those most vulnerable to an acute health care crisis. But the program was criticized for its narrow eligibility requirements as undermining health care and societal goals.²⁹ Excluding the working poor or people not yet disabled by illness, meant that many were unable to get routine check-ups or treatment for chronic conditions that could help prevent repeated hospitalizations and future disability. This was part of a broader critique of social welfare systems as simply providing reactive, crisis-driven help after a problem occurs, rather than intervening earlier to empower individuals' with the ability and resources to avoid crisis.³⁰ A similar critique was also being leveled at the insurance and medical community, for whom the predominant culture of *health care or insurance* was really *sick* insurance or care. Doctors were trained to cure illness or disease, and traditional insurance was designed to pay for treating the sick. The result has been a culture change in medicine and insurance generally—to increase access to preventative care and create medical homes to ensure that people with chronic conditions or other long term needs can successfully managing their conditions to prevent chronic episodes and deterioration.³¹

27. See ABRAHAM, *supra* note 24, at 37, 53-57; Stephen H. Long, *Public Versus Employment-Related Health Insurance: Experience and Implications for Black and Nonblack Americans*, in HEALTH POLICIES AND BLACK AMERICANS, *supra* note 2, at 200, 202-03 tbl.1 (citing statistics that show blacks are more likely to be covered by public insurance than non-blacks); see also Davis et al., *supra* note 2, at 220 ("Since about one-third of the poor were black, it was assumed that Medicaid would reduce disparities in access to care by race, as well as by income.").

28. See Davis et al., *supra* note 2, at 213, 222-23; Rosenbaum, *supra* note 22, at 16-17.

29. See Colleen Grogan & Eric Patashnik, *Medicaid at the Crossroads*, in HEALTHY, WEALTHY, & FAIR: HEALTH CARE AND THE GOOD SOCIETY 267, 283 (James A. Morone & Lawrence R. Jacobs eds., 2005) ("When Medicaid was originally created, the assumption was that aid should be concerned with those who could not afford health insurance because of their lack of employment. By the 1990s, however, it was widely acknowledged that being employed does not guarantee affordable health insurance coverage.").

30. See, e.g., ABRAHAM, *supra* note 24, at 44-57 (describing the perverse incentives and harmful effects created by a complicated patchwork of public insurance that was initially tied to welfare and a disability-based system that discouraged work).

31. See *Select ODPHP Activities*, OFFICE OF DISEASE PREVENTION & HEALTH PROMOTION, <http://odphp.osophs.dhhs.gov/odphpfact.htm> (last visited Mar. 19, 2012) (explaining that Congress created the Office of Disease Prevention and Health Promotion in 1976). This growing

A number of subsequent federal amendments to Medicaid encouraged, and many states have embraced, this perspective as they decide how to expand Medicaid to achieve health and cost containment goals.³² For example, states have expanded coverage to include the medical needy, individuals who do not fit the strict financial criteria for eligibility, but whose income is significantly reduced each month due to expensive medical treatment, often for chronic or other long term needs.³³ A number of states have also expanded community-based services, funding in-home care workers and adult day health care facilities that provide a broader range of services, including custodial care.³⁴ This enables beneficiaries typically suffering from some disability or illness to remain as independent and healthy as possible, and helps states avoid the more costly institutionalization that would likely result without such support. Finally, as policy makers develop a better understanding of the link between people's overall physical, emotional and financial well-being, and "optional" services (like mental health, dental, and rehabilitation care), and states have increasingly chosen to cover these services as well.³⁵

focus on prevention is reflected in amendments to expand prenatal, child, and maternal health care in the 1980s and 90s. See Grogan & Patashnik, *supra* note 29, at 277-78 tbl.9.1. A focus on prevention was also one of the benefits touted by proponents of a managed care model of health care coverage, rather than the catastrophic or traditional indemnity model. See DAVID DRANOVE, *THE ECONOMIC EVOLUTION OF AMERICAN HEALTH CARE: FROM MARCUS WELBY TO MANAGED CARE* 40 (2000). Finally, this is reflected in the federal government's current approach in the Affordable Care Act to require or encourage coverage of certain preventive services without cost sharing. See HENRY J. KAISER FAMILY FOUND., *FOCUS ON HEALTH REFORM: SUMMARY OF NEW HEALTH REFORM LAW 10-11* (2011), available at <http://www.kff.org/healthreform/upload/8061.pdf>.

32. See Grogan & Patashnik, *supra* note 29, at 274-82; see also Rosenbaum, *supra* note 22, at 16-22 (describing the history of expansions to mandatory categories of eligibility); Sara Rosenbaum & Paul S. Wise, *Crossing the Medicaid-Private Insurance Divide: The Case of EPSDT*, 26 *HEALTH AFFAIRS* 382, 383 (2007) (describing how the Early and Periodic Screening Diagnosis and Treatment (EPSDT) Program required states to cover comprehensive physical exams, immunizations, health education, and vision, dental, hearing, and other diagnostic services for children).

33. See JEFF CROWLEY, KAISER COMM'N ON MEDICAID & THE UNINSURED, *MEDICAID MEDICALLY NEEDED PROGRAMS: AN IMPORTANT SOURCE OF MEDICAID COVERAGE* 1 (2003), available at <http://www.kff.org/medicaid/loader.cfm?url=/commonspot/security/getfile.cfm&PageID=14325> (noting that as of 2000, thirty-five states and the District of Columbia operated medically needy programs, and these have been used to expand coverage primarily to low-income young adults, parents, and persons who incur enough medical expenses that their income falls below a state-established income limit).

34. See KAISER COMM'N ON MEDICAID & THE UNINSURED, *MEDICAID HOME AND COMMUNITY-BASED SERVICES PROGRAMS: DATA UPDATE* 12 (2011), available at <http://www.kff.org/medicaid/7720.cfm>.

35. See MARTHA HEBERLEIN ET AL., KAISER COMM'N ON MEDICAID & THE UNINSURED, *PERFORMING UNDER PRESSURE: ANNUAL FINDINGS OF A 50-STATE SURVEY OF ELIGIBILITY*,

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But does Medicaid coverage actually result in better and consistent health care access and improved health outcomes? Although these benefits of insurance coverage seem intuitive, studies have been done to try to document them for a couple of reasons. First, like other entitlement programs for the poor, Medicaid has been attacked repeatedly; some simply continue to try to chip away the program by suggesting ways to trim expenses, while others have offered more radical proposals to abolish it or restructure it to give states almost complete administrative discretion and much greater financial responsibility.³⁶ Thus studies documenting its benefits are important for proponents who use them to counter these attacks. But health advocates and lawmakers also need information that illustrates exactly how well Medicaid coverage works, where it falls short, and what is causing the gap between coverage and access. The remainder of this section describes the benefits of Medicaid coverage, and the next section focuses on evidence of access barriers.

A number of studies have been done to measure the health and financial benefits of health insurance generally,³⁷ but this section focuses on Medicaid specifically. These studies support a picture of

ENROLLMENT, RENEWAL, AND COST-SHARING POLICIES IN MEDICAID AND CHIP, 2011-2012, at 8, 13 (Jan. 2012).

36. See, e.g., JOST, *supra* note 18, at 18 (describing Congress' attempt to end the Medicaid program in the 1990s, and to replace it with a block grant program that would have devolved authority almost completely to the states); KU & FERGUSON, *supra* note 3, at 19 (describing the proposed budget developed by Congressman Paul Ryan and passed by the U.S. House of Representatives last year to turn Medicaid into a block grant program). To justify such proposals, claims have been made that Medicaid is not really necessary because people can simply go to community clinics and public hospitals for free care. See, e.g., *Barbour On Mississippi's 18 Percent Uninsured: No One Lacks Access To Health Care*, HUFFINGTON POST (Apr. 20, 2011), available at http://www.huffingtonpost.com/2011/04/20/barbour-on-mississippi-1_n_851690.html (describing Former President Bush's infamous comment in 2007 that everyone has access to health care because they can just go to the emergency room, and comparing it to recent statements by Mississippi Governor Haley Barbour suggesting that Mississippi would not benefit from federal resources to help expand Medicaid access because people had access to emergency care). Others have used evidence of problems in Medicaid to argue that is not a worthwhile investment. See, e.g., Scott Gottlieb, *Medicaid Is Worse Than No Coverage at All*, WALL ST. J., Mar. 10, 2011, at A17 (claiming that recent medical studies show that Medicaid patients would do just as well without health insurance). Such claims have been criticized as flawed. See KU & FERGUSON, *supra* note 3, at 14.

37. See Rosenbaum, *supra* note 22, at 23, 47 n.127; KU & FERGUSON, *supra* note 3, at 1 (reviewing studies demonstrating the health and financial benefits of Medicaid coverage). See generally INST. OF MED., AMERICA'S UNINSURED CRISIS: CONSEQUENCES FOR HEALTH AND HEALTH CARE 2 (2009) (reviewing the research evidence about the benefits of health insurance coverage). The Report concluded that insurance coverage is integral to personal well-being and health, finding that "[d]espite the availability of some safety net services, there is a chasm between the health care needs of people without health insurance and access to effective health care services [which] results in needless illness, suffering, and even death." *Id.*

Medicaid as a critical safety net that improves consistent access, and helps prevent crises that cause worse physical, mental, and fiscal harm. For example, studies of adult Medicaid beneficiaries show that areas with broader Medicaid eligibility have lower average rates of preventable hospitalizations for disorders such as diabetes or asthma, and patients are more likely to have their blood pressure under control.³⁸ A Utah study suggested similar benefits for those with serious mental health conditions, like schizophrenia, who need on-going help managing their illness: it found that schizophrenic patients were more likely to be hospitalized after interruptions in Medicaid coverage, suggesting that stable coverage helps prevent the crises that lead to hospitalization.³⁹ Another study found that “female breast and cervical cancer patients enrolled in Medicaid for longer periods of time had less severe cancers than those enrolled for shorter periods,” and that cancer patients enrolled in Medicaid before their cancer diagnoses lived longer than those who enrolled only after diagnosis.⁴⁰ Children also benefit in a number of ways: Medicaid coverage has been associated with a reduction in child mortality, fewer asthma attacks and hospitalization, and overall better health.⁴¹ Moreover, one study found that almost all children covered by Medicaid or CHIP had a usual source of care.⁴²

One noteworthy study from Oregon affirmed the health and fiscal benefits of Medicaid coverage.⁴³ The study is noteworthy because it is the only randomized, controlled study design to date comparing the cost and benefits of Medicaid coverage.⁴⁴ This randomization allowed the authors to compare Medicaid beneficiaries with uninsured

38. KU & FERGUSON, *supra* note 3, at 13; *cf.* ANDREW B. BINDMAN ET AL., CAL. HEALTH-CARE FOUND., PHYSICIAN PARTICIPATION IN MEDI-CAL, 2008, 3 (2010), available at <http://www.chcf.org/~media/MEDIA%20LIBRARY%20Files/PDF/P/PDF%20PhysicianParticipationMediCal2008.pdf> (“Barriers to primary care . . . contribute to delays in seeking care that can result in preventable hospitalizations for chronic conditions such as asthma, diabetes, and congestive heart failure . . .”).

39. *See* KU & FERGUSON, *supra* note 3, at 16.

40. *Id.* at 15.

41. *See id.* at 13.

42. *Id.* at 10.

43. AMY FINKELSTEIN ET AL., NAT’L BUREAU OF ECON. RESEARCH, THE OREGON HEALTH INSURANCE EXPERIMENT: EVIDENCE FROM THE FIRST YEAR 3 (2011), available at <http://www.nber.org/papers/w17190>.

44. *See id.* at 1. Because of a lottery system used by Oregon to new low-income adults into its Medicaid program, researchers were able to design a randomized, controlled study. *Id.* This is significant because randomization is a more rigorous methodology than is typically available for studying the effects of insurance, and thus may provide stronger evidence of the link between insurance and health care access, outcomes, and financial health. *See id.*

individuals at the same income level to test claims (like those pushing for elimination or radical cuts) that Medicaid beneficiaries did not necessarily receive better access to care than the uninsured who qualified for free health care services at local clinics and public hospitals.⁴⁵ It concluded that after one year of enrollment, “those selected by lottery [for Medicaid enrollment] have substantial and statistically significantly higher health care utilization, lower out-of-pocket medical expenditures and medical debt, and better self-reported health than the control group that was not given the opportunity to apply for Medicaid.”⁴⁶

B. Access Barriers for Medicaid Beneficiaries Linked to Low Reimbursement

Medicaid is typically described as a federal-state partnership, with focus on the division of federal and state responsibility in financing and administration. This picture ignores arguably the most important partner in this relationship: the health care provider. Success of the program depends overwhelmingly on the participation of private providers, like primary care physicians and specialists, hospitals and outpatient centers, dentists, pharmacists, in-home care workers, as well as publically-owned hospitals. Providers must be willing to treat Medicaid patients, and must be available in the areas where they are most needed so that Medicaid beneficiaries can access them in a timely manner. Yet for decades, problems with Medicaid access and quality have persisted:

Numerous studies documented that Medicaid recipients were much less likely than Americans with private health insurance to have a relationship with a primary care doctor or to receive needed preventive care, and much more likely to receive their care in hospital emergency room settings or public clinics with long waiting lines. Despite the targeted efforts to increase prenatal care and well-child care coverage in the 1980s, a large portion of Medicaid women received no, or only minimal, prenatal care services. Many children enrolled in Medicaid were failing to receive needed immunizations.⁴⁷

The lack of provider participation in Medicaid has been recognized as a serious problem that impedes access to regular, preventive

45. *Id.*

46. *Id.* at 3.

47. Grogan & Patashnik, *supra* note 29, at 283 (emphasis omitted).

care.⁴⁸ In fact this has contributed to the view of Medicaid as part of a two-tiered system of care: a lower tier for Medicaid beneficiaries and the uninsured who primarily utilize public clinics, and an upper tier for private-pay patients who have access to private office-based physician services.⁴⁹

A number of studies link this provider participation problem to low reimbursement.⁵⁰ For example, a 2011 study by the Kaiser Family Foundation found that a number of primary care physicians are either not accepting new Medicaid patients or limiting the numbers they will accept, and the most common reason cited for this is low Medicaid reimbursement.⁵¹ This is consistent with a recent study by the U.S. Government Accountability Office (GAO), a 2010 national survey of physicians that focused on Medicaid access for children, in which the most frequently identified factor for why physicians did not participate in Medicaid was low reimbursement (influencing 95 percent of physicians).⁵²

The GAO report also tried to construct a more accurate picture of Medicaid access by looking beyond the numbers of physicians who were simply participants in Medicaid; they asked the physicians how many of them were actually accepting new Medicaid patients, and how difficult it was for Medicaid patients to find the specialists they need. The study found that more than three-quarters of primary and specialty care physicians were enrolled as Medicaid and CHIP providers and serving children in those programs, but only 47 percent said they were still accepting children in Medicaid and CHIP.⁵³ Moreover,

48. See, e.g., BINDMAN ET AL., *supra* note 38, at 2; Grogan & Patashnik, *supra* note 29, at 284; Davis et al., *supra* note 2, at 225-26.

49. Grogan & Patashnik, *supra* note 29, at 284 (noting that this problem was identified as early as 1972); Sidney D. Watson, *Medicaid Physician Participation: Patients, Poverty, and Physician Self-Interest*, 21 AM. J. L. & MED. 191, 192-98 (1995) [hereinafter Watson, *Medicaid Physician Participation*] (describing a two-tiered system of care).

50. See Davis et al., *supra* note 2, at 226; Watson, *Medicaid Physician Participation*, *supra* note 49, at 192-98 (linking the problem of physician participation, low reimbursement, and the lower tiered system of care experienced by Medicaid recipients).

51. KAISER COMM'N ON MEDICAID & THE UNINSURED, PHYSICIAN WILLINGNESS AND RESOURCES TO SERVE MORE MEDICAID PATIENTS: PERSPECTIVE FROM PRIMARY CARE PHYSICIANS 3 (2011) [hereinafter PERSPECTIVE FROM PRIMARY CARE PHYSICIANS], available at <http://www.kff.org/medicaid/upload/8178.pdf>.

52. U.S. GOV'T ACCOUNTABILITY OFFICE, MEDICAID AND CHIP: MOST PHYSICIANS SERVE COVERED CHILDREN BUT HAVE DIFFICULTY REFERRING THEM FOR SPECIALTY CARE 18 (2011) [hereinafter GAO 2011 REPORT ON MEDICAID & CHIP], available at <http://www.gao.gov/new.items/d11624.pdf>.

53. *Id.* at 9-11.

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for most participating physicians, children in Medicaid and CHIP represented less than 20 percent of the children they served.⁵⁴

Physicians also reported difficulty finding specialists willing to take referrals for Medicaid patients (84%), and that the lack of available specialists and difficulty referring patients to other providers was also a factor in some primary care physicians' decision to not accept Medicaid patients (78%).⁵⁵ While there is a shortage of some specialists for all children, providers had a much more difficult time referring for Medicaid children, likely due to low reimbursement.⁵⁶ Finally, according to both the GAO Report and the Kaiser Study, other program defects seemed to influence providers' decisions to avoid Medicaid: burdens associated with billing, delayed reimbursement, and enrollment were cited as reasons by 85-87% of physicians surveyed.⁵⁷ Thus, the top five reasons given by providers all relate to defects in program administration like rate setting and payment.⁵⁸

These studies also revealed that Medicaid's low reimbursement help to create significant disparities in access between Medicaid beneficiaries and privately insured patients. For example, the Kaiser poll concluded that despite overall positive ratings by adults of their experience in the Medicaid program, about a third of those polled reported problems finding a doctor or other health care provider willing to accept Medicaid patients at some point, compared to 13% of those currently covered by private insurance.⁵⁹ And the disparities for children are just as stark. The GAO study found that about 79% of physicians

54. *Id.*

55. *Id.* at 18, 20.

56. *Id.* at 18 (noting that nonparticipating physicians—those not enrolled or not serving Medicaid and CHIP children—most commonly cite administrative issues such as low and delayed reimbursement and provider enrollment requirements as reasons for limiting their willingness to serve children in these programs).

57. *Id.* at 18; PERSPECTIVE FROM PRIMARY CARE PHYSICIANS, *supra* note 51, at 9.

58. Other studies paint a more complex picture of the factors that can inhibit physician participation. See, e.g., PETER J. CUNNINGHAM, STATE VARIATION IN PRIMARY CARE PHYSICIAN SUPPLY: IMPLICATIONS FOR HEALTH REFORM MEDICAID EXPANSIONS 3, 4 (2011), available at <http://www.rwjf.org/files/research/72046.pdf> (suggesting other factors that can influence participation, including gender, type of practice, physician ownership, and geography); Cathy Caldwell et al., *Healthcare Providers' Satisfaction with a State Children's Health Insurance Program (SCHIP)*, 12 MATERNAL & CHILD HEALTH J. 260, 263-64 (2008) (physicians may have a negative perception of the program or its beneficiaries); Peter Cunningham, Presentation to the Medicaid and CHIP Payment and Access Commission: Physician Reimbursement and Participation in Medicaid (Sept. 23, 2010), available at <http://www.hschange.com/CONTENT/1157/1157.pdf>. But see GAO 2011 REPORT ON MEDICAID & CHIP, *supra* note 52, at 21 (describing problems getting specialist for Medicaid children despite physician type and geographic location).

59. KAISER HEALTH TRACKING POLL, *supra* note 3, at 4.

participating in the study accepted all privately insured children as new patients, compared to about 47% for children in Medicaid and CHIP, and more than three times as many participating physicians (84%) experience difficulty referring Medicaid and CHIP children to specialty care as experience difficulty referring privately insured children (26%).⁶⁰ Evidence of declining Medicaid participation and refusals to treat associated with low reimbursement, as well as significant disparities in access between Medicaid and privately insured patients is a pervasive and longstanding problem.⁶¹

C. The Real Cost of the Medicaid Program and Impact of Further Cuts

As will be detailed further in the next Part, the federal government has actively encouraged state experimentation with various payment structures in order to keep federal costs down, and as innovators, states have already done a lot to contain cost in the Medicaid program.⁶² Some analysts describe Medicaid as “an exceptionally low cost insurance program” that is already very lean and efficient, and does not have much room for further cuts.⁶³ One survey found that, “after controlling for health status, age, gender, income, and other factors, the average per person annual cost of serving an adult on Medicaid was 20% less than under private insurance and the annual cost of serving a child on Medicaid or CHIP was 27% less than under private insurance.”⁶⁴ To the extent Medicaid costs are rising, it is due to the expansion of Medicaid rolls in this difficult economy, as well as nationwide trends in health care costs that are not unique to Medicaid.⁶⁵

60. GAO 2011 REPORT ON MEDICAID & CHIP, *supra* note 52, at 11, 20-21.

61. *See generally* ABRAHAM, *supra* note 24 (describing the poor hospital conditions that existed for hospitals serving the poor); Watson, *Inequalities and Incentives*, *supra* note 2 (discussing Medicaid reimbursement and the racial divide that occurred in the 1970s and 1980s which had an adverse racial impact); Watson, *Medicaid Physician Participation*, *supra* note 49 (discussing America’s history of dual-track medical care which either benefits those with money or those without money).

62. *See* KU & FERGUSON, *supra* note 3, at 17 (describing states’ roles as innovators of health care delivery and financing models, such as managed care, medical homes, hospital consolidations, and expansion of clinic-outpatient care).

63. *Id.* at 18-19.

64. *Id.* at 18.

65. *Id.* at 17, 18; *see also* JOST, *supra* note 18, at 176-77 (“[P]rogram abuses [like the manipulation of the system to maximize federal expenditures for minimal state effort] have badly distorted the ongoing debate regarding funding health care for the poor, as they have resulted in dramatic but artificial program cost increases and made the Medicaid program appear to be more of a burden on the states than in fact it is.”).

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Despite the fact that Medicaid already gives states the greatest bang for their buck, states continue to try to find ways to reduce Medicaid spending.⁶⁶ To some extent, rate reductions have been part of the broader cost containment movement in the private and public financing systems.⁶⁷ Concerned about waste and unnecessary spending by providers and states, Congress has actively encouraged, and at times pressured, states to find ways to reduce the cost of public programs like Medicaid.⁶⁸

Medicaid payment rate cuts and freezes are also directly related to state and local budgetary pressures that lawmakers experience in difficult economic times because these changes have an immediate impact on state budgets.⁶⁹ States and local officials are pressured to cut expenses quickly, and public health and welfare programs are common targets. Like other programs for the poor, the Medicaid program began as a marginalized and stigmatized program that kept it from being widely embraced and defended against budget cuts.⁷⁰ Though some policymakers have tried to remake Medicaid's image, especially as it has expanded to include more people and helped to fill coverage gaps for Medicare beneficiaries, this is an on-going struggle.⁷¹ States have also been particularly hard hit recently: they are recovering slowly from the recession, and as billions of dollars in the 2009 federal stimulus funding used to help state Medicaid programs weather the bad economy have come to an end.⁷² Worse provider shortages are

66. See generally MOVING AHEAD AMID FISCAL CHALLENGES, *supra* note 18, at 30-34 (describing trends in provider reimbursement in the midst of recent fiscal challenges, and noting the negative impact of rate freezes and cuts on provider participation).

67. See generally JOST, *supra* note 18, at 110-29 (discussing cost containment in Medicaid and Medicare).

68. See *infra* Part II.B.

69. See MOVING AHEAD AMID FISCAL CHALLENGES, *supra* note 18, at 31:

During the economic downturn from 2001 to 2004, every state froze or cut provider payment rates to control costs, but starting in 2005, as the economy improved, states were less likely to cut and more likely to increase provider rates. During this recent recession, states again turned to provider rate cuts to control costs.

Id. The report also explained that rate cuts are one of the few tools states have for immediately reducing spending because of the maintenance of eligibility requirements in health reform. *Id.*

70. See Grogan & Patashnik, *supra* note 29, at 274 (describing the evolution of the Medicaid program from its origin as “marginalized politically, complex administratively, and fragmented socially”). Because of this, expansions have been incremental and largely “hidden.” *Id.* at 276; see also STEVENS & STEVENS, *supra* note 2, xvi (explaining how “Medicaid has moved from a glittering symbol of the ‘Great Society’ to a problem to be tackled by the ‘New Federalism’” marked by “a period of legislative concern, fiscal retrenchment, and general skepticism”).

71. See *id.* at 267-76.

72. The Kaiser Commission on Medicaid and the Uninsured has made the following findings: “Nearly every state implemented at least one new Medicaid policy to control spending in FYs 2011 and 2012” and “[a]s in previous years, provider rate restrictions were the most com-

being predicted because of another round of cuts occurring this past summer in as many as sixteen states.⁷³

A recent snapshot of the programs and services targeted for cuts heightens this concern.⁷⁴ Some states target services, like community-based services, that disproportionately benefit particularly the elderly and people with disabilities.⁷⁵ While these services are very costly and may be perceived as less critical than others, the impact of not providing care will likely cost more in the short and longer term; if people can no longer afford community-based support, they are more likely to be institutionalized, suffer crises that result in frequent hospitaliza-

monly reported cost containment strategy.” MOVING AHEAD AMID FISCAL CHALLENGES, *supra* note 18, at 6, 7; *see also* *Medi-Cal to Face Hit from End of Stimulus Funding, Budget Cuts*, CAL. HEALTHLINE (June 30, 2011), available at <http://www.californiahealthline.org/articles/2011/6/30/medical-to-face-hit-from-end-of-stimulus-funding-budget-cuts.aspx?topic=medical>.

73. *See, e.g.*, MOVING AHEAD AMID FISCAL CHALLENGES, *supra* note 18, at 31; *Medicaid Pay Reductions Could Lead to Shortage of Providers in Program*, CAL. HEALTHLINE (July 6, 2011), available at <http://www.californiahealthline.org/articles/2011/7/6/medicaid-pay-reductions-could-lead-to-shortage-of-providers-in-program.aspx>.

Colorado, Nebraska, Oregon and South Carolina are reducing payments to physicians this month, while Arizona cut rates in April and will further reduce rates in October. Colorado, Connecticut, Florida, Nebraska, New Hampshire, North Carolina, Oregon, Pennsylvania, South Carolina, Texas, Virginia and Washington all are cutting payments to hospitals. New York already reduced hospital payment rates in April. California lawmakers approved a 10% payment reduction for doctors and hospitals . . .

Id.; Robert Pear, *Cuts Leave Patients with Medicaid Cards, but No Specialist to See*, N.Y. TIMES, Apr. 2, 2011, at A1.

74. The news is not all bad though, as some states are actively working to streamline Medicaid enrollment and are not shrinking eligibility. *See* HEBERLEIN ET AL., *supra* note 35, at 13 (finding that many states used technology to increase program efficiency and streamline enrollment, and that the “maintenance of eligibility” requirement in the Affordable Care Act has played a key role in preserving coverage levels).

75. *See, e.g.*, *Oster v. Lightbourne*, N.D. Cal., No. 09-cv-4688, 2012 WL 691833, at *1 (N.D. Cal. Mar. 2, 2012) (granting a preliminary injunction of state’s reduction of the hours available for elderly and disabled California residents to receive care at home based on allegations that it violated the Medicaid Act and the ADA); *see also* KAISER FAMILY FOUNDATION, *MEDICAID’S LONG-TERM CARE USERS: SPENDING PATTERNS ACROSS INSTITUTIONAL AND COMMUNITY-BASED SETTINGS 1* (2011) (finding that Medicaid long-term users accounted for six percent of the Medicaid population in 2007, but nearly half of total Medicaid spending). Additionally, *see* MOVING AHEAD AMID FISCAL CHALLENGES, *supra* note 18, at 50:

While most states already have limits in place for their community-based services such as coverage limits, enrollment caps, and waiting lists for services, this year’s survey found that seven states in both FY 2011 and FY 2012 imposed additional restrictions directed at HCBS [Home and Community-Based Services] programs and services (compared to nine states in FY 2010 and only two states in FY 2009). . . . Also, four states in FY 2011 and six states in FY 2012 are making reductions to personal care services . . .

Id. The same report notes that a “majority of states are continuing to increase HCBS service options, a trend that has continued for more than two decades. *Id.* at 49; Michael Campbell, *Did I Do That? An Argument for Requiring Pennsylvania to Evaluate the Racial Impact of Medicaid Policy Decisions Prior to Implementation*, 82 TEMP. L. REV. 1163, 1164-66 (2010) (describing Pennsylvania’s decision to limit nursing home growth in the early 1980s in response to the perceived explosion of nursing home growth and need for nursing facility care by Medicaid beneficiaries).

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tions, or both, which would take a significant financial, emotional, and physical toll on the individuals and their families.⁷⁶

A shortage of providers willing to serve Medicaid beneficiaries is particularly problematic for ensuring early and regular access for preventive care, and the consistent management of chronic conditions to prevent hospitalizations and chronic episodes. For this kind of care, patients need a regular health care provider or what is often referred to now as a “medical home” with an established relationship, continuity of care, appointment reminders, and ability to access care in a timely fashion. Rate cuts that shift even greater financial risk to providers who are already struggling undermine federal access and quality goals, as more providers refuse to accept Medicaid beneficiaries and leave communities with high number of Medicaid patients. Institutions that cannot easily relocate or choose not to leave may be tempted to cut costs by reducing staff or safety measures that jeopardize timely access and quality. Even communities that have publicly-owned hospitals and free clinics, cannot take access for granted because these institutions do not provide the full range of care needed by patients to realize the benefits described above. Moreover, because public institutions have a duty to treat the indigent, they rely heavily on Medicaid and other public funding for their survival, and many do not survive.⁷⁷

Hospitals that typically serve a disproportionate share of indigent patients, and thus do not have many privately insured patients to subsidize care for Medicaid patients and the uninsured, have been eligible for special funding under the Disproportionate Share Hospital pro-

76. See, e.g., David Gorn, *Will Ending Adult Day Health Care Services Save State Money?*, CAL. HEALTHLINE (Aug. 25, 2001), available at <http://www.californiahealthline.org/features/2011/will-ending-adult-day-health-care-services-save-state-money.aspx>; see also LEGISLATIVE ANALYST'S OFFICE, APPROACH TO THE 2011-12 IN-HOME SUPPORTIVE SERVICES BUDGET 8-10 (2011) (finding that savings from the California Governor's proposed across-the-board reductions in IHSS are likely overestimated; noting that eliminating IHSS services for those who live with others (“shared living rule”) would likely violate Medicaid comparability requirements and that eliminating domestic services for all recipients may discriminate against people with disabilities in violation of the ADA); Campbell, *supra* note 75, at 1165-67 (describing the discriminatory impact of Pennsylvania's decision to limit nursing home services to cut costs).

77. See Clark, *supra* note 5 (describing the problem of hospital closures in, and relocations from, underserved communities with significant numbers of Medicaid beneficiaries and the uninsured); Rosenbaum, *supra* note 22, at 20 (“Medicaid is the source of 33-40% of the funds required to operate federally-qualified health centers and public hospitals and health systems, as well as nearly two-thirds of publicly financed family planning services, much of it delivered through publicly supported clinics.”) (footnotes omitted).

gram (or DSH program).⁷⁸ This helps minimize the financial gap incurred as a result of treating the uninsured and Medicaid patients; yet plans by the federal government to phase out DSH funding is understandably fueling even greater fear about threats to access in the safety net.⁷⁹ Although hospitals do not have the same ability to control the number of Medicaid beneficiaries they treat as individual providers—the potential threat to access from inadequate funding is no less severe; it is simply less imminent and thus more difficult to predict or fix if closure or relocation ultimately comes to pass.

Thus, when states use their discretion to cut spending—through program cuts, DSH funding, or more specifically for the focus of this article, reducing reimbursement rates—this is likely to impact provider participation, and health care access. Cuts to Medicaid reimbursement that result in lack of a full range of providers for Medicaid beneficiaries means a disruption in care that not only has significant health costs, but could lead to disabling injury or illness that ultimately will increase societal costs as a result of unemployment, disability, or the need for more expensive acute care. Thus a focus on cutting costs by reducing Medicaid spending, without considering the costs ultimately incurred as a result of the cuts, is incomplete; this singular focus leads to policies that not only reduce access and quality care, but that increase the strain on the state's fisc. In places where the reimbursement is already low, access is already declining, and the disparities between Medicaid and private insurance are already stark, decisions to slash Medicaid payments as a way to fix state budget shortfalls draws criticism from patients advocates, providers, and policy analysts that the cuts may be penny wise, but pound foolish.

Such cuts certainly do not look like the kind of thoughtful and deliberate experimentation that state flexibility was designed to encourage and described in Section A. But assuming that such cuts

78. In 1981, Congress required states to reimburse hospitals that treat a disproportionate number of uninsured and Medicaid patients at a higher rate. See Omnibus Budget Reconciliation Act of 1981, Pub. L. No. 97-35 § 2173, 95 Stat. 357, 808.

79. See ACADEMYHEALTH, THE IMPACT OF THE AFFORDABLE CARE ACT ON THE SAFETY NET 4 (2011), available at http://www.academyhealth.org/files/FileDownloads/AHPolicybrief_Safetynet.pdf. The policy brief describes the importance of DSH funding for helping to subsidize hospitals for the unreimbursed costs they incur treating the uninsured and Medicaid patients, and fears about its phase out beginning in 2014. *Id.* “The expectation among lawmakers is that with fewer uninsured patients in a reformed system there will be fewer uncompensated costs and, therefore, less need for DSH payments. However, safety net providers worry that reductions in DSH payments may not comport with reductions in uncompensated care costs.” *Id.*

could be criticized as bad policy, does this mean they are illegal and thus subject to challenge in court? The next two Parts of the Article try to answer this question: Part III looks for guidance in the history of the Medicaid Act, and specifically at the relationship between law and policy in the evolution of rate-setting requirements. Part IV considers how courts have navigated this relationship in the dozens of payment challenges brought since Medicaid's enactment.

II. MEDICAID POLICY V. LAW: HOW THE MEDICAID ACT BALANCES SPENDING AND ACCESS GOALS

Medicaid payment suits present two challenges. First, in the case of agency funding decisions, like rate cuts it can be difficult to distinguish illegal action from legal policy decisions which have harsh and unfortunate health and cost effects in the case of agency funding decisions, like rate cuts. This is because of the inherently political character of public spending decisions, the degree of state and federal agency discretion provided in the Medicaid Act, and the lack of federal guidance with respect to rate-setting requirements. Relatedly, these disputes have triggered an on-going debate about which entity—federal court, state Medicaid agency, or the federal regulator charged with state oversight (HHS)—is in the best position to determine when such funding decisions violate federal law. In light of these challenges, it is important to understand the legal and political backdrop for balancing cost, access and quality goals under the Medicaid Act, and specifically how this balancing is done in the rate-setting context. This Part gives an overview of the evolution of the law with respect to rate-setting, and the changing understanding of the role that federal regulators and courts play in enforcement. It reveals inconsistent signals from Congress about the degree to which access and quality protections are expected to constrain states in practice, as well as contradictory messages about the relationship between regulatory review and litigation in enforcement.

A. Overview of Beneficiary and Provider Protections

From its enactment, the Medicaid Act has contemplated a system that is designed to expand access and improve quality, but in ways that are cost effective.⁸⁰ These are not simply policy aspirations—the

80. See KU & FERGUSON, *supra* note 3, at 17 (“State Medicaid programs have served as pioneers in reforming the health care system . . . [through the development of] accountable care

Medicaid Act expressly codifies efficiency, economy, access and quality as important legal requirements in a variety of ways. For example, the Medicaid Act requires that states ensure services are widely available and fairly distributed⁸¹ and that beneficiaries have timely access to care.⁸² The Act also requires states to administer the program with regard to what is in the “best interest” of program recipients.⁸³ As will be detailed further below, the relevance of these factors with respect to rate setting in particular is also expressly set out in the statute and constrains state discretion.

Other federal protections, not specific to the Medicaid program, have played an important role in reinforcing access and quality goals for Medicaid beneficiaries. For example, Title VI of the 1964 Civil Rights Act prohibits recipients of federal funding from discriminating on the basis of race or ethnicity,⁸⁴ and the Americans with Disabilities Act prohibits recipients of federal funding from discriminating on the basis of disability.⁸⁵ Both have been used, often in conjunction with

entities; patient-centered medical homes; public reporting and performance measurement; pay-for-performance; health information technology for meaningful uses; reducing racial and ethnic disparities; and integrated preventive care for patients with multiple chronic conditions.”).

81. The “statewideness” requirement comes from 42 U.S.C. § 1396a(a)(1), which provides that the State Medicaid plan “shall be in effect in all political subdivisions of the State . . .” 42 U.S.C. § 1396a(a)(1) (2006). The implementing regulation requires that each state plan “be in operation statewide.” 42 C.F.R. § 431.50 (2012). The “comparability” requirement refers to 42 U.S.C. § 1396a(a)(10)(B), which requires that the medical assistance made available to any recipient “shall not be less in amount, duration, or scope than the medical assistance made available” to other recipients. 42 U.S.C. § 1396a(a)(10)(B) (2006). Together, these provisions require medical benefits to be available throughout the state and to all eligible persons, across different communities, expressly taking into account patients’ needs.

82. 42 U.S.C. § 1396a(a)(8) requires the State plan to “provide that all individuals wishing to make application for medical assistance under the plan shall have opportunity to do so, and that such assistance shall be furnished with reasonable promptness to all eligible individuals.” 42 U.S.C. § 1396a(a)(8) (2006). Courts have interpreted this as applying not only to coverage, but to the delivery of care. *See, e.g., Sabree ex rel. v. Richman*, 367 F.3d 180 (3d Cir. 2004). *But see Westside Mothers v. Olszewski*, 454 F.3d 532 (6th Cir. 2006) (limiting promptness requirement to payment for services only).

83. 42 U.S.C. 1396a(a)(19) (2006) (“[The State Plan must] provide such safeguards, as may be necessary to assure that eligibility for care and services under the plan will be determined, and such services will be provided, in a manner consistent with simplicity of administration and the best interests of the recipients.”).

84. 42 U.S.C.A. § 2000d (2010) (“No person in the United States shall, on the ground of race, color, or national origin, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.”). The implementing regulations expressly prohibit the use of criteria or methods, or choice of site locations that have a discriminatory effect. *See* 45 C.F.R. § 80.3(b)(2) (2012). Since 2001, however, private plaintiffs can only use Title VI to challenge intentional discrimination. *See Alexander v. Sandoval*, 532 U.S. 275 (2001). As a result, Title VI enforcement in the case of policies that have a disparate impact rests solely with the U.S. Office of Civil Rights.

85. 42 U.S.C. § 12132 (2006) (“Subject to the provisions of this subchapter, no qualified individual with a disability shall, by reason of such disability, be excluded from participation in

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the Medicaid Act, to successfully challenge state cuts that disproportionately harm protected groups who are also Medicaid beneficiaries.⁸⁶ The 1980s also brought special protections for access to emergency hospital care and nursing home quality. The Emergency Medical Treatment and Labor Act (EMTALA), enacted in 1986, required Medicare-participating hospitals with emergency rooms to screen and stabilize anyone coming to the ER, regardless of their ability to pay.⁸⁷ This helped to protect not only the uninsured, but also Medicaid patients who may have been viewed as “undesirable” due to low reimbursement and the risk that they would need continuing non-emergency care after admission and be difficult to transfer.⁸⁸ In 1987, the Nursing Home Reform Act was enacted in response to wide-

or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity.”). The ADA extended protection against discrimination from an earlier statute, the Federal Rehabilitation Act of 1973. *See* 29 U.S.C. § 794 (2006):

No otherwise qualified individual with a disability . . . shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance or under any program or activity conducted by any Executive agency

Id.

86. *See, e.g.*, *Rodde v. Bonta*, 357 F.3d 988 (9th Cir. 2003) (issuing a preliminary injunction to prevent closure of a county rehabilitation hospital based on the ADA’s prohibition on disability-based discrimination and finding that it did not need to reach the question of whether the closure also violated certain provisions of the Medicaid Act); *Oster v. Lightbourne*, No. 09-cv-4688, 2012 WL 691833, at *9-13 (N.D. Cal. Mar. 2, 2012) (enjoining state’s attempt to cut the hours available for elderly and disabled California residents to receive care at home based on allegations that it violated the Medicaid Act and the ADA); *V.L. v. Wagner*, 669 F. Supp. 2d 1106 (N.D. Cal. 2009) (granting a preliminary injunction of changes in state eligibility criteria for the In-Home Supportive Services Program based on the likelihood that plaintiffs would succeed on their allegations of violations of the Medicaid Act and the ADA); *see also Rosen v. Tenn. Comm’r Fin. & Admin.*, 280 F. Supp. 2d 743, 756-57 (M.D. Tenn. 2002) (alleging that the Tenn-Care Medicaid managed care plan did not adequately accommodate LEP enrollees in the plan’s communication about eligibility re-verification and appeals of benefits termination, which would likely result in benefits denial and coverage termination without due process); *Linton ex rel. v. Carney ex rel.*, 779 F. Supp. 925 (M.D. Tenn. 1990) (patients successfully challenged a Tennessee policy allowing nursing homes to only certify a portion of beds to be available for Medicaid patients as a violation of Title VI and federal Medicaid law); *NAACP v. Wilmington*, 426 F. Supp. 919 (D. Del. 1977) and 491 F. Supp. 290 (D. Del. 1978) (finding that plaintiffs raised a credible Title VI claim based on a private hospital’s relocation of specialty and high-risk services from its downtown location, an underserved urban neighborhood comprised disproportionately of racial and ethnic minorities, to a predominantly white suburb).

87. 42 U.S.C. § 1395dd(a) (2006). Under EMTALA, a “participating hospital may not delay provision of an appropriate medical screening examination . . . [or] further medical examination and [stabilizing] treatment . . . in order to inquire about the individual’s method of payment or insurance status.” *Id.* §1395dd(h).

88. *See generally* Lisa M. Enfeld & David P. Sklar, *Patient Dumping in the Hospital Emergency Department: Renewed Interest in an Old Problem*, 13 AM. J.L. & MED. 561 (1988) (describing the problem of private hospitals refusing to treat the medically indigent, and evaluating different approaches to addressing the problem).

spread reports of serious quality problems in nursing homes.⁸⁹ Medicaid was (and still is) the primary funding source of long-term care, and nursing home patients were considered particularly vulnerable to abuse due to their health condition, mental capacity, lack of resources, and isolation from family and friends.⁹⁰ The Act included important quality reforms to ensure adequate staffing, supervision, mental health care, as well as to reduce the inappropriate use of restraints.⁹¹

Thus, access and quality goals have always been important as a policy and legal matter, specifically within the Medicaid Act, and as a condition of federal funding more generally. More importantly for this Article, however, these goals were incorporated into statutory and regulatory provisions governing rate setting. This Article focuses on the legal provisions governing rate setting because they explicitly link concerns about the sufficiency of payment rates with access and quality concerns, and have been among the most important legal tools for providers and patients challenging rate freezes and cuts that jeopardize access. Rate-setting challenges are also gaining national attention: nationwide states struggle to deal with the cost of expanding demand for Medicaid by cutting rates further; federal regulators have proposed new rules to enforce compliance with these protections; and providers' and beneficiaries' ability to challenge payment cuts in federal court are being heard by the Supreme Court.

B. Rate Setting

1. Initial Medicaid Payment Rules & DHEW's Regulatory Power

From the beginning, there were concerns about the funding commitment that Medicaid would entail because health care costs were largely driven by the providers, who determined what care was needed and the amount charged to payors.⁹² Despite the fact that the Medicaid Act did not create a uniform rule with respect to payment

89. See David A. Bohm, *Striving for Quality Care in America's Nursing Homes: Tracing the History of Nursing Homes and Noting the Effect of Recent Federal Government Initiatives to Ensure Quality Care in the Nursing Home Setting*, 4 DEPAUL J. HEALTH CARE L. 317, 331-32 (2001).

90. See KAISER COMMISSION ON MEDICAID AND THE UNINSURED, EXAMINING MEDICAID MANAGED LONG-TERM SERVICE AND SUPPORT PROGRAMS: KEY ISSUES TO CONSIDER 3 (2011) (noting that Medicaid accounted for almost half of the spending for long-term services and supports in 2009, 48 percent of \$264 billion); Campbell, *supra* note 75, at 1165 (describing the "historical love-hate relationship" between the nursing home industry and Medicaid, and noting that Medicaid is the primary payment source for most nursing home care).

91. See *infra* Part III.B.1 for a discussion of the *Kansas Health Care Ass'n* case.

92. See Rosenbaum, *supra* note 22, at 27.

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methodology, the U.S. Department of Health, Education, and Welfare (DHEW) was charged with program oversight and had the power to review and approve rates.⁹³ DHEW used its power in two important ways. First, it essentially created a de facto parity standard that deemed Medicare rates presumptively reasonable for Medicaid.⁹⁴ Second, DHEW promulgated a regulation in 1969 that seemed to put access on par with efficiency and economy goals, and explicitly recognized the link between amount of reimbursement and access, the precursor to today's Equal Access requirement.⁹⁵ In this way, DHEW made clear that the success of the Medicaid program depended on private providers' willingness to participate, and that participation depended on sufficiency of reimbursement.

Over the next couple of decades, greater attention was paid to rising health care costs—in public programs and in the private insurance market.⁹⁶ Payors were concerned that providers were being wasteful and spending without regard to rising costs. This was attributed to a fee-for-service system that rewarded doctors for doing more tests and procedures, a culture among physicians to push technological advances and use them whenever possible, a lack of reporting and measurement to determine if care was actually efficacious and resulting in better health, and a fear of malpractice liability that led physicians to practice defensive medicine. The federal government was particularly concerned with waste in hospital and nursing home care, and it wanted to encourage states to experiment with different payment models to try to contain these costs. The federal government did not want states to feel constrained by Medicare rates or DHEW's early approach to rate review, and so Congress decided to push for reforms that would encourage state experimentation.⁹⁷

93. The U.S. Department of Health and Human Services (HHS) originated as part of DHEW, which no longer exists. Currently, CMS (the Centers for Medicaid and Medicare Services) is the division of HHS charged with Medicaid oversight. CMS was formerly called the Health Care Financing Administration (HCFA).

94. See *Miss. Hosp. Ass'n v. Heckler*, 701 F.2d 511, 515 (5th Cir. 1983).

95. See *Wilder v. Va. Hosp. Ass'n*, 496 U.S. 498 (1990) (describing the history of rate-setting regulation and legislation, and earlier iterations of the Equal Access Provision); see also *infra* note 137 and accompanying text for the current version of the Equal Access provision.

96. See generally Kenneth R. Wing, *American Health Policy in the 1980's*, 36 CASE W. RES. L. REV. 608 (1986) (describing the cost debate as it pertained to health care).

97. See JOST, *supra* note 18, at 168-72 (describing the trend toward greater state discretion in Medicaid policy in the 1980s and 1990s).

2. The Boren Amendment: Increasing State Flexibility in Rate Setting

Congress began the process of trying to dial back some of DHEW's control and increase state flexibility as early as 1972, but the most significant change came in 1981, with enactment of the Boren Amendment.⁹⁸ As originally enacted, the Boren Amendment applied to reimbursement for nursing and intermediate care facilities, but the following year it was expanded to include reimbursement for hospital in-patient services—both of which represented the most significant percentage of health care costs.⁹⁹ Prior to Boren, federal law required state agencies to pay hospitals the “reasonable cost” of inpatient services they rendered to Medicaid recipients, and the term “reasonable cost” was a term used and defined in detail in the federal Medicare program.¹⁰⁰ Moreover, the “reasonable cost” was typically reimbursed retrospectively, with rates determined by the providers' actual costs.¹⁰¹ The Boren Amendment changed this to require states to use rates “determined in accordance with methods and standards developed by the State” and which:

[t]he State finds and makes assurances satisfactory to the Secretary, are *reasonable and adequate to meet the costs* which must be incurred by *efficiently and economically operated facilities* in order to provide care and services in conformity with applicable State and Federal laws, regulations, and quality and safety standards and to assure that individuals eligible for medical assistance have reasonable access (taking into account geographic location and reasonable travel time) to inpatient hospital services of adequate quality¹⁰²

What may appear to be a subtle change in language actually effected two important substantive changes in the rate-setting process. First, it delinked Medicaid and Medicare rates so that states had flexibility to set Medicaid rates lower than those for Medicare providers

98. *See Wilder*, 496 U.S. at 505-06, 515-16.

99. *See id.* at 502 n.2. The Boren Amendment was enacted as part of the Omnibus Budget Reconciliation Act of 1981. *Id.* at 506; *see also infra* notes 137-38 and accompanying text for statutory language.

100. *See Wilder*, 496 U.S. at 505-07 (describing rising health care costs as motivation for the Boren Amendment and the changes in health care rates the amendment hoped to encourage).

101. Because this method operated retrospectively, hospitals would receive an interim rate during the fiscal year based on initial estimates, and then receive adjustments (or corrections) at the end of the year once they established their actual, allowable costs for the year. *Id.* at 507 n.7.

102. 42 U.S.C. 1396a(a)(13)(A) (1982) (current version at 42 U.S.C. § 1396a(13)(A) (2006)) (emphasis added).

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without making them vulnerable to legal challenge.¹⁰³ More fundamentally, however, Congress used Boren to encourage states to experiment with a prospective payment system (PPS).¹⁰⁴ Unlike the retrospective payment system which reimbursed each facility according to its own costs, PPS set reimbursement based on an estimate of future costs and based on assumptions about what costs should be deemed “reasonable” for facilities that are economical and efficient.¹⁰⁵ Practically this meant that states could set rates based on generalizations about which criteria or characteristics should be relevant to assessing cost, and based on assumptions that providers or services that share these characteristics should be reimbursed at the same amount; if providers’ actual costs exceeded this rate, providers must absorb the loss, even if their actual costs of providing the service were reasonable. The assumption underlying this change was that the old system was inherently inflationary, and that shifting more financial risk to hospitals and nursing facilities would force them to become more efficient and less costly.¹⁰⁶ At the same time, Congress imposed significant financial constraints on the states forcing them to contain Medicaid spending; this provided a powerful economic incentive for states to accept Congress’ invitation to experiment with new models, like PPS, to reduce cost.¹⁰⁷

While states did use their flexibility as Congress had hoped, payment disputes continued as hospitals and nursing homes filed legal challenges to new rate-setting processes based on the Boren Amendment.¹⁰⁸ This was possible because Boren included important protections for providers and beneficiaries despite its intent to increase state flexibility. Although states were no longer required to reimburse facilities for their actual costs, states could not set rates arbitrarily ei-

103. *See Wilder*, 496 U.S. at 515.

104. *See Mary Washington Hosp., Inc. v. Fisher*, 635 F. Supp. 891, 894 (E.D. Va. 1985).

105. *See id.*

106. *See id.*

107. *See id.* at 894:

Working somewhat against [the] assurance [against arbitrary reductions in payment] in the legislative history, other provisions of OBRA strongly encouraged the states to contain their Medicaid costs within fixed limits starting in 1982. If a state failed to stay within the limits suggested, it would suffer substantial financial penalties in the form of reduced federal contributions to the program. . . . In short, OBRA of 1981 put the state Medicaid agencies in an intractable position and left them to their own devices as to how to cope with the situation.

Id.; *see also* JOST, *supra* note 18, at 122-23 (noting that cost was the primary driving force for most states adopting managed care; better care coordination was secondary).

108. *See Wilder*, 496 U.S. at 507 n.7 (noting that after passage of the Boren Amendment most states adopted plans that were prospective in nature).

ther; they had to set rates that would, in fact, be consistent with the “reasonable costs” of efficient and economical facilities, and ensure “equal access” and “quality” guarantees.¹⁰⁹ As will be detailed in the next Part, some states blatantly ignored these requirements, while others undertook processes that seemed inadequate, making them vulnerable to attacks by providers and beneficiaries. Moreover, Congress was aware of these suits; before and at the time of the Boren Amendment, Congress took these legal protections seriously and expressed concern about state disregard of federal law.¹¹⁰ In fact, despite federal cost-cutting goals, Congress enacted other beneficiary access and quality protections for hospital and nursing care that would likely increase the costs of these services.¹¹¹

3. Codification of Rate-Setting Requirements and the Equal Access Provision Under 30A

In 1989 Congress codified a similar rate setting provision,¹¹² which unlike the Boren Amendment, was not limited to specific services or providers. This provision, commonly known as 30A, or the Equal Access Provision, contains the same basic requirement that payments be consistent with economy, efficiency, and quality care, and sufficient to enlist enough providers so services under the plan are available to recipients at least to the extent those services are available to the general population.¹¹³ It does not contain the express re-

109. See *infra* Part III.

110. For a discussion of the Medicaid payment suits that plagued the system from the beginning, see RAND E. ROSENBLATT ET AL., LAW AND THE AMERICAN HEALTH CARE SYSTEM (2001-2002 Supp.), at 410-24 (1997); ROBERT STEVENS & ROSEMARY STEVENS, WELFARE MEDICINE IN AMERICA: A CASE STUDY OF MEDICAID 305-15 (1974). Early on Congress seemed concerned about state disregard of federal law and sympathized with providers who were not being treated fairly. In 1975, Congress tried to expand provider protections by amending the Act to require states to sign an Eleventh Amendment waiver so that providers could sue states for past payments. Because of the Eleventh Amendment right to state sovereignty, providers could only seek injunctive relief against state officials to halt illegal payment cuts for the future, but if illegal cuts had already been implemented, providers could not sue the state for retrospective monetary relief. The amendment was repealed almost immediately due to significant opposition. Nonetheless, legislators were careful to make clear that the repeal “should not be construed as in any way contravening or constraining the rights of the providers of Medicaid services, the State Medicaid agencies, or the Department to seek prospective, injunctive [relief].” S. REP. NO. 94-1240, at 4 (1976). Legislative history reflected concern about noncompliance and the limits of existing enforcement mechanisms. H.R. REP. NO. 94-1122, at 4 (1976); 121 CONG. REC. 42259 (1975); see also *Wilder*, 496 U.S. at 516-17.

111. See the discussion of EMTALA and Nursing Home Reform in Section A of this Part.

112. This provision was based on the earlier Equal Access regulation promulgated by DHEW. See *supra* Part II.B.

113. 42 U.S.C. § 1396a(a)(30)(A); see *infra* note 138.

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quirement that states “make findings” to this effect, as Boren did, but the implementing regulations do require states to submit assurances of 30A compliance to HHS when it submits a state plan amendment.¹¹⁴

This was yet another notable step by Congress to ensure that state flexibility in rate-setting did not result in state disregard for federal protections with respect to the adequacy of rates, and their impact on access and quality. Through 30A, Congress re-emphasized the payment-access link and expanded these rate-setting protections to all kinds of care. Not only was Congress aware of Medicaid payment suits at this time, but also it stated that one reason for codifying 30A was the inadequate enforcement it had been receiving as a regulation.¹¹⁵ Ironically, Congress bears some responsibility for this under enforcement because of the very limited oversight it delegated to the federal agency that administers the Medicaid program. Although states have been required to make assurances to the federal government of compliance with the Boren Amendment and 30A, these statutes have not required the state to submit these findings or its underlying data to the federal agency, nor has it explicitly required the agency to review the findings.¹¹⁶ In practice, the Secretary has relied heavily on state assurances without any underlying documentation or scrutiny, exacerbating providers and beneficiaries’ concerns that states are abusing their discretion to freeze or cut rates arbitrarily and causing them to seek help in federal court using the Boren Amendment or 30A.¹¹⁷

Thus, throughout the 1980s and most of the 90s, the federal government sent three very strong signals to states that were not always consistent. First, reducing cost was important and the government would not let Medicaid providers dictate the government’s financial commitment. Congress wanted states to use their flexibility to create new payment models that would force providers to deliver care in a more efficient and economical way, and it encouraged rate reductions. Second, federal law and regulations continually reinforced the idea that Medicaid access depends on participation by private providers and that providers’ cost, access and quality goals must be balanced in

114. See *infra* Part III.B.2 for a discussion of the significance of the absence of this language.

115. See H.R. Rep. No. 101-247(1989), *reprinted in* 1989 U.S.C.C.A.N. 2060.

116. See, e.g., *Wilder*, 496 U.S. at 507-08 (noting that the Secretary’s review of state assurances of compliance with the Boren Amendment focuses only on the assurances themselves; it does not require States to submit its findings nor does it review the findings upon which state assurances are based).

117. See *id.*

rate setting. Finally, although Congress did not create a very robust mechanism for federal oversight, it codified legal protections that enabled providers and beneficiaries to seek enforcement in the federal courts.

4. Congressional Retrenchment and the Boren Repeal of 1997

Although the 1980s and early 90s reflected a time when Congress and the federal courts seemed to take seriously their role as a protector of these rights, a growing number of legislators viewed payment suits as impeding state flexibility and driving up costs. Moreover, some Supreme Court justices and federal courts increasingly viewed HHS, and not federal judges, as the appropriate enforcer of these rights.¹¹⁸ These forces ultimately ushered in legislative and judicial changes designed to increase state flexibility and decrease accountability, though the actual effect of these changes was not so predictable.

In 1997, a Republican Congress gutted the Boren Amendment by repealing the explicit substantive requirements that rates must be adequate to meet providers' reasonable costs and that states must make findings to that effect. It was replaced with a far more limited public notice-and-comment process for hospital and nursing home ratemaking decisions.¹¹⁹ The legislative history reveals that some legislators intended this amendment to effect a radical reversal – they wanted to prevent providers' suits over the sufficiency of Medicaid rates because of concerns that the suits impeded states' attempts to contain spending. No change was made to 30A, however, which had been used to bring similar challenges for other kinds of services. Thus the Boren repeal did not stop Medicaid payment suits because providers and beneficiaries simply started using 30A to challenge hospital and nursing rates.¹²⁰ The fact that 30A did not contain exactly the same language that rates are "reasonable and adequate to meet costs" did raise questions, however, about whether 30A would be an equally effective tool for challenging payment rates.¹²¹

The Boren repeal was not the last attack on Medicaid payment suits. States have also tried to attack providers and beneficiaries' right

118. See generally Lisa Colosi, Comment, *Wilder v. Virginia Hospital Association: Making the Medicaid Reimbursement Rate Challenge a Federal Case*, 12 PACE L. REV. 139 (1992) (discussing the appropriate governmental body to review and enforce the Medicaid Act).

119. See *infra* note 149 and accompanying text describing the notice requirements under the current version of 42 U.S.C. § 1396a(a)(13)(A).

120. See *infra* Part III.B.

121. See *infra* Part III.A.

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to challenge rate-setting violations in federal court.¹²² Previously these challenges had been unsuccessful, but this changed in 2002 as the result of the Supreme Court's decision in *Gonzaga University v. Doe*.¹²³ *Gonzaga* did not involve the Medicaid Act, but it did involve a question about when private individuals could use 42 U.S.C. § 1983 to enforce federal law.¹²⁴ Section 1983 provides a cause of action for "the deprivation of any rights, privileges, or immunities secured by the Constitution and laws" of the United States.¹²⁵ Prior to *Gonzaga*, providers and beneficiaries successfully used § 1983 to challenge rates or state rate-setting processes that violated the Boren Amendment and 30A.¹²⁶ The *Gonzaga* court issued a decision that severely narrowed the test for when § 1983 could be used to enforce federal law, a decision interpreted by federal courts as eliminating § 1983 as a tool for challenging Medicaid payment cuts and freezes.¹²⁷ The Court seemed particularly skeptical about Congressional intent to create a right to sue to enforce conditions attached to spending statutes (like the Medicaid Act), especially where the conditions related to the more complex administrative aspects of the program. The *Gonzaga* Court held that a § 1983 action is only available to enforce provisions of a spending statute where Congress uses explicit, individually focused, rights-creating language that reveals congressional intent to create an individually enforceable right.¹²⁸ Most federal courts agreed

122. See, e.g., *Douglas*, 132 S. Ct. at 1207-08 (refusing to deny private plaintiffs the right to challenge Medicaid rates that violate 30A using the Supremacy Clause); *Wilder*, 496 U.S. 498 (affirming that §1983 could be used by private plaintiffs to challenge Medicaid rates that violate federal law).

123. 536 U.S. 273 (2002).

124. *Gonzaga* involved an alleged violation of the Family Educational Rights and Privacy Act of 1974 ("FERPA"), which prohibits "the federal funding of educational institutions that have a policy and practice of releasing educational records to unauthorized persons." *Id.* at 276. The Court held that FERPA did not create personal rights enforceable under 42 U.S.C. § 1983. *Id.*

125. 42 U.S.C. § 1983 (2006).

126. See *Wilder*, 496 U.S. at 524; see also *Sanchez v. Johnson*, 416 F.3d 1051, 1058 (9th Cir. 2005) (listing the Circuits holding that providers and/or recipients could use §1983 to enforce 30A obligations prior to *Gonzaga*).

127. See Sara Rosenbaum, *Medicaid Payment Rate Lawsuits: Evolving Court Views Mean Uncertain Future for Medi-Cal*, CAL. HEALTHCARE FOUND. ISSUE, Oct. 2009 at 1, 6, 13-14 [hereinafter Rosenbaum, *Medicaid Payment Rate Lawsuits*].

128. The Court held that in order for a statute to create a right enforceable under § 1983, three factors must be considered: (i) whether Congress "intended that the provision in question benefit the plaintiff"; (ii) the right protected by the statute cannot be so "vague and amorphous" that its enforcement would strain judicial competence, and (iii) "the statute must unambiguously impose a binding obligation on the States"; "[i]n other words, the provision giving rise to the asserted right must be couched in mandatory, rather than precatory, terms." *Gonzaga*, 536 U.S. at 282 (quoting *Blessing v. Freestone*, 520 U.S. 329, 340-41 (1997)). The *Gonzaga* Court then made clear that despite reference to a "benefit" in the first factor of the *Blessing* test, §1983 is

that based on this test, claims that a state's rate-setting process were inadequate could no longer be challenged using § 1983.¹²⁹ Nonetheless, Medicaid payment suits proved resilient because of an alternative legal theory: providers and beneficiaries started to bring challenges under the Supremacy Clause¹³⁰ – arguing that a state law or regulatory action that reduced rates in violation of 30A was preempted by federal law and thus invalid.¹³¹

This approach has been largely successful so far,¹³² but was recently challenged in the Supreme Court in *Douglas v. Independent Living Center*, a consolidation of several suits in which providers and beneficiaries successfully challenged Medicaid cuts in California.¹³³ The Court recently issued a decision that effectively preserves the right to sue,¹³⁴ but the Court reframed and remanded the case back to the Ninth Circuit based on what it perceived to be a significant change in the posture of the litigation: CMS approval of California's proposed rate cut.¹³⁵ The deeper implications of this decision will be explored further in the Conclusion, however, for now, it is important to understand that the decision indicates a majority of the Supreme Court is unwilling to foreclose private plaintiffs' ability to challenge payment

only available to enforce provisions of a federal statute where Congress uses “explicit, rights-creating terms” that “manifest[] an intent ‘to create not just a private *right* but also a private *remedy*.’” *Id.* at 284 (quoting *Alexander v. Sandoval*, 532 U.S. 275, 286 (2001)).

129. *See, e.g., Sanchez*, 416 F.3d at 1061; *Long Term Care Pharm. Alliance v. Ferguson*, 362 F.3d 50, 59 (1st Cir. 2004).

130. U.S. CONST. art. VI, cl. 2 (“This Constitution, and the Laws of the United States which shall be made in Pursuance thereof; and all Treaties made, or which shall be made, under the Authority of the United States, shall be the supreme Law of the Land; and the Judges in every State shall be bound thereby, any Thing in the Constitution or Laws of any State to the Contrary notwithstanding.”).

131. *See generally* Rosenbaum, *Medicaid Payment Rate Lawsuits*, *supra* note 127, at 1, 9-11 (discussing the evolution of payment suits and the shift in legal theories after the demise of private challenges under §1983). *See also Douglas*, 132 S. Ct. at 1210 (explaining that plaintiffs began using the Supremacy Clause to enforce 30A obligations once federal courts began finding that 30A did not create rights enforceable by private parties through § 1983).

132. *See, e.g., Indep. Living Ctr. of S. Cal., Inc. v. Maxwell-Jolly*, 572 F.3d 644, 652-53 (9th Cir. 2009), *vacated and remanded sub nom. Douglas*, 132 S. Ct. at 1204. *Affiliates, Inc. v. Armstrong*, No. CV-09-149-BLW, 2009 US Dist. LEXIS 37136, at *10 (D. Idaho 2009); *Kerr v. Hol-singer*, No. 03-68-JMH, 2004 US Dist. LEXIS 7804, at *9, 38 (E.D. Ky 2004); *New Hampshire Health Care Ass'n v. Governor*, 13 A.3d 145, 163 (N.H. 2011).

133. *Douglas v. Indep. Living Ctr. of S. Cal.*, 132 S. Ct. 1204 (2012). Two other cases have been consolidated into this appeal: *California Pharmacists Ass'n v. Maxwell-Jolly*, 596 F.3d 1098 (9th Cir. 2010); *Santa Rosa Mem'l Hosp. v. Maxwell-Jolly*, 2010 U.S. App. LEXIS 10860 (9th Cir.).

134. *Douglas*, 132 S. Ct. at 1207-08. The dissent would have sided with states and HHS in broadly prohibiting use of the Supremacy Clause to challenge rates. *Id.* at 1213. The majority declined to follow the dissent's approach, but it also failed to affirmatively decide that such suits are available and why. *See id.*

135. *Id.* at 1207-08.

cuts that violate federal law in federal court.¹³⁶ Medicaid payment suits remain an important tool for protecting Medicaid access.

III. CHALLENGES TO MEDICAID PAYMENT CUTS: THE ROLE OF FEDERAL COURTS¹³⁷

Part II provided the policy and legal context within which Medicaid payment suits have to be decided. If there is one dominant theme reflected in the evolution of laws governing rate-setting in Medicaid, it is balancing. States are expected to balance cost, access, and quality goals in program administration. The regulatory enforcement mechanism in the Act tries to balance federal oversight with state flexibility to experiment and tailor the program to its needs. And various Congressional amendments have been motivated by changing legislative perceptions about the role of courts in balancing policy and law when rates are challenged: can federal courts enforce legal mandates without impeding state discretion in policymaking?

Part II also revealed conflicting signals sent by the federal government with respect to how this balancing should be done. At times, the government seems to take access and quality protections seriously: first promulgating regulations, and then codifying and preserving legislative mandates linking the sufficiency of rates to access and quality guarantees; providing for federal regulatory oversight of rate changes; and expressly acknowledging the important role of courts in checking state violations. On the other hand, the federal government has done things to undermine these protections: increasing financial pressure on states that made compliance difficult; creating a very limited oversight structure that has proven ineffective; and removing Boren Amend-

136. *See infra* Conclusion.

137. Although challenges to Medicaid administrative decisions or methodology can and are brought in both state and federal courts, federal courts have long been considered more instrumental in challenging state policies that violate federal law. *See Jost, supra* note 18, at 37. Jost says that although litigants in state court have only been slightly less successful than those in federal court, the nature of federal litigation is very different. For example in the year 2000, “three-quarters of reported cases challenging Medicaid agency policies or decisions in federal court were brought as class actions or had multiple or organizational plaintiffs, and only one-quarter were brought by individuals. In reported state court cases, the statistics were almost precisely the reverse Nearly three-quarters of the cases, moreover, were cases appealing administrative decisions rather than original cases brought to challenge agency policies. . . . [Such cases] have far less influence on state Medicaid policy than does corresponding federal litigation involving class actions.” *Id.* He also notes that state court judges, because they are appointed, “are understandably reluctant to order the state to adopt policies that might significantly increase state expenditures.” *Id.*

ment protections used to challenge state rate cuts in skilled nursing and hospital services.

It is against this legal and political backdrop that battles over payment rates occur. This Part looks more closely at these disputes to understand exactly what kind of state behavior is alleged to violate federal rate-setting requirements, and to see how courts attempt to balance their respect for state flexibility in rate setting, while ensuring compliance with federal access and quality protections. The cases reviewed here also begin to illuminate the role that federal regulators play, or rather fail to play, in rate-setting disputes, but this is explored more fully in Part IV.

A. The Easy Cases: No Process or Failure to Follow Express State & Federal Requirements

Recall that both the Boren Amendment and 30A require states to assure that payments are consistent with *efficiency, economy, and quality of care* and that they are sufficient to ensure *equal access* for Medicaid beneficiaries.¹³⁸ The Boren Amendment, which applied only to rates for hospital in-patient and nursing facility services, also explicitly required that the state “*finds*” and makes “*assurances satisfactory*” to the federal agency that rates are “*reasonable and adequate to meet the costs* which must be incurred by efficiently and economically operated facilities.”¹³⁹ Courts have interpreted these provisions as creating two distinct, yet, related, kinds of requirements: (i) substantive guarantees of the adequacy of payments to ensure cost, access, and quality goals; and (ii) process-oriented requirements that states will consider certain criteria (cost, access, and quality) and follow certain procedures in their rate-setting process.¹⁴⁰ Suits challenging rates on the first basis are discussed in Section C, but this substantive guarantee is important for understanding the nature of the

138. 42 U.S.C. § 1396a(a)(30)(A) requires a State Plan to “provide such methods and procedures relating to the utilization of, and the payment for, care and service available under the plan . . . as may be necessary to safeguard against unnecessary utilization of such care and services and to assure that payments are consistent with efficiency, economy, and quality of care and are sufficient to enlist enough providers so that care and services are available under the plan at least to the extent that such care and services are available to the general population in the geographic area” (emphasis added). The latter requirement is often referred to as the Equal Access Provision.

139. For the text of the Boren Amendment prior to its repeal in 1997, see *supra* note 102 and accompanying text.

140. See, e.g., *Wilder v. Va. Hosp. Ass’n*, 496 U.S. at 512-13.

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suits brought on procedural grounds, which are fleshed out in this Section and Section B.

The easiest cases in which to identify a violation occur where there is no process to consider the effects of rates on access, or to determine whether rates are in fact consistent with the efficient and economical delivery of quality health care. Courts have routinely held that rate cuts motivated exclusively by budgetary concerns violate Boren and 30A because of the failure to consider statutorily mandated factors. Nonetheless, state legislatures and Medicaid agencies have ignored these requirements repeatedly, by making across-the-board cuts or implementing rate freezes for a wide range of health care services without any analysis into the adequacy of the rates and without any assessment of the effect of the rates on access or quality.¹⁴¹ In these cases, it is typically undisputed that states are responding to budgetary shortfalls or other pressure to reduce spending.

In 30A challenges, states have fought such suits claiming that the law does not actually create procedural requirements that the state must follow, and that are judicially enforceable. Rather they argue that 30A merely identifies important policy goals and leave it to state discretion to determine how to achieve them. To support this claim, they point to the fact that the specific language in Boren mandating states “make findings” is absent in 30A, however most courts have rejected this argument. They have held that states must take the stat-

141. *See, e.g., Affiliates, Inc.*, 2009 U.S. Dist. LEXIS 37136, at *7-13. A group of Idaho Residential Habilitation Affiliates (“RHA”) successfully sought a temporary restraining order to halt state changes in Medicaid reimbursement to RHAs for the provision of non-institutional, residential care due to a violation of 30A. The plaintiffs alleged that the Department “admitted that the only consideration in determining the new rates were budgetary demands, ignoring quality of care issues.” They also claimed that the Department “admitted having little knowledge of what RHAs do, that no RHAs were involved in the determination of new rates, and that federal regulation requirements were not considered . . . [and] that the Department admitted to not knowing how the new rates would allow for clients to receive sufficient services.” *Id.* at *5-7, *19; *see also Wilder*, 496 U.S. at 516-17 (describing the problem of several states freezing rates in 1975 and Congress responding by attempting to require states to waive Eleventh Amendment immunity). *See generally* *Dominguez v. Schwarzenegger*, 596 F.3d 1087 (9th Cir. 2010) (affirming a preliminary injunction of cuts that impacted wages workers in the state’s In-Home Supportive Services program where “the State conceded that the legislature did not consider any analysis of the § 30(A) factors prior to enacting [the cuts]”); *Arkansas Med. Soc’y, Inc. v. Reynolds*, 6 F.3d 519 (8th Cir. 1999) (successful challenge to an emergency rule that cut Medicaid rates 20 percent across the board for services provided by non-institutional providers where cuts were made for exclusively budgetary reasons); *Oklahoma Nursing Home Ass’n v. Demps*, 792 F. Supp. 721, 724 (W.D. Okl. 1992) (holding that if rate cuts were motivated solely by budgetary considerations, they would violate the Boren Amendment); *Ohio Hosp. Ass’n v. Ohio Dept. of Human Servs.*, 579 N.E. 2d 695, 698 (Ohio 1991) (finding that rate reduction based solely on budgetary concerns violated 30A).

utorily enumerated factors in 30A into account, because otherwise they could not ensure compliance with 30A's explicit substantive requirements, let alone make credible assurances to the federal government to this effect.¹⁴²

Two circuits have rejected this approach, agreeing with states that 30A does not create a independent judicially-enforceable procedural requirement.¹⁴³ Nonetheless, these courts were still willing to review agency action implementing rate cuts, and considered 30A factors relevant to its review.¹⁴⁴ Under the Administrative Procedure Act, agency action can be challenged in court typically, under a deferential standard of review. A reviewing court must affirm an agency's determination unless it is "arbitrary, capricious, an abuse of discretion, or otherwise not in accordance with law."¹⁴⁵ The Supreme Court has provided further guidance to lower courts for this kind inquiry: "A decision is arbitrary and capricious if the agency 'has relied on factors which Congress has not intended it to consider, entirely failed to consider an important aspect of the problem, offered an explanation for its decision that runs counter to the evidence before the agency, or is so implausible that it could not be ascribed to a difference in view or the product of agency expertise.'"¹⁴⁶ Thus, even where 30A is not interpreted to create an independent procedural requirement for states to follow, the fact that a state ignores 30A factors is evidence

142. Numerous courts have found that 30A creates a sufficiently definite right for providers to enforce through §1983 despite the absence of the more specific Boren language concerning "reasonable costs." See, e.g., *Visiting Nurse Ass'n of N. Shore, Inc. v. Bullen*, 93 F.3d 997, 1004 (1st Cir. 1996); *Methodist Hosps., Inc. v. Sullivan* 91 F.3d 1026, 1029 (7th Cir. 1996); *Arkansas Med. Soc'y*, 6 F.3d at 526; *Moody Emergency Med. Serv., Inc. v. City of Millbrook*, 967 F. Supp. 488, 494 (M.D. Ala. 1997).

143. *Methodist Hosps.* 91 F. 3d at 1030 ("Nothing in the language of [30A], or any implementing regulation, requires a state to conduct studies in advance of every modification. It requires each state to produce a result, not to employ any particular methodology for getting there."); see also *Rite Aid of Pennsylvania, Inc. v. Houstoun Pennsylvania Pharmacists Ass'n*, 171 F. 3d 842, 845-51 (3d Cir. 1999) (reversing lower court decision to halt rate changes for prescription drugs and holding that 30A does not have a procedural component, let alone require states to perform a cost study); *Minnesota Homecare Ass'n, Inc. v. Gomez*, 108 F. 3d 917, 918 (8th Cir.1997). Other courts have cited the absence of a specific findings requirement in holding that 30A is too vague and indefinite to create a private right of action. See e.g., *Pennsylvania Pharmacist Ass'n. v. Houstoun*, 283 F. 3d 521, 538 (3d Cir. 2002); *Walgreen v. Hood*, 275 F.3d 475, 477 (5th Cir. 2001); *Evergreen Presbyterian Ministries, Inc. v. Hood*, 236 F.3d 908, 928-29 (5th Cir. 2000) (holding that providers do not have a right to challenge payment sufficiency under 30A).

144. See *Arkansas Med. Soc'y*, 6 F.3d at 530-31; *Methodist Hosps.*, 91 F. 3d at 1026.

145. 5 U.S.C. § 706(2)(A) (2006).

146. *O'Keeffe's, Inc. v. U.S. Consumer Prod. Safety Comm'n*, 92 F. 3d 940, 942 (9th Cir. 1996) (quoting *Motor Vehicle Mfrs. Ass'n v. State Farm Mut. Auto Ins. Co.*, 463 U.S. 29, 43 (1983)).

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that the state has entirely failed to consider important aspects of rate setting, and that its decision is arbitrary and capricious. On this basis, the Eighth Circuit invalidated state cuts that were made exclusively for budgetary reasons and without any consideration of the kind of the factors identified in 30A.¹⁴⁷

The rule that states cannot ignore 30A factors in rate-setting is really at the heart of many of Medicaid payment suits because of the connection to substantive guarantees mentioned at the beginning of this Section: although a process that considers these factors will not necessarily result in rates that are sufficient, failure to consider these factors at all means that the state will not be able to identify potential problems, increasing the likelihood that cuts will jeopardize access and quality. In addition, there are other, more technical, procedural federal requirements imposed on states relevant to rate setting, which states have also ignored and which have led some courts to halt cuts, at least temporarily. For example, states must get approval for “significant” or “material” rate changes or changes in rate-setting methodology by submitting state plan amendments (SPAs) to the federal government for approval.¹⁴⁸ This facilitates federal oversight of state compliance, and, in theory, should help ensure that states can articulate a rational justification for its decision. Federal regulations also require public notice and opportunity to comment on such changes,¹⁴⁹ as well as consultation with Medicaid Consumer Advisory Commit-

147. See *Arkansas Med. Soc’y*, 6 F.3d at 531.

148. Since 1981, 42 C.F.R. § 447.250(a) has required that “the State plan provide for payment for hospital and long-term care facility services through the use of rates that the State *finds, and makes assurances satisfactory to the Secretary, are reasonable and adequate to meet the costs that must be incurred by efficiently and economically operated facilities to provide services in conformity with State and Federal laws, regulations, and quality and safety standards.*” (2012). Section 447.253(a) says that “[i]n order to receive CMS approval of a State plan change in payment methods and standards, the Medicaid agency must make assurances satisfactory to CMS that the [rate-setting] requirements set forth [in the rest of this section are met]. Section 447.253(b) provides that states are required to make findings with respect to the reasonableness and adequacy of rates paid for inpatient hospital services and long-term care facility services, and the State must make these findings “[w]henver the Medicaid agency makes a change in its methods and standards, but not less often than annually.”

149. Regulations also specify that the notice must provide (1) the “proposed change in methods and standards,” and (2) an explanation of “why the agency is changing its methods and standards.” 42 C.F.R. § 447.205(c) (2012). When Congress repealed the substantive protections of the Boren Amendment, it replaced it with a public process requirement. Since 1997, 42 U.S.C. § 1396a(13)(A) has required State plans to:

[P]rovide for a public process for determination of rates of payment under the plan for hospital services, nursing facility services, and services of intermediate care facilities for the mentally retarded under which – (i) [the] proposed rates, the methodologies underlying the establishment for such rates, and justifications for the proposed rates are published, (ii) providers, beneficiaries and their representatives, and other concerned State residents are given a reasonable opportunity for review and comment on the proposed

tees (MCACs).¹⁵⁰ These requirements are designed to ensure provider and beneficiary participation to ensure that the process is a rational and informed one, and to help identify potential problems or deficiencies before it is too late. Finally, state law may create additional procedures with which states must comply.¹⁵¹

In many cases, Boren Amendment or 30A challenges reveal violations of these requirements, and attempts to implement rate changes without federal approval is a particularly significant problem.¹⁵² Courts have consistently held such approval to be necessary prior to the implementation of rate changes, and the practical effect of these violations is clear: courts will delay implementation of changes until the requisite notice or amendment has been filed, and the federal regulator has acted.¹⁵³ Such continuing disregard of this express require-

rates, methodologies, and justifications, (iii) final rates, the methodologies underlying the establishment of such rates, and justifications for such final rates are published. . . .

See *Visiting Nurse Ass'n of N. Shore, Inc.*, 93 F.3d at 1010 (finding notice inadequate, but noting that most cases addressing this problem deal with situations in which there was total absence of statutory notice).

150. 42 C.F.R. § 431.12(b) (2012). Before amending a State Plan, states must consult with a medical care advisory committee (MCAC). MCACs must include physicians, other health professionals, members of consumer groups, including Medicaid beneficiaries, and state officials. See *id.*

151. See, e.g., *Okla. Nursing Home Ass'n*, 792 F. Supp. at 725-28 (finding that the state failed to comply with its own rate-setting criteria established in its state plan); *Ohio Hospital Ass'n v. Ohio DHS*, 579 N.E. 2d; *N.H. Health Care Ass'n v. Governor*, 13 A.3d 145 (N.H. 2011) (hearing state constitutional challenge to cuts in reimbursement to private nursing homes).

152. See, e.g., *Developmental Servs. Network v. Douglas*, 666 F.3d 540 (9th Cir. 2011) (lamenting the fact that the state continues to ignore federal SPA requirements); *Wash. State Health Facilities Ass'n v. Wash. Dept. of Soc. & Health Servs.*, 698 F.2d 964, 965 (9th Cir. 1982); *Okla. Nursing Home Ass'n*, 792 F. Supp. at 721. In rare cases, a state may have a credible question about whether a change is significant enough to trigger the SPA requirement. See, e.g., *Or. Ass'n of Homes for Aging, Inc. v. Oregon*, 5 F.3d 1239 (9th Cir. 1993). Plaintiffs argued that a temporary state reclassification of certain nursing services in response to federal eligibility changes did not require a plan amendment because the reclassification did not constitute a change in methods or standards for setting rates. It also argued that the change was not significant because it did not meet the prior threshold test federal regulators had been using to determine when changes required approval, and the changes would result in an increase that benefitted rather than harmed providers. The court rejected this argument because the reclassification directly affected reimbursement for a particular service. See *Visiting Nurse Ass'n of North Shore*, 93 F.3d at 1011 (finding that the state had to submit a SPA for interim and phase-in rates that effected a reduction in reimbursement, even though they did not differ from the prior rate-setting methodology); *Evergreen Presbyterian Ministries, Inc.*, 235 F.3d at 915-17 (there is no discussion of the state gathering any access or cost data prior to implementation of cuts, though it did comply with public notice requirements).

153. See generally *Developmental Servs. Network*, 663 F.3d (affirming a long line of Ninth Circuit cases holding that Medicaid rate changes cannot be implemented before SPA federal approval, but noting that there was no private right of action to enforce this requirement); *North Carolina v. U.S. Dep't of Health & Human Servs.*, 999 F.2d 767 (4th Cir. 1993) (emphasizing the clear statutory mandate of federal review and approval without exception, regardless of whether the change is perceived as harming or benefitting providers, and upholding federal officials' rejection of the state's retroactive application of proposed changes to Medicaid plan).

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ment is significant because it shows how states try to eschew federal regulatory oversight—oversight that states, and most recently the Obama administration, have argued makes judicial review unnecessary. The fact that such violations occur so frequently and end up before courts because of patient or provider suits, as opposed to enforcement action by federal regulators also reveals a profound federal regulatory failure.

In these *easy* cases, where state violations are clear and federal enforcement is nonexistent, courts seem to have no qualms about intervening. The rule that states cannot make rate decisions based solely on budgetary concerns is a nice, bright-line legal rule that does not require second guessing states' health policy judgment or expertise: there are no competing visions of how to balance cost, access, and quality goals and there is no dispute about the relevant criteria or process required in order to properly balance these goals. In fact, no balancing is taking place at all. Moreover, a pattern of egregious violations not only signals disregard of statutory requirements, it also signals disrespect for federal regulators and courts.¹⁵⁴ Finally, troubling data about existing access problems, occurring in the midst of payment freezes and the threat of deeper cuts, presents a compelling link between rate-setting violations and the threat to the health of Medicaid beneficiaries.

Although the effect of these cases is clear, it also limited. Courts can provide injunctive relief to halt cuts or rate changes, but this is only a temporary fix—lasting until states comply with the procedural requirements. The courts are sending a message to states to engage in some kind of process, but what kind of process has been a much harder question.

B. The Harder Cases: Challenging the Quality of the Rate-Setting Process

Cases challenging the quality of the rate-setting process are hard for a number of reasons. One is the critical connection between the quality of the process and substantive guarantees: while these requirements create independent causes of action, in reality they are interdependent. A *good* process is more likely to ensure that rates compensate for “reasonable costs” and to identify when rates are so

154. In California, for example, courts' frustration with state officials is palpable. *See infra* note 314.

low as to lead to problems in beneficiary access and quality. Inversely, a *bad* process is more likely to obscure such a problem and thus lead to changes that will have a negative impact and potentially violate substantive guarantees. This means that not only does the likelihood of satisfying substantive goals turn on the quality of the process used, substantive violations will be harder to prove if the process used is so defective that it cannot possibly generate meaningful information about rates or detect potential problems.

Despite the importance of a good process for both procedural and substantive guarantees, there is no clear rule on what kind of process is *good* or *bad*. As explored more fully below, the statutes identify the relevant considerations (*economy, efficiency, quality, and access*, and, in the case of the Boren Amendment, *reasonable cost*), and mandate some additional considerations for rate setting for hospitals and nursing homes. But neither Congress nor HHS has given specific guidance beyond this. They leave open important questions about the criteria to be used in the process, how they should be measured, and assumptions underlying decisions about each.

Such questions could implicate the kind of policy judgments and expertise that courts typically try to avoid. Recall from Part II that the payment reforms encouraged by the federal government reflected assumptions about waste and inefficiency, as well as a judgment that cutting rates could force providers to deliver care more efficiently and economically without violating quality and access goals. On the other hand, we have already seen that federal and local pressure to reduce costs, without commensurate attention paid to access and quality concerns, has led states to disregard federal law, at the expense of access and quality guarantees. If courts are not willing to take a hard look at the rate-setting process, a state can simply dress up its rate cuts in a superficial or seriously defective process that allows them to avoid a court injunction, but that could not possibly ensure state compliance with federal law. Courts that take their role as a check on such public failures seriously must navigate the line between the legal and policy concerns implicated in Medicaid payment suits. This section takes a closer look at how courts have done this, especially with respect to questions about the role of provider cost, the methodology used to measure access, and the relationship between provider cost and access in rate setting.

1. Adequate Process Under the Boren Amendment: Determining Reasonable Costs

Boren Amendment challenges to rate setting in the hospital and nursing home context are particularly illustrative of this challenge given the explicit legislative goals motivating the Boren Amendment. The Amendment reflected certain assumptions about inherent flaws in the then-existing health care payment and delivery system: (i) that inflation and waste were endemic to a fee-for-service system that encouraged spending; (ii) that the medical community could not be trusted to police its own health care spending; and (iii) that payment reforms designed to shift more cost onto health care providers could force providers to become more efficient without jeopardizing access and quality. The federal government relied on states to use their flexibility to experiment with new payment models, and specifically believed that switching from a retrospective payment system to a prospective payment system (PPS) would help accomplish these goals.¹⁵⁵

As the cases show below, neither these broad policy goals nor these generalized assumptions were being challenged in Boren suits. Rather, providers challenged the implementation of these reforms, specifically the determination of the reasonable costs of economically and efficiently run facilities. Establishing prospective rates, as opposed to simply reimbursing actual costs, required states to classify providers according to shared relevant characteristics, from which the state could make certain generalizations about their reasonable costs. The Medicaid Act provided limited guidance about the relevant criteria for determining reasonable cost. In the case of hospitals, for example, it required states to “take into account the situation of hospitals which serve a disproportionate number of low-income patients with special needs.”¹⁵⁶ Beyond this limited guidance, states were left to make assumptions about which characteristics or factors were relevant to measuring cost generally, and specifically how to account for cost factors outside of the facility’s control—assumptions which were ripe for attack by providers.

One early example occurred in *Mary Washington Hospital v. Fisher*, where a hospital brought a Boren challenge after Virginia adopted a prospective system for hospitals in July of 1982 shortly after

155. See *supra* Part II.B.

156. 42 U.S.C. § 1396a(13)(A)(iv).

Boren was enacted.¹⁵⁷ As part of this new system, Virginia grouped hospitals into various classifications (according to their bed capacity and location), and it established a reimbursement ceiling on the allowable costs for each group.¹⁵⁸ These allowable costs were based on the median operating costs for each group from the prior year. The median costs for the urban groups were then further adjusted to account for wage variations between different Standard Metropolitan Statistical Areas (SMSA).¹⁵⁹

Because Mary Washington was grouped with other rural facilities, it was not entitled to the adjustment increase that urban hospitals received. Mary Washington alleged that this grouping violated the Boren Amendment because it did not take into account two critical factors that affected its costs. First, although it was technically located in a rural area, its location near two SMSA's meant that its wage costs were disproportionately high compared to the other hospitals in its grouping.¹⁶⁰ Second, it was a "sole community provider," a term used in Medicare's new prospective payment system to denominate a hospital that must offer a wider range of service than would typically be expected because of the absence of other hospitals in the community.¹⁶¹ Because of the increased cost associated with sole provider status, the hospital would have been entitled to a higher than usual price ceiling under Medicare, but was not under Medicaid.¹⁶²

Notably, Mary Washington was not fundamentally challenging Virginia's new payment system; it was making far more limited and credible claims about problems with the way the system was being applied. The claim was limited because based on Virginia's own rate-

157. 635 F. Supp. 891 (E.D. Va. 1985).

158. *Id.* at 895-96.

159. *Id.* In the prospective payment system that Virginia adopted, the hospitals were grouped into "peer groups" according to their number of beds ("bedsize") and whether they were located in an urban or rural area. Rates were determined based on the median operating costs for each group. Costs were determined by the allowable cost data for the hospitals in calendar year 1981, and were advanced by a "reimbursement escalator" from the hospitals' fiscal year end to July 1, 1982. The medians for the urban groups were then further adjusted to account for wage variations between different Standard Metropolitan Statistical Areas (SMSAs), and became the reimbursement ceiling rates for the year beginning July 1, 1982. Hospitals whose actual costs were above the applicable median were reimbursed at their actual costs plus a percentage of the difference between their actual costs and the median, as an incentive for staying below the median. *Id.* at 895-96. The state could also make adjustments for hospitals considered outliers or for compelling reasons, such as serving a disproportionate number of Medicaid patients or providing high intensity neonatal care. *Id.*

160. *Id.* at 896.

161. *Id.*

162. *See id.*

setting criteria, wage variation was an important cost factor; the hospital simply claimed that Virginia's grouping did not accurately reflect the wage variation affecting Mary Washington's because of its proximity to the SMSAs. The claim was credible because at trial expert testimony was indeed divided over the reasonableness of this assumption.¹⁶³ Even the challenge to Virginia's disregard of "sole provider" status was based on the federal government's own admission about the relevance of this status to cost under the Medicare program; it was hard to see why this status would suddenly become irrelevant in the context of Medicaid reimbursement for the same providers.

Despite the plaintiff's complaints, however, the court found for the state, deferring to its rate-setting process.¹⁶⁴ The courts' reasoning was particularly revealing in terms of how it balanced its proper role as a check on state compliance with federal law versus the improper second-guessing of state policy and value judgments based on agency expertise. First, the court focused on the federal pressure to reduce cost and found that pressure to shift to a prospective payment system, coupled with harsh federal penalties for states that did not stay within fixed limits for Medicaid costs, put state Medicaid agencies in an "intractable position" when it came to rate setting.¹⁶⁵

Second, the court's understanding of state flexibility and discretion, in light of these pressures, was extremely broad. The court interpreted the plaintiffs complaints about how the state determined reasonable costs as based on a flawed assumption that the "reasonable costs" language in 13A meant that the plaintiff was entitled to reimbursement for *its* reasonable costs, unless it was inefficient or uneconomical.¹⁶⁶ The court rejected this individualized approach to determining reimbursement as inconsistent with a prospective payment system that is "inherently less precise."¹⁶⁷ It likened the state to any other consumer of goods or services with the right to shop around and determine the rate it is *willing* to pay, rather than letting each health care provider essentially force it to buy services at the rate the provider prefers.¹⁶⁸

163. *Id.* at 899.

164. *Id.*

165. *Id.*

166. *Id.*

167. *Id.*

168. *Id.*

More fundamentally, though, the court seemed to want to avoid second-guessing the state's judgment. It acknowledged the plaintiff's concerns that the criteria used made the process less than ideal. Nonetheless, the court held that given the legislature's goals, broad state discretion, and the fact that some rational process was undertaken by the state, these problems did not result in the kind of arbitrary reductions prohibited by Boren.¹⁶⁹ Though the court was likely motivated in part by its sympathy for the state's "intractable position" and what it viewed as the state's good faith in trying to respond to federal pressure, the court also seemed particularly mindful of its own limits:

It would be inappropriate for the Court to determine what cost influencing factors are significant enough that Virginia should have incorporated them into its rate-setting formula. This is the task Congress specifically left to the states when it said that rates should be "determined in accordance with methods and standards developed by the State."¹⁷⁰

On the other hand, several decisions came down in the late 80s and early 90s, in which courts did invalidate rate changes based on procedural defects in the rate-setting process, despite federal regulatory approval. One recurring problem was the failure by states to consider actual cost data in determining what costs were reasonable. Some courts held that the failure by states to consider actual cost data was a flagrant violation of the Boren requirement to make required

169. The court noted that, contrary to the plaintiffs' claims that the state's process was arbitrary because it was based on overriding budgetary considerations, the state considered many options and it rejected the one with potentially the most significant immediate effect on the budget (elimination of the medically needy program). *Id.* at 900. Additionally, the task force explicitly considered the "economy and efficiency" standard, ultimately concluding that it was met, and it employed an independent consultant to help determine that hospital bed-size and urban/rural distinctions were adequate proxies for case-mix and other cost variations between hospitals. *Id.* at 898. The court did note a troubling problem with the state's future use of the reimbursement escalator, but it held that, in light of other assurances made by the state, there was no justiciable issue yet. *See id.* at 901.

170. *Id.* at 899. Other courts have used similar reasoning to reject such challenges. *See, e.g., Miss. Hosp. Ass'n, Inc.*, 701 F.2d at 517-18. Mississippi enacted a new prospective rate-setting plan similar to the one challenged in *Mary Washington*, and plaintiffs' claimed that the state's use of occupancy penalties and bed-size classifications to determine reimbursement were irrational. It pointed to other defects in the state's process, such as the failure to consult the MCAC in a timely fashion. *Id.* at 520. The Fifth Circuit rejected the plaintiffs' challenge, in part, because it found that the state engaged in a careful and lengthy review of data used to come up with the new rates, which is precisely the kind of task the federal government chose to leave to the state's discretion. *Id.* at 520-21. The court also viewed the complaint as more political than legal, holding that the "function and expertise of the federal courts in this sphere is limited, and our role does not extend to reweighing or rethinking the political and financial concerns behind a particular payment plan." *Id.* at 516.

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findings with respect to the reasonableness and adequacy of rates.¹⁷¹ In other cases, courts found that the failure to consider actual cost, in light of other defects, made the state rate changes look like they were really driven solely by budgetary concerns, as opposed to a genuine attempt to balance the Boren factors.¹⁷²

In some challenges brought because of defects in the determination of reasonable costs, courts have highlighted the important link between the role of provider cost in rate setting, and access or quality guarantees. For example, in *Lapeer County Medical Facilities v. Michigan*, a federal district court invalidated a rate reduction of up to thirty percent mandated by the state legislature, in part because of the state's failure to consider the hospitals' costs.¹⁷³ The court criticized the state's assumption that the higher cost of these hospitals was due to inefficiency and that reduced rates could be used to force greater efficiency, because this assumption ignored significant cost factors beyond the hospitals' control. Public hospitals have a duty to serve any low income patient in need, and they are typically located in communities with high need and few resources; they are thus uniquely burdened with the costs associated with these legal obligations, and are not easily able to make up those costs through private pay patients, as private hospitals did. This reality was particularly stark in this case, as eighty percent of the County hospitals' patient census comprised Medicaid patients.¹⁷⁴

The court evidenced concern about access in light of the economic reality and vulnerability of the patient population served by the County hospitals. Though sensitive to the state's budget crisis, the court was mindful of the health and financial consequences of such a significant reduction in County funding, noting that "sacrifice is one thing [but] [c]reating conditions that are short sighted, not shown to

171. See, e.g., *AMISUB (PSL), Inc. v. Colo. Dep't of Soc. Servs.*, 879 F.2d 789 (10th Cir. 1989) (challenging Colorado's prospective payment system for hospital inpatient services).

172. *Okla. Nursing Home Ass'n*, 792 F. Supp. at 721 (refusing to dismiss a Boren claim based on plaintiffs' allegation that state officials failed to properly take into account economic trends and conditions in rate-setting). In some cases, more nuanced challenges to rate-setting criteria may be accompanied by other technical procedural violations. See, e.g., *id.* at 727 (noting that the state violated explicit rate-setting requirements set forth in its own state plan and failed to comply with other bright-line procedural requirements). The extent to which other egregious and/or recurring violations make courts more willing to hear challenges to the state's rate-setting criteria is not clear; but it is likely that such violations undermine the typical justification for deference to administrative agencies: that they are attempting in good faith to use their expertise and discretion in ways that are consistent with federal law and policy goals. *Id.* at 723.

173. *Lapeer Cnty. Med. Care Facility v. State*, 765 F. Supp. 1291, 1297-98 (W.D. Mich.1991).

174. See *id.* at 1298.

be cost effective, and potentially life threatening is another.”¹⁷⁵ Although not explicitly mentioned by the court, this case arose after public hospital closures in, and private hospital flight from, underserved urban and rural areas were becoming recognized as a nationwide problem; indeed many were beginning to refer to such hospitals as *endangered*.¹⁷⁶ The societal, as well as individual cost—financial and personal—of these dwindling health care resources were also receiving greater attention as patient advocates and providers fought public funding cuts.¹⁷⁷ The *laissez faire*, free market approach embraced by the *Mary Washington* court, which allowed states to act like other consumers in determining the price it was willing to pay and to take a wait-and-see approach with respect to the effect on access and quality, would not work in the case of funding cuts that struck at the heart of the public safety net.

In *Kansas Health Care Ass’n Inc. v. Kansas Dept of Social & Rehab Services*, a district court rejected a state plan for failure to make the requisite findings regarding cost, but went further in discussing the potential impact on patient care.¹⁷⁸ Specifically, the court was concerned that the arbitrariness of the state’s rate-setting method would undermine other important quality protections enacted a few years earlier by Congress in the Nursing Home Reform Act to eliminate problems of widespread abuse and neglect.¹⁷⁹ It required each state to show that its Medicaid reimbursement rates accounted for the costs providers incur to comply with various reforms, such as bringing the level of skill of ICFs up to that of SNFs, ensuring 24-hour nursing coverage, employing physicians as designated medical directors, employing a social worker for each nursing facility with more than 120

175. *See id.* at 1301.

176. *See, e.g.*, Geraldine Dallek, *The Loss of Hospitals Serving the Poor*, 18 HEALTH SERVICES RESEARCH 593, 593, 595 (1983) (describing hospitals which served a disproportionate number of poor and minorities as “endangered” after closures of several hundred hospitals closing between 1970 and 1980 and arguing that these hospitals should be treated differently in setting Medicare and Medicaid reimbursement rates); *see also* Clark, *supra* note 5, at 1023-42 (describing losses of public and private hospitals in underserved areas throughout the 1970s, 80s, and 90s).

177. *See, e.g.*, Dallek, *supra* note 176, at 593-95; Clark, *supra* note 5, at 1023-42.

178. 958 F.2d 1018 (10th Cir. 1992). Nursing homes challenged a Medicaid rate freeze; reimbursement would no longer be based on yearly cost reports, but would be fixed from Oct. 1, 1990 and only adjusted for based for inflation. Pursuant to a SPA, the state agency implemented a “rate freeze.” This meant that the state agency no longer adjusted rates based on the most current cost reports; instead it determined each facility’s rate of reimbursement from that facility’s last cost report prior to Oct. 1, 1990, corrected only for inflation. *Id.*

179. *Id.* at 1020 & 1020 n.3; *see also* Bohm, *supra* note 89, 331-32.

beds, and providing standardized assessments of residents.¹⁸⁰ The district court was concerned that the new rates did not account for these and other federal protections, especially given that 78 percent of the facilities that had recently filed cost reports were not being reimbursed for all medical costs.¹⁸¹ The district court granted plaintiffs' request for a preliminary injunction preventing implementation of the state's plan, however the ruling was overturned on appeal, based on lack of standing; the appellate court did not review the merits.¹⁸²

These Boren era cases help show that while courts had a difficult line to navigate, courts were willing to take a hard look at state processes to ensure states were engaged in reasoned decision making, as opposed to arbitrary rate reductions. It also gave teeth to the "reasonable costs" requirement by making clear that states could not ignore significant cost factors, and by reinforcing the link between provider cost, rates, and access and quality guarantees. Despite states' attempts to deflect these challenges, in 1990 the Supreme Court in *Wilder v. Virginia Hospital Association* affirmed the right of providers and beneficiaries to sue to enforce these requirements.¹⁸³ While it acknowledged the importance of state flexibility, it emphasized that "[i]n passing the Boren Amendment, Congress sought to decentralize the method for determining rates, but not to eliminate a State's fundamental obligation to pay reasonable rates."¹⁸⁴ *Wilder* also affirmed the federal courts' critical role in enforcing this obligation, in light of the problems with under enforcement by federal regulators charged with oversight.¹⁸⁵

2. 30A Challenges & the Role of Provider Cost

Recall that 30A was codified in 1989, and that it contains essentially the same protections with respect to the adequacy of rates as the Boren Amendment—that they be consistent with economy, efficiency, quality and sufficient to ensure equal access. There were two differences between 30A and the Boren Amendment, however. First, unlike the Boren Amendment, 30A was not limited to services provided

180. *Id.*

181. *Id.* at 1022. For example, the alleged rates did not account for the increase in the federal minimum wage. *Id.*

182. *Id.* at 1020-22.

183. *See* 496 U.S. 498 (1990).

184. *Id.* at 515.

185. *Id.* at 516-18.

in hospitals and nursing facilities.¹⁸⁶ So while the Boren Amendment was in effect, hospitals and nursing facilities used it to challenge rates for in-patient services and skilled nursing care, but 30A was used by hospitals challenging outpatient rates and other providers (like primary care physicians, specialists, dentists, pharmacists).¹⁸⁷ After the Boren Amendment was repealed, hospitals and nursing homes continued to challenge in-patient and skilled nursing rates, but now they brought their challenges under 30A.¹⁸⁸ Essentially, providers and beneficiaries believed 30A was a meaningful alternative to the Boren Amendment, challenging rate-setting processes on the same grounds as before: that they failed to adequately consider provider costs, access or quality guarantees.

Second, as noted in Section B.1., 30A does not contain an explicit requirement that the state make findings with respect to “reasonable cost.” Although not generally viewed as relevant for determining whether 30A creates an independent procedural requirement, the absence of this requirement has created questions about the specific role of cost data in 30A compliance. Specifically, courts have been faced with the question of whether 30A requires states to always consider cost data to determine whether rates meet reasonable costs or whether states have absolute discretion to determine what kind of data they should consider in determining whether rates are sufficient to achieve economy, efficiency, access and quality goals.

The Ninth Circuit has the most robust understanding of 30A, interpreting it as requiring the state to undertake cost studies before setting rates.¹⁸⁹ The Ninth Circuit established this rule in its 1997 case, *Orthopaedic Hospital v. Belshe*.¹⁹⁰ In this case, Orthopaedic Hospital and the California Hospital Association challenged the state’s prospective payment system for outpatient services.¹⁹¹ The hospitals challenged the fact that rates were based on the type of service provided, but without regard to the setting in which the service

186. See *supra* Part III.A.

187. See, e.g., *Orthopaedic Hosp. v. Belshe*, 103 F.3d 1491 (9th Cir. 1997).

188. See, e.g., *Evergreen Presbyterian Ministries, Inc.*, 235 F.3d at 928 (holding that recipients, but not providers, can enforce 30A protections using § 1983).

189. See Rosenbaum, *Medicaid Payment Rate Lawsuits*, *supra* note 127, at 10.

190. See *Orthopaedic*, 103 F.3d 1491, *cert. denied*, 522 U.S. 1044 (1998).

191. *Orthopaedic*, 103 F.3d at 1498. These rates were challenged twice: The state’s first attempt to cut rates occurred without any process or consideration of 30A factors was enjoined by the court. Based on that decision, the state undertook a rate-setting process that it used to try to justify the prior rate cuts, but the rates were challenged again, this time based on inadequate process. *Id.* at 1494 (describing the prior litigation).

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was performed; consequently, hospitals and outpatient centers were reimbursed at the same rate for certain services, despite the fact that hospitals had much higher costs due to their special legal obligations and the range of care they provided—factors unique to hospitals and outside of their control.¹⁹² Plaintiffs claimed that the state’s failure to take these cost disparities into account in setting rates violated 30A.¹⁹³

State officials argued that 30A did not require them to take into account the higher costs that hospitals incur setting outpatient rates. They noted that the explicit mandate to make findings with respect to whether rates meet reasonable costs present in *Boren*, was not included in 30A.¹⁹⁴ Moreover, they argued (and the District Court agreed) that states had the right to set rates at a level that was based on the costs incurred by the most efficient providers of outpatient services, which were freestanding clinics, doctors’ offices or doctors’ offices in order to encourage a shift in treatment to these more efficient settings.¹⁹⁵ These settings were viewed as more efficient because they had lower fixed costs but hospitals had higher costs because of factors beyond their control: most of the outpatient services were provided through emergency rooms and hospitals had special legal obligations to treat anyone who came to the emergency room.¹⁹⁶ The Ninth Circuit agreed with the plaintiffs, invalidating the proposed rates because of the state’s failure to consider hospitals’ costs.¹⁹⁷

First, the court reiterated that the state could not make good faith and rational assurances of 30A compliance without some kind of study to determine that rates were in fact consistent with economy, efficiency, and quality, and sufficient to ensure equal access. In order to demonstrate compliance with 30A substantive guarantees, state officials had to be able to demonstrate a reasonable nexus between the rates and the 30A factors, which it could not do without cost data.¹⁹⁸ Thus, an explicit “findings” requirement with respect to reasonable cost was unnecessary because such findings were implicitly required by virtue of the assurances states were required to make.

Although the Court acknowledged the importance of state flexibility in rate setting, it seemed very concerned about states’ abuse of

192. *Id.* at 1495.

193. *Id.*

194. *Id.* at 1498-99.

195. *Id.* at 1496.

196. *Id.* at 1498.

197. *Id.* at 1499.

198. *Id.* at 1498.

this flexibility. The court made a distinction between the legitimate use of state flexibility to incentivize efficient delivery of care and influence utilization, from the illegal disregard of federal requirements to ensure the sufficiency of rates.¹⁹⁹ The court agreed that the state should be able to provide incentives for one type of care over the other, but undercompensating providers does not serve this purpose, and it ignores access and quality guarantees.²⁰⁰ Failing to consider the reasonable costs that must be incurred by different kinds of providers, especially in light of the other violations in this case, helped paint a picture of a state that was using its power to force rates down, rather than using it to encourage cost-conscious innovation:

The result is that the Department has not sought to shift services to entities that could provide them more economically and efficiently but rather to force hospitals to provide the service and to shift the cost to other patients. This technique of underpayment for services received is not economic, efficient or attentive to adequate access. It is neither economical nor efficient for the system as a whole.²⁰¹

Other courts have not been willing to create such a robust rule with respect to requiring cost studies for 30A compliance, but have still been willing to take a hard look at the state's process to ensure that it is not arbitrary, and that it adequately considers 30A factors.²⁰²

199. The court made clear that it was not dictating a "rigid formula" for states that excluded the use of incentives or utilization controls. *Id.* at 1498. But cost containment motives could not be used by the state to ignore the clear requirement that rates be consistent with 30A factors. The court also acknowledged that the requirements of 30A are more flexible than the Boren Amendment, "but not so flexible as to allow the Department to ignore the costs of providing services." *Id.* at 1499.

200. *Id.* at 1496-98. Incentives to non-hospital providers to treat Medicaid outpatients, encouraging Medicaid patients to utilize alternate providers, and the use of utilization controls to discourage nonemergency outpatient care at hospitals are the kinds of tools that are available to the state and directly impact utilization patterns. *Id.* at 1497-98.

201. *Id.* at 1498. The state similarly ignored the rate-quality link in 30A when it failed to consider the impact that rate reduction might have on quality. The state insisted that it did not have to determine whether the rates were sufficient to ensure quality care because quality is assured by external licensing and other laws that mandate health care quality. *Id.* at 1497. The court rejected this argument. *Id.*

202. *See, e.g., Minn. Homecare Ass'n, Inc.*, 108 F.3d at 918.

The Medicaid Act mandates consideration of the [30A] factors . . . however, it does not require the State to utilize any prescribed method of analyzing and considering said factors. In the instant case, it is undisputed that the DHS had informal monitoring procedures in effect to evaluate the operation of its Medicaid program and to gauge the adequacy of its reimbursement rates.

Id. *See Evergreen Presbyterian Ministries, Inc.*, 235 F.3d at 918, 930 (noting that 30A does not require a cost study and plaintiffs have the burden to offer evidence of a violation of the equal access provision).

3. Equal Access Suits: Substantive Guarantees Relating to Access & Quality

Many of the cases described above, especially the Boren Amendment cases, explicitly focused on the role of provider cost and challenges to rate-setting processes based on assumptions about, and criteria used to determine, reasonable cost. Contained within the Boren and 30A provisions, however, is an express link between the sufficiency of rates and promises of equal access and quality for beneficiaries. As seen above, at times access and quality concerns played a supporting role in rate challenges and courts decisions to invalidate process.²⁰³ But direct challenges to the substantive requirements were likely more difficult to bring because no specific process had been mandated to ensure that data needed to identify problems would be considered, nor were there clear minimum comparative or other criteria established so that a violation could be easily identified even if the data were available.

A few courts did not seem to believe that access must be explicitly considered or measured as part of the rate-setting process. They suggested that it was okay for a state to take a wait-and-see approach with respect to access as long as they made an adjustment later if necessary to correct an access problem.²⁰⁴ But these courts did not explain how such a problem would be revealed without requiring access data as part of the rate-setting process. At least one court raised concerns about the viability of undertaking such an analysis, suggesting that it would require asking providers to predict their behavior based on proposed rates, which would be inherently unreliable and self-serving in ways that would clearly impede cost-cutting goals.²⁰⁵

203. See *supra* Part III.B.1 for a discussion of the *Lapeer* and *Kansas Healthcare Ass'n* cases; see also *Ark. Med. Soc'y, Inc. v. Reynolds*, 6 F.3d 519, 522 (8th Cir. 1993) (issuing a preliminary injunction for rate cuts to children's services, but ultimately invalidating all cuts).

204. See, e.g., *Methodist Hosps., Inc. v. Sullivan*, 91 F.3d at 1026, 1026, 1030 (7th Cir. 1996).

Nothing in the language of § 1396a(a)(30), or any implementing regulation, requires a state to conduct studies in advance of every modification. It requires each state to produce a *result*, not to employ any particular methodology for getting there. . . . [S]tates may behave like other buyers of goods and services in the marketplace: they may say what they are willing to pay and see whether this brings forth an adequate supply. If not, the state may (and under § 1396a(a)(30), must) raise the price until the market clears.

Id.; see also *Mary Washington Hosp., Inc.*, 635 F. Supp. at 899-900, 902 (comparing states to consumers who engage in price-conscious shopping, and finding that neither an efficiency study nor an access study is required prior to setting rates).

205. See *Methodist Hosp.*, 91 F.3d at 1030. After noting that "it is exceptionally difficult to determine demand and supply schedules for a single product" the court went on to say: "Doing this for the entire medical segment of the economy would be more than difficult; it would be

A couple of courts even seemed to doubt the link between rates and access in certain cases, especially in challenges brought by hospitals and nursing facilities.²⁰⁶ Given the kind of care they provide, their special regulatory obligations, and the investment needed for construction and operation in the first place, hospitals and nursing homes cannot react to market changes as nimbly as individual providers that can easily limit patients or flee certain communities quickly. The fact that many of these facilities served private pay patients and Medicare patients (both of which were more generously funded) supported the court's view of them as less vulnerable to effects of significant rate reductions, making the link between Medicaid rates and threats to access like closure seem even more remote.²⁰⁷ These courts were dismissive of such allegations in Boren cases, especially without strong evidence suggesting an access problem.²⁰⁸

Other courts have been more sympathetic to the access and quality implications of rate reductions in hospitals, precisely because of their special legal obligations and inability to avoid reductions by refusing to treat Medicaid beneficiaries. For example, the *Orthopaedic* court discussed the access and quality implications of a rate that could not adequately compensate hospitals for reasonable costs. Despite the fact that no provider participation problem was alleged as part of the complaint, the court held that state officials violated 30A by not considering this in the rate setting process.²⁰⁹

Making out a claim that rates are inconsistent with access, or alleging that a rate cut poses imminent threat to access in order to support a preliminary injunction, is still challenging under 30A, but easier to show in the case of individual health care providers. Although all courts have agreed that 30A (and the former Boren Amendment) contain a substantive guarantee with respect to the adequacy of rates

impossible. A state could send out a survey, but questions such as 'Tell us the minimum amount you would accept without withdrawing from the market' would not elicit honest answers. People often do not even *know* their reservation prices; they do not willingly reveal them." *Id.*

206. See *Mary Washington Hosp.*, 635 F. Supp. at 902.

207. See *id.* at 902 ("Mary Washington has suggested that it may someday be forced to withdraw from the Medicaid program, but there is no reason to believe that such a result is likely or imminent. In fact, the evidence is to the contrary, *i.e.* that Mary Washington financially needs Medicaid as much as Medicaid needs Mary Washington.").

208. See, e.g., *Methodist Hosp.*, 91 F.3d at 1030 (noting that plaintiffs did not assert that they have withdrawn based on new rules and there is no proof that any provider withdrew, anywhere in the state.). The court's skepticism of providers' claims was palpable: "Plaintiffs offered dire predictions, but Indiana used 1994 to check predictions against reality." *Id.*

209. See *Orthopaedic Hosp. v. Belshe*, 103 F.3d 1491, 1498-99 (9th Cir. 1997).

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distinct from the procedural requirements,²¹⁰ decisions about the merits of substantive challenges are rare. Judging the substantive adequacy of rates, especially without some clear regulatory benchmark, is more likely to implicate concerns about policy making by judges, and trigger courts' concern about the lack of expertise necessary to make this kind of determination.

Nonetheless, the equal access provision increasingly has become the focus of 30A challenges, particularly those brought by beneficiaries.²¹¹ One case where the access requirement of 30A was addressed as both a procedural requirement and substantive guarantee was in *Clark v. Kizer*.²¹² In *Clark*, Medicaid beneficiaries sued state officials because of access problems in the state's Medicaid Dental program (Denti-Cal).²¹³ One of the claims was that payment rates were inadequate to ensure equal access under 30A, but beneficiaries cited to a number of other Medicaid protections that were being violated including the requirement that care be delivered in a timely manner, and be available throughout the state.²¹⁴ Plaintiffs won summary judgment on all of these claims.²¹⁵

Clark was an exceptional case that proves the general rule that courts are likely to avoid reviewing substantive challenges based on access. In this case, there was no real question that there was an access problem because of extreme disparities in access for Medicaid beneficiaries as compared to other insureds, and the overwhelming amount of evidence provided by plaintiffs,²¹⁶ including "smoking-gun"

210. See, e.g., *Visiting Nurse Ass'n of N. Shore, Inc.*, 93 F.3d at 1011.

211. See, e.g., *Pa. Pharmacists Ass'n v. Houstoun*, 283 F.3d 531 (3rd Cir. 2002) (holding that pharmacists could not assert a § 1983 claim under 30A to enforce the equal access provision). The dissent would have held otherwise. *Id.* at 556. It emphasized the link between providers' costs, reimbursement, and equal access concerns as illustrated by the plaintiffs' allegations:

[T]he recent change in the Medicaid system in the five-county Philadelphia metropolitan area from fee-for-service to managed care . . . [has] squeezed the pharmacies and reduced provider reimbursement rates to levels that . . . are below any reasonable measure of the cost of providing care and services [and that] 50% of the pharmacies that participated in Medicaid . . . have dropped out since 1997. [N]o pharmacy within fifteen contiguous zip codes in Bucks and Montgomery counties participates in Medicaid, and that among those pharmacies . . . [that do participate] quality of care has suffered as a result of inadequate reimbursement rates."

Id. at 545.

212. *Clark v. Kizer*, 758 F. Supp. 572 (E.D. Cal. 1990).

213. *Id.* at 575.

214. *Id.* at 575-80.

215. Plaintiffs successfully proved that the program violated Medicaid's state-wideness, comparability, and timeliness protections. *Id.* They also alleged that the program violated Medicaid's free choice of provider requirement, but lost on this count. *Id.* at 579-80.

216. There was undisputed evidence, for example, that no dentist would accept referrals of new Denti-Cal patients through the telephone referral service in twelve counties, that specialists

admissions by public officials.²¹⁷ The procedural posture of this case did pose a new challenge however: here the plaintiffs were not simply asking court to maintain the status quo by preventing a state reduction of rates, they wanted the court to force the state to engage in a process to increase rates to a level that would comply with the federal access protections concerning timeliness.²¹⁸ Courts were thrust into a more active role of not only requiring the state to engage in some process to come up with new rates, but also to make sure they were adequate. Federal regulators also played a more active role with respect to 30A compliance: although it had not promulgated formal regulations with respect to 30A procedural and substantive obligations, HHS had begun to provide informal guidance through its Medicaid manuals, and even filed an amicus brief suggesting a multi-factor approach and several criteria for measuring compliance with the equal access provision.²¹⁹

This decision, and, perhaps more importantly, HHS's suggested framework helped establish a meaningful process and criteria that would be necessary to ensure an informed and non-arbitrary rate-setting process. More specifically, the federal court and HHS affirmed several important principles with respect to 30A challenges that remain the subject of ongoing debate. First, HHS affirmed the importance of the link between the adequacy of rates, providers' cost, and access, both for determining 30A compliance and devising a remedy to address a 30A violation.²²⁰ The court held that there was compelling evidence that rates were inadequate based on the fact that state officials admitted in a memo that the rates paid were far below any reasonable estimate of what it costs providers and a report found that a 50% increase was needed for dentists to be able to even meet overhead.²²¹ The court was also troubled by the disparity in reimbursement rates, as dentists were reimbursed 40% of the usual rates.

routinely rejected patients in twenty-seven counties, and only accepted limited referrals in another twenty-one counties. *Id.* at 580.

217. There were declarations of county public health officials that class members frequently experienced delays, and state officials' own admission that accessibility varied widely from county to county. *Id.*

218. See *Clark v. Coye*, 1992 WL 140827, *1-2 (9th Cir. June 23, 1992) (unpublished decision) (discussing the role of the magistrate in overseeing the district court's order to set new rates that comply with 30A and specifically the magistrate's power to order a higher level of reimbursement if the state is found noncompliant).

219. *Clark*, 758 F. Supp. at 576-78.

220. *Id.* at 576 (discussing the amicus brief filed by HHS which explained that the two major factors it used to measure equal access were level of participation and level of reimbursement).

221. *Id.* at 577-78.

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Although there was no clear rule on an acceptable gap between Medicaid and private rates, the draft State Medicaid manual suggested rates at 90% of private insurance.

The state tried shifting the focus away from its rate setting process in discussing the cause of the access problem and in fashioning a remedy. It claimed provider racism was the reason for low participation and asserted that other improvements would remedy the problem, such as a complaint system, mobile clinics, and improvement in claims processing.²²² The court rejected these arguments in part because of the state's failure to produce supporting evidence, but it also took this opportunity to affirm the legal significance of the access-rate link:

[T]he focus of the [Equal Access Provision] is on the State's ability to encourage participation by setting adequate reimbursement rates. Although other factors may affect provider participation, the statute directs the State's attention to reimbursement levels. Regardless of the interplay of other factors, if the reimbursement levels are not enough to ensure equal access to dental care, then the state has failed in its statutory duty. Moreover, from the record before the court, it is undisputed that that the major concern with the Denti-Cal program on the part of dentists is the low reimbursement level.²²³

Second, HHS made clear that states were expected to investigate the impact of rate changes on access prior to implementation, and to use direct, as well as indirect, measures of access. Although the level of physician participation was one of the primary factors used,²²⁴ determining compliance for 30A was challenging due to the comparative nature of 30A. HHS did offer further guidance, such as its "long-standing criterion . . . for implementing the equal access requirement [which] is a two-thirds participation ratio."²²⁵ Moreover, because plaintiffs also alleged a violation of the timeliness and availability requirements, HHS suggested a minimum benchmark for access based on a minimum participation ratio of 50% as the standard, assuming full participation (i.e. that the provider accepts all Medicaid patients who present themselves for treatment).²²⁶ Neither the comparative

222. *Id.* at 578.

223. *Id.* at 578. One of plaintiff's exhibits was a survey showing that 97% of dentists surveyed listed low reimbursement as the reason for not accepting Denti-Cal patients. *Id.*

224. *Id.* at 576.

225. *Id.*

226. *Id.*

nor the minimal criteria offered by HHS was met in this case, however, because less than 40 percent of licensed dentists participated in Medicaid, and the dentists that did participate severely restricted their practice for Medicaid.²²⁷ HHS noted the relevance of a number of other access factors which indicated a problem: whether providers were widely opting out of the program or restricting their Medicaid caseloads; whether there was a steady stream of reports that recipients are having difficulty obtaining care; and disparity in utilization of patients.²²⁸ In this case, there was compelling evidence of severe problems in each of these categories that made it easy to identify a substantive 30A violation.

Perhaps most importantly, the case emphasized the importance of methodology and the quality of rate setting for ensuring equal access. HHS's criteria and the court make clear that a process that looks superficially at participation and coverage on paper, but fails to investigate the reality of access on the ground is not consistent with 30A requirements.²²⁹ Such a process could not possibly yield the information necessary for states to determine the adequacy of rates, let alone make assurances about this to the federal government. The opinion affirmed the value and necessity of seeking input from beneficiaries and providers in order to measure access, which stands in stark contrast to the suspicion by other courts of the trustworthiness of provider reports for assessing the adequacy of rates.

227. *Id.* at 576-77.

228. The evidence showed that participation fell from about 30 percent from 1974-1984 and that another third dropped out during the next three years (1985-1988). Denti-Cal recipients had a 32 percent utilization rate compared to the 67 percent utilization rate for the insured population. *Id.* at 577-78.

229. Consider, for example, the court's analysis of the physician participation data used as an indicator of access:

"It is undisputed that the majority of participating providers are not full participants, with only 12.5% of *active* dentists accepting new patients through the toll-free referral line and many of these dentists placing restrictions on their Denti-Cal practices. Eleven percent of the participants treated only one Denti-Cal recipient during the entire year; 21 percent treated two to five recipients; and 21% treated 6 to 19 recipients. These figures stand in stark contrast to the 1,300 different patients a year typically treated by a general practitioner. . . . Since the Denti-Cal population comprises approximately 10% of the population, the minimal participation by 54% of the dentists who treat fewer than 20 recipients simply cannot be characterized as full participation where their proportionate share should be 130 recipients per participating dentist. No matter how one massages the statistics, the level of dentist participation in Denti-Cal falls dismally below the administrative standard established to measure participation at an acceptable level." *Id.* at 576-77 (citations omitted).

IV. THE FEDERAL ROLE IN MEDICAID ACCESS: PAST, PRESENT, AND FUTURE

The state flexibility and limited federal oversight created in the Medicaid Act was supposed to encourage thoughtful and creative state experimentation with various health care delivery and payment systems. And in some cases, it has. As shown in Part III, however, providers and beneficiaries believe and have successfully shown that states often abuse this flexibility by ignoring federal law and making cuts that jeopardized access and quality. States, on the other hand, feel that this flexibility has had the unintended consequence of making them more vulnerable to suits in federal court, where judges tread on state expertise and discretion by second-guessing their policy decisions. Courts also seem frustrated with the lack of clear guidance for the state rate-setting process, suggesting that greater federal guidance would be welcome in mediating disputes. This Part takes a closer look at past regulatory failures that have exacerbated this problem, and future indications of more recent regulatory activity under the Obama Administration.

A. History of the Role of Federal Regulators in Medicaid Payment Disputes

Parts II and III paint a picture of a federal regulatory void enabling states to cut rates or change rate setting in ways that violate federal law.²³⁰ With few exceptions, federal regulators are noticeably absent in this process—failing to deny rate cuts despite clear procedural violations, failing to prevent or penalize premature rate implementation, and failing to participate in litigation when the issue is before federal courts.²³¹ Where the federal government reviews and ap-

230. See generally Lisa Colosi, *Wilder v. Virginia Hospital Association: Making the Medicaid Reimbursement Rate Challenge a Federal Case*, 12 PACE L. REV. 139 (1992) (discussing courts' reviews of Medicaid reimbursement rates); Rand E. Rosenblatt, *The Courts, Health Care Reform, and the Reconstruction of American Social Legislation*, 18 J. OF HEALTH POL. POL'Y & L. 439 (1993) (describing the problem of under-enforcement in health care).

231. See *Pinnacle Nursing Home v. Axelrod*, 928 F.2d 1306 (2d Cir. 1991). Despite HCFA's initial rejection of the SPA and not receiving the additional information it requested, it ultimately approved the state's plan. The proposal was successfully challenged by providers due to procedural violations under Boren and implementing regulations, and HCFA did not join in the appeal to support the state's argument during the litigation. *Id.* at 1308; see also *Wash. State Health Facilities Assoc.*, 698 F.2d at 964 (holding that despite failure to comply with federal requirements, there was no evidence of federal regulatory action to penalize the state or join legal action to prevent implementation; in fact it appears that during the proceedings the state plan amendment was approved by the federal regulator); *Lapeer Cnty. Med. Care Facility*, 765 F. Supp. at 1291 (finding that no SPAs were submitted). *But see Clark*, 758 F. Supp. at 572.

proves state plans, courts have lamented that this oversight is “cursory at best” in light of the fact that its review is limited to whether the “documentation submitted by the State Medicaid Agency complies with procedural requirements.”²³² The failure to issue regulatory guidance for compliance is also seen as making it easier for states and the federal government to use their discretion in ways that undermine federal law.²³³ At the same time, HHS and Congress continues to pressure states to reduce costs, increasing the likelihood that states will cut costs in blatant disregard of federal law.²³⁴

In the kind of *easy* cases described in Part III.A., federal regulatory approval is irrelevant. Although the general rule is to defer to federal agency expertise on such matters, the lack of process in which any “expertise” or “judgment” is being exercised, by state or federal officials, means that deference is not justified.²³⁵ Despite the deferential standard of review applied to agency action, courts have routinely held that they will not “rubber stamp” federal approval of state plans that are clearly arbitrary and a violation of federal law.²³⁶

The relevance of federal approval in the *harder* cases, predictably, is not as clear cut. For courts that are particularly sympathetic to the federal and local pressure on states to cut costs, and see evidence of some rate-setting process as involving policy judgments reserved for state discretion, federal approval reinforces the deferential ap-

232. *AMISUB, Inc.*, 879 F. 2d at 794 (citation omitted); see also *Wilder*, 496 U.S. at 508 & n.8.

233. In one case, plaintiffs asked the court to require federal regulators to use their rulemaking power to provide guidance with respect to the “reasonable costs” requirement under the Boren Amendment. They argued that in the absence of guidance specifying the criteria used to determine when a facility is “economical” or “efficient,” federal approval of state plans would be arbitrary and entitled to no deference. See *Ala. Nursing Home Assoc. v. Harris*, 617 F.2d 388, 394 (5th Cir. 1980). Courts have refused to go this far, however, as it is very difficult to force federal regulatory action on a specific matter, absent an unambiguous statutory mandate. See generally *Rosenbaum*, *supra* note 22 (discussing Medicaid law and lawsuits brought in California).

234. See *Iowa v. Centers for Medicare and Medicaid Services*, 576 F.3d 885, 887 (8th Cir. 2009) (discussing CMS’s efforts to contain Medicaid provider payments by states that seek to expand access to certain types of services, in this case, prescription drugs); *Alaska Dep’t of Health and Soc. Servs. v. Ctrs. for Medicare and Medicaid Servs.*, 424 F. 3d 931 (9th Cir. 2005).

235. See *Chevron U.S.A., Inc. v. Nat’l Res. Def. Council, Inc.*, 467 U.S. 837, 865-66 (1984). *Chevron* deference is required when it appears that Congress has delegated authority to an agency generally to make rules carrying the force of law, and the agency interpretation claiming deference was promulgated in the exercise of that authority. *Id.* “[I]f a statute is silent or ambiguous with respect to a specific issue, the question for the court is whether the agency’s answer is based on a permissible construction of the statute.” *Id.* at 843; see *Douglas*, 123 S. Ct. at 1209.

236. *Douglas*, 123 S.Ct. at 1210; see *AMISUB, Inc.*, 879 F. 2d at 797 (In this case, HCFA’s approval based on the state’s assurances of compliance did not warrant deference because of the state’s failure to undertake a “bona fide finding process” to support the assurances).

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proach they are likely to apply anyway.²³⁷ On the other hand, courts particularly troubled by a history of federal regulatory failures in the face of repeated and egregious state violations of provider and beneficiary protections, and the limited federal oversight of state plans, are much less willing to give weight to federal approval as a default rule.²³⁸ Rather, these courts take seriously their role as a check on public law failures, reviewing the state rate-setting process for Boren and 30A compliance, and asking whether federal regulators' reliance on this process is rational.

The federal regulatory void in the area of equal access enforcement raises significant concerns about HHS's capacity for effective enforcement. This void stands in stark contrast to federal regulators' approach to Medicaid rate increases. HHS (and its predecessors) have been aggressive agents for spending reductions,²³⁹ promulgating regulations that establish payment ceilings,²⁴⁰ and denying proposed rates thought to be too high.²⁴¹ This suggests that HHS has enforcement tools and the will to use them in some cases but not others: it has encouraged rate reduction, without paying commensurate attention to

237. *See, e.g., Miss. Hosp. Ass'n.*, 701 F.2d at 516-18; *Mary Wash. Hosp., Inc.*, 635 F.Supp. at 898-900.

238. *See AMISUB, Inc.*, 879 F.2d at 794.

239. *See, e.g., Long Term Care Pharmacy Alliance v. Ferguson*, 362 F.3d 50, 52 (1st Cir. 2004) (describing how an HHS report in 2002 suggested that a number of states were overpaying for drugs, leading to changes in the State Medicaid system designed to lower reimbursement to pharmacies). The increasing attention to drug costs and changing reimbursement triggered a number of 30A challenges by pharmacists. *See id.* at 52-53; *Penn. Pharmacist Ass'n*, 283 F.3d at 531; *Walgreen Co.*, 275 F.3d at 475; *Am. Soc'y of Consultant Pharmacists v. Concannon*, 214 F. Supp. 2d 23 (D. Me. 2002).

240. *See, e.g.,* 42 C.F.R. § 447.272 (2010) (setting an upper limit or overall aggregate payment for all facilities); 42 C.F.R. § 447.321 (2010) (implementing separate payment limits for state-owned facilities versus non-state government-owned facilities); 42 C.F.R. § 447.325 (2012) (establishing an upper payment limit for other facilities); *see also Alaska Dep't of Health & Soc. Servs. v. Ctrs. for Medicare & Medicaid Servs.*, 424 F.3d 931, 935-36 (9th Cir. 2005) (explaining the federal government's concern about state manipulation of federal funding through intergovernmental transfers, and revision of upper payment limits to address this concern).

241. *See, e.g., Alaska Dep't of Health & Soc. Servs.*, 424 F.3d at 931-32 (hearing state challenge to HHS denial of SPA based on concerns that rates were too high); *N.C. Dep't of Human Res. v. U.S. Dep't of Health & Human Servs.*, 999 F.2d 767, 768-69 (4th Cir. 1993) (discussing federal officials' rejection of a retroactive application proposing changes that would have increased rates); *see also Pinnacle Nursing Home*, 928 F.2d at 1309. The state submitted its SAP plan late, claiming it was not an amendment that required prior notice and approval by HCFA because it was budget neutral and thus not a significant change. Initially HCFA disagreed and advised that additional info required before approval. New York failed to comply with HCFA's request until forced to do so by a court over a year later. In this case, the change in methodology appeared to be one that was designed to provide a slight increase adjustment to correct a perceived problem with the prior plan and alleviate the financial stress on nursing homes that had higher costs. HCFA's initial rejection was likely motivated by its concern that rates were too high, not that they were too low to satisfy the Boren Amendment. *Id.*

access and quality concerns. This singular focus suggests that HHS has an inherent conflict of interest, as do the states, which makes it unwilling to enforce 30A because of the chance that it will impede attempts to reduce rates.²⁴²

Now that HHS is finally becoming more active in the enforcement of 30A access and quality concerns, should this troubling regulatory history and apparent conflict shape our expectations for future enforcement and influence the level of deference that we give to federal approval? Before answering this, it is important to consider the recent activity undertaken by the Obama Administration and HHS: its role in the states' current challenge to such suits before the Supreme Court; reviews and dispositions of state proposals for rate cuts so far; and its proposed rules for compliance with the 30A equal access requirement.

B. Current Regulatory Activity: Mixed Messages from the Obama Administration

In light of the Obama Administration's focus on health reform, including Medicaid expansion, as a tool for improving our ability to meet cost, access, and quality goals, there has been a flurry of regulatory activity with important and specific implications for these disputes. Unlike prior administrations, President Obama is giving much more attention to the issue of 30A compliance: he has stepped up plan reviews and proposed regulations to help clarify state obligations. Nonetheless, President Obama is continuing to send conflicting messages and HHS's recent activity raises serious questions about its commitment to enforcing 30A protections.

1. Advocating for the Elimination of Beneficiaries and Providers' Right to Sue

As noted in Part II, one approach consistently taken by states is to try to eliminate providers' and beneficiaries' access to federal court

242. See Rosenbaum, *supra* note 22, at 22 ("Congress has done virtually nothing to address the larger cost drivers in American health care; the preferred option for federal policy making has been to leave the tough task of cost containment responsibility in the hands of the employers and state agencies, while trying to limit its own financial exposure. This federal non-response also has included an utter failure to help states weather Medicaid's costs during economic downturns."). Rosenbaum also argues that "the Medicaid funding formula has resulted in an unworkable distribution of financial obligations, devolving too much responsibility to states, whose economies are relatively ill-equipped to withstand the punishment of rapidly rising health care costs, particularly in the care of the poorest and sickest persons." *Id.* at 27.

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as a means to enforce 30A compliance. States have actively fought legal accountability in federal courts and resisted regulatory oversight by HHS. And in October, the Supreme Court heard consolidated Medicaid payment challenges to California's budget cuts, in which California argued that even if states do violate Medicaid requirements, private individuals should not be able to use the federal courts to invalidate illegal rates on Supremacy law grounds. Numerous amicus briefs have been filed on both sides.²⁴³ States argue that enforcement should be vested solely with HHS,²⁴⁴ and the Obama administration has filed an amicus brief siding with the states.²⁴⁵ It urges the elimination of this judicial last resort, even as it has entertained significant federal funding cuts to Medicaid that would surely exacerbate states existing budget crises by shifting more cost to the states.²⁴⁶ HHS cites as the main reason for eliminating the right to sue the fact that this is a joint federal-state partnership in which HHS has been given authority to, and can effectively, oversee the state administration of federal funds.²⁴⁷ Notably, however, former HHS officials and some members of Congress disagree, arguing that access to the federal courts for 30A enforcement is necessary, and that the Supremacy Clause provides a longstanding legal basis for challenging state laws that conflict with federal protections.²⁴⁸

President Obama's position seems odd in light of the pervasive federal regulatory failures that have exacerbated these rate disputes and access concerns since enactment. Apart from a brief period of regulatory activity at the beginning of Medicaid when DHEW seemed to take seriously its regulatory role—promulgating the precursor to 30A and using its power to insist on relative parity with Medicare rates—HHS has been almost nonexistent on this question. Prior to the

243. For access to all of the briefs filed in this case, see *Douglas v. Independent Living Center of Southern California*, SCOTUS BLOG, <http://www.scotusblog.com/case-files/cases/maxwell-jolly-v-independent-living-center-of-southern-california/> (last visited Apr. 13, 2012).

244. See Brief of Nat'l Governors Ass'n, et al. as Amici Curiae in Support of Petitioner, *Douglas*, 123 S. Ct. 1204 (Nos. 09-958, 09-1158, 10-283), 2011 WL 2132704 at *22-23.

245. Brief for the United States as Amicus Curiae Supporting Petitioner, *Douglas*, 123 S. Ct. 1204 (Nos. 09-958, 09-1158, 10-283), 2011 WL 2132705.

246. See Steve Teske, *Obama Proposes to Cut Medicare, Medicaid Spending by \$360 Billion Over 10 Years*, BNA (Feb. 14, 2012) (describing President Obama's fiscal 2013 budget proposal released February 13, 2012).

247. See Brief for the United States, *supra* note 245, at *10-11.

248. See Brief of Former HHS Officials as Amici Curiae Supporting Respondents, *Douglas*, 123 S. Ct. 1204 (Nos. 09-958, 09-1158, 10-283), 2011 WL 3706105 at *4-5; Brief of Members of Congress as Amici Curiae in Support of Respondents, *Douglas*, 123 S. Ct. 1204 (Nos. 09-958, 09-1158, 10-280), 2011 WL 3467244 at *21.

Obama administration, federal regulators had not promulgated regulations to give guidance concerning reasonable cost or access analyses, it had not used its authority to investigate access concerns, it had rarely, if ever, used its enforcement power to demand additional information or reject a SPAs based on payment sufficiency concerns, and it had never terminated federal funding due to noncompliance with access and reasonable cost protections. Indeed HHS would seem utterly impotent, were it not for its display of effective pressure and influence when it came to pushing states to reduce payments.

The administration's position is also troublesome in light of HHS's own recent findings about state noncompliance as a result of its stepped up review.²⁴⁹ The good news is that since Obama has come into office, HHS has more actively reviewed state plans and requested additional information in order to determine how different states approach their 30A obligations. What it found, however, were the same problem described in Part III - that despite making assurances to the federal government that rate changes comply with 30A and would not adversely affect access, only a few states indicated that they actually relied on data to make this determination, and a closer look at the process used by even these few states revealed serious defects in their assessments.²⁵⁰ Moreover, HHS's recent enforcement record is troubling: Despite its findings of widespread defects and lack of proper support for state assurances, HHS admits that it still generally relies on state assurances in approving Medicaid plan changes and it could only give two examples where they rejected state SPAs due to access concerns.²⁵¹ So how seriously can we take HHS claims that it can be trusted with oversight in place of federal courts?

Perhaps one reason HHS is reluctant to reject state plans despite evidence of 30A defects is the lack of clear guidance to states from the

249. Methods for Assuring Access to Covered Medicaid Services, 76 Fed. Reg. 26,342, 26,348-49 (May 6, 2011) (to be codified at 42 C.F.R. pt. 447). As background for its proposed regulations concerning the state plan review process, HHS described its oversight activities and what it has learned since President Obama took office: "Since 2008, as more States sought to amend Medicaid State plan payment methodologies by instituting significant provider rate changes, we have requested that States provide information to help the agency determine that the changes to rates resulting from State plan amendments will continue to provide for access to care consistent with the Act and the implementing regulations." *Id.* at 26,348.

250. *See id.* at 26,344-45.

251. *Id.* at 26,349. In one case, apparently there was persistent, widespread negative reaction by providers in response to the reduction that seemed to shine a light on significant enough access concerns to compel HHS to act. In the other case, not only were access concerns raised, but the state failed to provide any information or analysis on how the rate changes would impact access. *Id.*

federal government with respect to a proper state process. This could be one interpretation of HHS's introduction in its recently proposed rule for 30A compliance. HHS notes its responsibility to ensure sufficient beneficiary access, on the one hand, but, on the other, its sensitivity to the "uncertainties and problems that arise for States in the absence of Federal guidance on methods and standards for States to demonstrate compliance with this requirement."²⁵² HHS seems to want to balance its enforcement obligations on behalf of beneficiaries with fairness to states. HHS likely expects that through greater regulatory guidance, there will be fewer problems at the state level, but where problems do exist, HHS will be on stronger regulatory footing to reject SPAs or require corrective action.

A less generous interpretation, however, is that HHS will not become more proactive in the review and approval process, but rather intends for its regulatory guidance to provide greater protection for states from federal suit, as long as the states follow certain basic requirements. This approach is more consistent with the overall tone of the regulations, as well as the content of the rules themselves, described in greater detail below.

2. Proposed Rules for 30A Compliance

There are some key themes in the proposed rule that seem to reflect a commitment to 30A compliance, and particularly equal access concerns. The introduction and background discussion reflect HHS's increased attention to the access problem,²⁵³ acknowledgement of its legal obligation to enforce compliance, and the fact that its own regulatory failures have contributed to 30A disputes.²⁵⁴ It also specifi-

252. *Id.* at 26,344 (explaining that states have sought guidance on 30A compliance in the past, which the federal government failed to provide).

253. According to the federal government's own studies and literature review, there are a number of access problems that implicate the Equal Access Provision. *See generally* GAO 2011 REPORT ON MEDICAID & CHIP, *supra* note 52, at 46-47 (describing how many children did not get regular well-child checkups, did not receive required covered health screening services, and difficulty getting needed tests, treatment, and referral to specialists); U.S. GOV'T ACCOUNTABILITY OFFICE, GAO-09-578, MEDICAID PREVENTIVE SERVICES: CONCERTED EFFORTS NEEDED TO ENSURE BENEFICIARIES RECEIVE SERVICES (2009) (basing findings on MEPS and the National Health and Nutrition Examination Survey conducted by HHS from 2003-2006); U.S. DEP'T OF HEALTH AND HUMAN SERVS., OFFICE OF THE INSPECTOR GENERAL, OEI-5-08-00520, MOST MEDICAID CHILDREN IN NINE STATES ARE NOT RECEIVING ALL REQUIRED PREVENTIVE SCREENING SERVICES (2010) (finding that in nine states, three of four children did not receive all required covered health screening services).

254. *See* Methods for Assuring Access to Covered Medicaid Services, 76 Fed. Reg., at 26,344. HHS's failure to ensure that states submit adequate information for review is also a problem. *See* GAO 2011 REPORT ON MEDICAID & CHIP, *supra* note 52, at 8 ("We also found that the

cally acknowledges that effective federal oversight depends on meaningful data collection by states, and proposes a rule focused on creating a “standardized, transparent process for States to follow as part of their broader efforts to assure [30A compliance].”²⁵⁵

On the other hand, HHS is also clearly concerned about keeping costs down and preserving state flexibility as an important tool for accomplishing this. For example, HHS emphasizes that it wants “States [to be] *empowered to seek the best value through their rate-setting policies*” and does not want to “impair States’ ability pursue that goal.”²⁵⁶ In fact, the background discussion begins with an emphasis on state flexibility, especially with respect to cost-cutting goals, and flexibility is often explicitly or implicitly coupled with discussion of the 30A statutory requirement.²⁵⁷ State flexibility is used to qualify so much of the framing of the proposed rule that this theme, rather than access, seems to be the dominant one. Thus, while the regulations are designed to help ensure 30A compliance, HHS presents the proposed rule as a compromise that echoes the structure of the federal-state Medicaid partnership itself: there are very few mandatory rules for states to follow; and while the federal government offers some detailed “guidance” to states, the most important of the details with respect to process and substantive measures of access are left to state discretion.²⁵⁸

required state reports submitted to CMS regarding services provided to children in Medicaid lacked detail [W]hether children referred to providers for treatment actually receive the services they need. We recommend that the Administrator of CMS work with states to identify additional improvements that could be made to the annual reports that states are required to submit to CMS, including options for capturing information on children’s receipt of the services for which they are referred.”).

255. Methods for Assuring Access to Covered Medicaid Services, 76 Fed. Reg., at 26,359.

256. *Id.* at 26,343 (emphasis added). HHS goes on to say: “Achieving best value has been a key strategy for some States that have attempted to reduce costs in the Medicaid program in these difficult fiscal times. We do not intend to impair States’ ability to pursue that goal, or their ability to explore innovative approaches to providing services and lowering costs for other reasons. Indeed, the Secretary and CMS, including through the new Center for Medicare and Medicaid Innovation, is actively engaged in helping States achieve better value and better care while lowering per-person costs.” *Id.*

257. *Id.* at 26,344 (“[S]tates must have some flexibility in designing the appropriate measures to demonstrate and monitor access to care, . . . [in which] a singular approach to meeting the statutory requirement under [30A] could prove to be ineffective given current limitations on data, local variations in service delivery, beneficiary needs, and provider practice roles. For these reasons, we are proposing to frame alternative approaches for States to demonstrate consistency with the access requirement . . . rather than setting nationwide standards [We now propose] to allow for State and Federal review of beneficiary access to evolve over time.”).

258. *See id.*

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HHS establishes some basic procedural requirements that states must follow: States are required to conduct *access reviews* for all covered services at least once every five years²⁵⁹ and prior to submission of state plan amendments that involve payment reductions or restructuring that could affect access.²⁶⁰ States are also required to do the following: compare Medicaid payment rates to other rates (as part of the access review);²⁶¹ develop procedures to monitor continued access to care after implementation of a state plan rate reduction or restructuring; perform “updated” reviews for services affected by proposed payment cuts in a state plan amendment; develop a corrective action plan where an access problem is discovered; and ensure public reporting and ongoing input by Medicaid beneficiaries.²⁶² Access reviews must be “published” or “promptly made available upon request to the public, and furnished, upon request, to CMS.”²⁶³

These technical procedural requirements are helpful because they essentially bring back a more explicit “findings” requirement, like the one in the former Boren Amendment that provided more robust protection, according to some federal courts. However, the part of the process that is most relevant to determining the adequacy of the rates and ensuring an informed federal review—the rate setting method itself and the criteria used for assessing 30A compliance—is still left to state discretion. The proposed rules would require states to conduct their assessment based on a three-part framework²⁶⁴ that considers whether enrollee needs are being met; the number of enrolled provid-

259. *Id.* at 26,351 (explaining that Section 447.203(b)(2) provides that some subset of these services must be completed each year, but leaves determination of which services to the state).

260. *See id.*

261. “[Section] 447.203(b)(1)(iii)(B) would require that the review include: (1) An estimate of the percentile which Medicaid payment represents of the estimate average customary provider charges; (2) an estimate of the percentile which Medicaid payment represents of one, or more, of the following: Medicare payment rates, the average commercial payment rates, or the applicable Medicaid allowable cost of the services; and (3) an estimate of the composite average percentage increase or decrease resulting from any proposed revision in payment rates.” *Id.* at 26,351.

262. *See id.* at 26,350-52 (describing provisions of the proposed rule). HHS does propose a standardized template for public reporting and ongoing input by Medicaid beneficiaries.

263. *See id.* at 26,361.

264. *Id.* at 26,344. This guidance began with the Medicaid and CHIP Program Access Commission, a bi-partisan Congressionally-authorized committee, charged with developing recommendations on standards and methodologies for defining access to health care and health care services. It issued its report in March 2011, and the proposed rule adopts this framework. For the full report, see MEDICAID & CHIP PAYMENT & ACCESS COMMISSION, REPORT TO THE CONGRESS ON MEDICAID AND CHIP (2011).

ers; and beneficiary service utilization data.²⁶⁵ But the most impactful decisions with respect to the quality of the rate-setting process—how to measure each factor; what data to collect to determine whether there is an access problem; fashioning corrective action; and the design of the monitoring process—are all left to state discretion and thus potentially vulnerable to the same kinds of procedural defects identified in Part III.²⁶⁶ The proposed regulations do provide some guidance and discussion, though merely advisory, on each of these aspects of the process. However, as shown below, HHS’s suggested approach reflects some of the problems identified in Parts III that have led to courts to find 30A violations.

a. Direct Measures of Access

The failure to create mandatory criteria for measuring access is significant because to the extent states have been using some kind of process, the process could not really measure beneficiaries’ access—rather it used proxies for access, some which were questionable, and others which were clearly inadequate. For example, states may have data about the number of providers enrolled in Medicaid, but they do not go further to inquire about whether they are currently treating or accepting new Medicaid patients nor do they consider trends in provider loss and retention. Given the longstanding problem of providers refusing to treat Medicaid beneficiaries, ignoring this element cannot produce a realistic picture of access. HHS acknowledges this and seems to deal with it in a couple of ways. First, by creating a three part framework that looks not only at provider enrollment, but also at whether enrollee needs are being met and beneficiary utilization, it makes clear that access must be assessed from the beneficiary’s point of view and based on the reality on the ground.²⁶⁷

265. While these may seem to be obvious criteria for measuring access, there was no federal requirement for such data and such data has often not been considered by states.

266. See *Methods for Assuring Access to Covered Medicaid Services*, 76 Fed. Reg., at 26,349 (explaining why HHS declined to propose setting a single uniform federal standard for reviewing substantive compliance with access requirements).

267. This focus on the reality of access on the ground is evident in HHS’s discussion of the kind of data needed to measure access. For example, HHS states:

We believe the meeting of enrollee needs should be the primary driver to determine whether access to care is sufficient,” and that “[s]tates may need to rely on qualitative information that is received through beneficiary surveys or other means, such as hot-lines or beneficiary Ombudsman offices . . . and may request that community-based organizations, primary care providers, hospitals case management, and other providers assist in soliciting the information from beneficiaries.

Id. at 26,345. It also says that:

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HHS also suggests a number of optional data elements that, if used, would require a more in-depth inquiry into the reality of health care access for patients.²⁶⁸ For example, for determining whether enrollee needs are being met, HHS suggests looking at the following factors: the extent of beneficiaries' knowledge that services are covered by Medicaid; success in scheduling appointments (even after hours); satisfaction with availability of providers within a reasonable distance from home; ability to get transportation to and from appointments; the number and reasons for emergency room visits and missed appointments; the ability to schedule appointment and get service for individuals who have limited English proficiency; turnover in providers (such as homecare workers); and the means and ability to seek help in scheduling appointments.²⁶⁹ In looking at the number of enrolled providers, HHS suggests getting more probing data about the extent to which providers are able and willing to accept new Medicaid patients, as well as looking at access from a comparative perspective, in light of the specific duty to ensure *equal access* under 30A.²⁷⁰ These data elements are treated as optional, yet it is not clear how one could accurately assess access without them. The fact that these elements are only "suggested" and "optional" is clearly not as desirable as making them mandatory, especially in light of the history of some states'

The connection between the number of enrolled provider and the availability of services is seemingly obvious, but there are many qualifications that affect the meaningfulness of such data. It may be important to know the number of enrolled providers in relation to the overall number of providers in the community. And in order to contribute to beneficiary access, it is significant to know whether enrolled providers . . . are accepting Medicaid patients.

Id.

268. *Id.* at 26,345-46. In its discussion of beneficiary service utilization, HHS suggests that states could consider the following: whether there is a drop in service utilization that coincides with payment changes; patterns of beneficiaries obtaining access to care through hospital emergency rooms, which may indicate an access problem for certain kinds of services; and review of avoidable emergency room visits and hospital admissions, which may indicate a problem with accessing preventive care. *Id.* The rule also suggests states take into account services that apply to certain subsets of the population, such as pediatric and obstetrical services. *Id.* at 26,346.

269. *Id.* at 26,345-46.

270. HHS suggests the following criteria for measuring 30A compliance based on provider enrollment: Availability of care in fee-for-service (FFS) compared to access standards for Medicaid managed care; availability of care in FFS compared to access standards for commercial insurance; number of providers with open panels; the extent to which timely follow-up visits occur after emergency room visits or inpatient stay; Medicaid enrollment of providers with open panels compared to licensed providers; provider Medicaid enrollment compared to actual provider Medicaid participation; provider Medicaid enrollment (with open panels) compared to provider enrollment in one of the four largest commercial insurers in the state; provider loss and retention; average amount of time from provider application for enrollment to approval of provider agreement; and average amount of time from provider claim submission to payment of claim by Medicaid agency. *Id.* at 26,345-46.

abuse of discretion. One might expect that even optional factors would likely be taken seriously by the states, especially in the face of increased scrutiny by CMS; but three recent California cases provide evidence to the contrary, as will be shown in Section C below.

b. Role of Cost and Payment-Access Link

Another important concern for providers and beneficiaries is the apparent de-linking of rates and access, and a corresponding devaluation of the role of cost in rate setting. In the background discussion, HHS acknowledges that provider costs have been used as a measure of rate sufficiency, but mentions it simply as one of a number of possible approaches for setting rates.²⁷¹ Nowhere in the three-part MACPAC framework adopted by HHS does it explicitly include provider cost studies or data as a measure of access or payment sufficiency. In fact HHS expressly rejects the Ninth circuit's interpretation of 30A as requiring cost studies.²⁷² HHS devalues the importance of cost considerations by implicitly leaving the choice to consider cost to state discretion, and noting that “[d]epending upon State circumstances, cost-based studies may not always be informative or necessary.”²⁷³

This devaluation is troubling because it does not account for the reality that sufficiency of rates depends on providers' ability to meet reasonable costs, and the reality that providers who consistently suffer unmet costs will either opt out of the program (assuming they can leave the market easily, like primary care physicians, specialists, dentists or pharmacists) or that they will suffer a potentially slower, but devastating financial loss that could ultimately lead to closure or flight (as for hospitals and nursing homes). This strikes at the heart of the

271. *See id.* at 26,344.

272. *See id.* at 26,344.

273. *Id.* at 26,344. In the background of the proposed rule, HHS describes the various approaches that have developed as a result of state experimentation and that do not necessarily depend on cost data:

As State delivery system models have evolved, so too have their provider payment systems. Many States develop rates based on the costs of providing the service, a review of the amount paid by commercial payers in the private market, or as a percentage of rates paid under the Medicare program for equivalent services. Often, rates are updated based on specific trending factors such as the Medicare Economic Index or a Medicaid trend factor that incorporates a State-determined inflation adjustment rate. Rates may include supplemental or incentive payments that encourage providers to serve Medicaid populations. For instance, some States have authorized Medicaid providers to receive supplemental payments for care coordination and care management, or for achieving certain specified quality measures.

Id. at 26,342. It specifically notes that this kind of flexibility “is consistent with [30A].” *Id.* at 26,343.

substantive protection of 30A, which specifically contemplates a rate-access link. It is also surprising given the legal significance between rates, cost, and access as expressed in Medicaid legislation, the practical significance of this link as evidenced by lawsuits and surveys, and the fact that a number of federal courts have held that provider costs cannot be ignored under 30A.²⁷⁴

This approach also potentially weakens the kind of remedy or corrective action that would be required for 30A compliance. Indeed, HHS expressly de-links access concerns from rate sufficiency in its discussion of corrective options for states, noting that the access review required by 30A does not demand a particular result regarding payment rates, and that even if access issues are discovered as a result, “[s]tates may be able to resolve those issues through means other than increasing payment rates.”²⁷⁵ While there may be other causes of, and thus potential remedies, to address access disparities for Medicaid beneficiaries, this has been used by states to avoid a searching inquiry into the rate-access link, and courts have viewed states’ attempts to shift the focus away from rates with suspicion; they have rejected states’ attempts to avoid adjusting rates by proposing other remedies that are untested and do not have a proven connection to the access problem.²⁷⁶

c. Data Gathering: The Public’s Role

One important goal, according to HHS, is to create a standardized template for public reporting in order to facilitate meaningful participation by the public.²⁷⁷ Public reporting requirements have existed, but have been ignored by some states or not designed to ensure meaningful participation. HHS criticized states for holding public meetings seemed focused on making the public aware of the upcoming rate changes, rather than soliciting information on the potential impact that such changes might have, in ways that would inform the

274. To be clear, I am not arguing that HHS should go as far as to expressly require that each provider have an individual right to be entitled to its reasonable costs – this kind of individualized, retrospective, cost-based approach was clearly rejected with the Boren Amendment in 1981 and through other legislative reforms. Rather, I am arguing that the reasonable costs that an efficient and economical provider would need to incur to help ensure access to quality care is an important consideration.

275. *See id.* at 26,344, 26,347 (“The precise nature of needed corrective action depends on individual State circumstances.”).

276. *See, e.g.,* Clark v. Kizer, 758 F. Supp. 572, 578 (E.D. Cal. 1990).

277. *See* Methods for Assuring Access, *supra* note 15, at 26,346-47.

decision making process.²⁷⁸ In its guidance on data collection, HHS also notes that “meeting of enrollee needs should be the primary driver to determine whether access to care is sufficient” and that reaching out to beneficiaries to gather this information is important.²⁷⁹ Thus, HHS’s intention is clearly to encourage a public process that ensures meaningful public participation.

On the other hand, HHS quickly concedes that [m]easurable data on the beneficiaries’ experiences and needs, however, may be difficult for states to attain and allows states to determine “the most efficient means to reach beneficiaries.”²⁸⁰ Although there is nothing inherently wrong about leaving this to state discretion in light of the varying needs and characteristics of the beneficiary population that states will need to engage in the process, there are a couple of concerns this raises. One concern is how much states can be trusted to use their discretion to engage beneficiaries where there is a history of poor compliance with even the most basic notice requirements. This concern is heightened when other potential barriers to beneficiary participation are considered, such as health literacy challenges, a lack of assertiveness and comfort voicing complaints, mistrust of the system, and as Medicaid expands to include more of the working poor, time constraints.²⁸¹ In order to get meaningful participation, it will take active outreach and resources, and a process that is culturally and linguistically appropriate.²⁸² State flexibility is important, but rather than merely giving states the option of relying on others to help solicit information states should be required to demonstrate how they are engaging with community-based organizations, independent policy organizations that regularly perform surveys, and the frontline service providers (like social workers and primary care physicians) responsible for helping, and finding referrals for, Medicaid patients.

Another problem is that although beneficiary input is encouraged by HHS, it is not required where data collection and monitoring un-

278. *See id.* at 26,348.

279. *See id.* at 26,345.

280. *Id.*

281. *See* Brietta Clark, *Using Law to Fight a Silent Epidemic: The Role of Health Literacy in Health Care Access, Quality, & Cost*, 20 *ANNALS HEALTH L.* 253, 258-72 (2011) (describing the impact of health literacy in health care access and quality).

282. *See generally* COLLEN M. GROGAN & MICHAEL K. GUSMANO, *HEALTHY VOICES, UNHEALTHY SILENCE: ADVOCACY AND HEALTH POLICY FOR THE POOR* (2007) (examining Connecticut’s Medicaid advisory board process, and providing prescriptive advice for creating a participatory process in state level health policymaking that meaningfully addresses the health concerns for the poor and dispossessed).

covers an access problem.²⁸³ Given that beneficiary input is viewed as important in determining whether a problem exists in the first place, it is not clear why this becomes less important once a threat to beneficiary access has been identified and must be corrected. The failure to require beneficiary input is particularly troubling in light of the great flexibility states are given to establish corrective action through a variety of means other than altering rates, such as ombuds programs and other resources designed to increase access.

d. Process v. Substantive Guarantees

HHS explicitly rejects setting national access thresholds or even requiring states to establish and demonstrate access thresholds. It says that it “do[es] not intend to develop independent analyses of beneficiary access to services, but instead will review State analyses to ensure that the State-level review process operated to reasonably demonstrate substantive compliance with the access requirements.”²⁸⁴ Thus its enforcement focus is on ensuring an adequate process that will produce the necessary data for determining 30A compliance; it will not use its review to assess the adequacy of the rates themselves. In explaining its approach, it uses the state laboratory metaphor: it conceives of its role as encouraging the kind of state experimentation described in Part I, and even suggests that this experimentation might eventually yield one best approach or optimal benchmark.²⁸⁵ One reason HHS gives for this flexibility is that a “singular approach” may not account for differences in Medicaid benefits or state/local delivery models. Another reason is that 30A access is comparative in nature, so that benchmarks will likely vary for different states and localities.²⁸⁶ There are challenges to setting firm requirements for substantive guarantees in light of local variations are real, and a focus on process is understandable for its administrative ease. This is troubling, however, because of HHS’s resistance to establishing certain minimum criteria for ensuring a meaningful process that will yield relevant information about the impact of rates on access and quality. The *Clark* case, in which California’s Denti-Cal program was found to violate 30A and other access requirements,²⁸⁷ illustrates the importance

283. See *Methods for Assuring Access*, *supra* note 15, at 26,347.

284. *Id.* at 26,344, 26,349.

285. *Id.* at 26,344, 26,349-50.

286. *Id.* at 26,344, 26,349-50.

287. See *supra* Part III.B.3.

of federal guidelines to establish a process that enables states (and courts when intervention is necessary) to identify disparities that raise 30A concerns. It also shows that HHS has had ample time to allow states to experiment with different approaches and to learn what kind of information is essential for measuring access.

HHS's strategy is based on the faith that states will use their flexibility to create a meaningful process to identify access and quality problems that would at least slow down their rate cuts, if not halt them altogether. In light of the obvious conflict of interest by state officials whose primary, if not exclusive concerns are really budgetary, and a history of noncompliance with even unambiguous requirements, this faith is not warranted.

C. The Future Impact of HHS Enforcement and Rulemaking on Medicaid Access

These proposed rules, when considered against the political and legal backdrop laid out in Parts II and III, raise two questions about role of HHS in these disputes going forward: First, will HHS use its enforcement power to review state proposals more closely for 30A compliance and reject rates resulting from processes that are inadequate or raise access and quality concerns? Second, what impact will HHS regulatory action have in this area, specifically its rulemaking power and its approval of rate cuts that beneficiaries and providers believe violate federal law? HHS's proposed rules and three recent California Medicaid payment cases offer hints at what we can expect.

1. HHS Enforcement Under the Proposed Rule

In addition to establishing guidance for states, the proposed rules reveal HHS's own vision of its enforcement role, and once again, flexibility seems to be key. First, HHS attributes the lack of prior federal guidance to the fact that it is "not aware of any standardized, transparent methodology that is broadly accepted to definitively measure access to health care and service."²⁸⁸ It uses this to justify a flexible "strategy . . . to allow for State and Federal review of beneficiary access to evolve over time"²⁸⁹ CMS seems to view this as an experi-

288. See *Methods for Assuring Access*, *supra* note 15, at 26,344.

289. *Id.*; see also *id.* at 26,349 ("Determinations of compliance will necessarily involve judgments as to how to weigh the data States develop on access measures, and at least without more experience and analysis we do not believe those judgments can be readily reduced to procedural or substantive formulas.").

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mental or learning phase that will yield valuable lessons and lead to a knowledge of “best practices.” This suggests that HHS itself is unclear about what the law requires, making it difficult to see how it can be effective at enforcement.

Second, there seems to be an inconsistency between the federal government’s strong rhetoric about enforcement in the background discussion of the proposed rule and the enforcement language used in the actual proposed rule. At one point in the background, HHS says that it will not approve plan amendments that do not comply with these requirements,²⁹⁰ but in the rule itself, denial does not appear to be mandatory; rather the language seems to leave this to HHS’s discretion.²⁹¹ While this may seem a subtle distinction, the analysis in Parts III and IV.A. should make its significance clear. Like many states, HHS has used its discretion to ignore its enforcement obligations, approving by default state plan amendments that were the result of clear and unambiguous violations. The primary motivation behind HHS’s enforcement action in the past seems to be the same one driving state rate changes—to lower rates.

Again, though one might hope that HHS under the Obama administration will be different, the problems in the proposed rules identified above do not justify this hope. In fact, three recent California cases discussed below provide a particularly vivid picture of the kind of regulatory enforcement that we can expect in the immediate future. And what happens when President Obama leaves office? We cannot assume that future administrations will take this obligation even as seriously as the Obama Administration with all of its flaws. Without a clear mandate to HHS to reject SPAs that do not comply with access review requirements, important access protections will be left to the will of a federal agency whose pervasive regulatory failures have exacerbated this problem, and whose commitment to enforcement of Medicaid law will vary based on political will.

290. *Id.* at 26,349 (“When a State has not complied with the access review requirements, [HHS] would not approve such a State plan amendment.”).

291. *See id.* at 26,362 (“If CMS determines that service rates are modified without such an analysis, the agency may disapprove a proposed State plan amendment . . . or may take a compliance action. . . .”).

2. How HHS Action Will Impact Medicaid Payment Disputes: The California Case Study

Three recent decisions issued by a California district court provide a window into what we can expect from the current HHS, as well as the likely impact that this more active and engaged regulator might have on Medicaid payment suits going forward.²⁹² The rate cuts challenged in these cases were the latest of several attempts by California lawmakers to cut Medicaid reimbursement for a wide range of services including those provided by physicians, hospitals, dentists, pharmacists, medical transportation companies, and durable medical equipment companies.²⁹³ Because the earlier attempts resulted in across-the-board-cuts made without any process (and thus no consideration of 30A factors), the cuts were halted by federal courts.²⁹⁴ These earlier cuts were the basis of the legal challenge that reached the Supreme Court in *Douglas v. Independent Living Center*. This time, however, when the California Department of Health Care Services (DHCS) submitted its state plan amendment (SPA) to cut rates, CMS requested additional information about the impact of the rates on access.²⁹⁵ DHCS responded with an access analysis justifying the rate cuts originally proposed, as well as a plan for monitoring access.²⁹⁶ After reviewing the information, CMS issued a letter approving the cuts.²⁹⁷

Providers and beneficiaries brought three new lawsuits challenging these cuts, alleging that the process was inadequate and that the

292. See *Cal. Med. Ass'n v. Douglas*, No. 11-9688, 2012 U.S. Dist. LEXIS 12074, at *4-7 (C.D. Cal. Jan. 31, 2012) (challenging Assembly Bill 97 (AB 97) which authorized the Director of DHCS to reduce rates for hospitals services, including skilled nursing services); *Managed Pharm. Care v. Sebellius*, No. 11-9211, 2011 U.S. Dist. LEXIS 148866, at *3-4 (C.D. Cal. Dec. 28, 2011) (challenging reductions in fee-for-service and managed care rates for pharmacy services also enacted as part of AB 97); *Cal. Hosp. Ass'n v. Douglas*, 2011 U.S. Dist. LEXIS 148876, at *3-4 (C.D. Cal. Dec. 28, 2011) (challenging rate cuts for physician, clinic, dental, pharmaceutical, emergency medical transportation, and durable medical equipment services enacted as part of AB97).

293. See *Douglas*, 572 F.3d at 649-51 (describing the earlier round of cuts which were challenged and blocked by federal courts).

294. See *id.* at 649-50.

295. See *Cal. Med. Ass'n*, 2012 U.S. Dist. LEXIS 12074, at *5; *Cal. Hosp. Ass'n*, 2011 U.S. Dist. LEXIS 148876, at *3. In the case of *Managed Care Pharmacy Care v. Sebellius*, DHCS submitted an access analysis with its SPA. *Managed Pharm. Care*, 2011 U.S. Dist. LEXIS 148866, at *3-4.

296. See *Cal. Med. Ass'n*, 2012 U.S. Dist. LEXIS 12074, at *5-6; *Cal. Hosp. Ass'n*, 2011 U.S. Dist. LEXIS 148876, at *3.

297. See *Cal. Med. Ass'n*, 2012 U.S. Dist. LEXIS 12074, at *6; *Cal. Hosp. Ass'n*, 2011 U.S. Dist. LEXIS 148876, at *3-4; *Managed Pharm. Care*, 2011 U.S. Dist. LEXIS 148866, at *4.

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process and rates themselves violated 30A and the APA.²⁹⁸ In issuing temporary injunctions to halt the cuts in each case, the court refused to defer to federal regulators' approval.²⁹⁹ Rather, the court closely scrutinized the state's process, and held that neither CMS's interpretation of what 30A required nor its approval of the cuts warranted deference.³⁰⁰ In each case, the court detailed numerous and significant defects in the process that made it impossible to ensure 30A compliance, and which cast serious doubts on the effectiveness and willingness of federal regulators to enforce 30A.

For example, in *California Medical Association v. Douglas*,³⁰¹ the court temporarily enjoined cuts in reimbursement for physician, dental, pharmaceutical, durable medical equipment, and emergency transportation services.³⁰² The court found a likelihood that plaintiffs could show that the state's rate changes were arbitrary and capricious, and thus violated Section 30(A), because the state did not do cost studies in clear violation of *Orthopaedic*.³⁰³ The state's methodology for measuring access was also "fundamentally flawed"³⁰⁴ because the state failed to investigate access on the ground, using data that created a distorted picture of access.³⁰⁵ In the case of physician services, for example, the state measured access by the number of participating physicians who submitted at least one claim per year, but did not gather information about how many Medi-Cal beneficiaries these physicians were actually willing and able to see with regularity.³⁰⁶ It also ignored data on beneficiary need and utilization patterns based on

298. See *Cal. Med. Ass'n*, 2012 U.S. Dist. LEXIS 12074, at *6; *Cal. Hosp. Ass'n*, 2011 U.S. Dist. LEXIS 148876, at *4; *Managed Pharm. Care*, 2011 U.S. Dist. LEXIS 148866, at *4. Plaintiffs alleged other violations, such as a violation of the Takings Clause in the U.S. Constitution and California Constitution, the Due Process of the Fourteenth Amendment to the U.S. Constitution, and other provisions of Medicaid; however the court focused on the 30A and APA claims.

299. See *Cal. Med. Ass'n*, 2012 U.S. Dist. LEXIS 12074, at *53; *Cal. Hosp. Ass'n*, 2011 U.S. Dist. LEXIS 148876, at *49; *Managed Pharm. Care*, 2011 U.S. Dist. LEXIS 148866, at *39.

300. In each case, the court held that the state's rate-setting process and CMS's approval were arbitrary and capricious because they failed to adequately consider 30A factors. Specifically, it cited the failure to do cost studies, defects in the access analysis, failure to consider the impact on quality, and an inadequate monitoring plan. See *Cal. Med. Ass'n*, 2012 U.S. Dist. LEXIS 12074, at *19-37; *Cal. Hosp. Ass'n*, 2011 U.S. Dist. LEXIS 148876, at *15-30; *Managed Pharm. Care*, 2011 U.S. Dist. LEXIS 148866, at 11-22, 24-29.

301. See *Cal. Med. Ass'n*, 2012 U.S. Dist. LEXIS 12074, at *1.

302. *Id.* at *53-54.

303. *Id.* at *18-26.

304. *Id.* at *28-33.

305. *Id.* at *33-43.

306. *Id.* at *33-34.

type of service and location.³⁰⁷ Finally, the state's proposed plan to monitor access was found inadequate because it took a wait-and-see approach, creating a potential response to an access problem only after the problem had been identified.³⁰⁸

According to the court, these decisions not only revealed defects in the state's process, they also highlighted serious failures in CMS oversight, significant enough to undermine the normal rule that courts will defer to agency action. For example, one argument made by the state and CMS in all three cases was that HHS's interpretation of what 30A required was different from the Ninth Circuit's decision in *Orthopaedic*; HHS did not interpret 30A to require cost studies, and the state argued that HHS's interpretation should receive deference.³⁰⁹

The Court rejected CMS's interpretation and argument for deference for a few reasons. It was troubled by CMS's failure to explain *why* 30A did not require DHCS to consider provider cost, especially in light of *Orthopaedic* and "[g]iven the logical and empirical relationship between reimbursement rates and the willingness of providers to make services available"³¹⁰ The "absence of a reasoned decision to not require cost studies" to justify the SPA also was found to be arbitrary and capricious because of CMS's own inconsistency in this regard. Although CMS was now treating provider cost as irrelevant for determining whether rates are too low to ensure equal access, in 2004 it argued the opposite position when it denied a state plan amendment by Alaska that would have increased Medicaid payment rates.³¹¹ In that case, CMS denied the plan, in part because of Alaska's failure to consider provider cost; it even quoted language from the Ninth Circuit's *Orthopaedic* decision which said that "the requirements of § 1396a(a)(30)(A) are . . . not so flexible as to allow the [State] to ignore the costs of providing services."³¹² To take such apparently inconsistent positions without a rational explanation looks like precisely the kind of arbitrary action that does not warrant APA

307. *Id.* at *34.

308. *Id.* at *29-30.

309. *See, e.g., id.* at *18-19.

310. *Id.* at *23.

311. *Id.* at *23-26 (describing the position CMS asserted in a brief to support its denial of the SPA, which was being challenged at the Ninth Circuit). *See also* Brief of Respondents, Alaska Dept. of Health & Soc. Servs. v. Centers for Medicare & Medicaid Servs., 424 F.3d 931 (9th Cir. 2005) (No. 04-74204), 2004 WL 3155124 at *3.

312. *See also* Brief of Respondents, *supra* note 308, at *32.

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deference. Finally, the court was troubled by CMS's approval of the cuts despite the state's failure to consider the kind of data necessary to accurately measure access.³¹³ Despite the fact that HHS (through past informal guidance and recently proposed rules) has made clear that this kind of analysis is inadequate, CMS approved the rate cuts.³¹⁴

While the court did not specifically highlight the fact that this latest round of cuts came after the legislature's earlier attempts to cut rates without any process, in clear disregard of the law. It is hard to ignore this recent troubling history if one is trying to determine how much deference should be due: in fact it seems critical in trying to determine whether process defects should be overlooked as simply a "less than ideal" process developed by state officials making a good faith attempt to engage in reasoned decision making, or as further evidence that such defects reflect an attempt to dress up arbitrary cuts motivated exclusively by budgetary concerns in process that will let them avoid meaningful scrutiny. HHS's approval of cuts justified by such a defective process, and so close on the heels of cuts attempted without any process or consideration of access, does not engender faith in a regulatory process that depends on state discretion, and with limited federal oversight.

While these cases provide a dim picture of what HHS enforcement activity and priorities will look like going forward, they may not necessarily be an accurate predictor for how federal courts generally will treat CMS approval in future payment suits. First, the holdings should not be overstated: each case only resulted in a preliminary injunction by a district court, and a full hearing on the merits might turn out differently. Moreover, California courts have tended to be more proactive in this area: the Ninth Circuit has gone the farthest of the federal courts in finding that 30A requires the state to do cost studies before setting rates, and it has been willing to closely scrutinize state rate-setting processes.³¹⁵ Some courts have been more deferential to state and federal regulatory action in rate setting, and this trend may continue.³¹⁶

313. See, e.g., *Cal. Med. Ass'n*, 2012 U.S. Dist. LEXIS 12074, at *27-29.

314. See *supra* Part III.B.3 for a discussion of *Clark v. Kizer* and *supra* Part IV.B.2 for a discussion of CMS's proposed rules.

315. See *supra* Part III. See also Rosenbaum, *Medicaid Payment Rate Lawsuits*, *supra* note 127, at 11 ("California has seen an uncommonly large number of legal challenges regarding provider payment rates, a testament perhaps to the low payment rates that characterize the Medi-Cal program.").

316. See *supra* Part III.B.

These decisions might also reflect California's frustration with state officials who repeatedly disregard federal law, increasing its suspicion that when the state does act, it is simply dressing up rate cuts in a process designed to shield it from legal challenge, as opposed to creating a meaningful process for ensuring that its 30A obligations are met.³¹⁷ To the extent that recent rulemaking and attention to the problem causes states to comply with obvious procedural requirements and proceed more deliberatively before rate setting, courts may be inclined to be more deferential. In fact, one reason the court gave for refusing to defer to HHS's interpretation of 30A is that there had not been a formal adjudication or final rulemaking process, which includes the kind of procedural safeguards that typically warrant judicial deference.³¹⁸ Once HHS's approach to rate setting and equal access reviews is finalized, even California courts may be more willing to defer to CMS.

On the other hand, this decision may signal that increased regulatory action by HHS will not change courts' willingness to scrutinize

317. See, e.g., *V.L. v. Wagner*, No. C 09-04668-CW, 2009 U.S. Dist. LEXIS 116880, at *3-4 (N.D. Cal. Nov. 25, 2009) (granting plaintiffs' motion for civil contempt sanctions to remedy non-compliance and to compel prospective compliance, after state officials violated the federal court's injunction to prevent changes in the eligibility for In-Home Supportive Services recipients). In fact, the Ninth Circuit has openly lamented state officials' failure to follow federal law:

Despite our contrary holdings over the past decades the State has allowed its economic difficulties to obfuscate its analysis and render it purblind to the simple fact that it cannot properly implement changes to its Medicaid plan before the [CMS] has approved a submitted SPA. . . . [I]t is regrettable that the State refuses to abide by the law.

See *Developmental Servs. Network*; see also *Clark*, 758 F.Supp. at 578. Recall that in *Clark*, a federal district court found that California's adult dental program violated several provisions of the Medicaid Act, including the Equal Access Provision. See *supra* Part III.B.3. Two years later, the Ninth Circuit had to mediate a dispute between state officials and the magistrate overseeing the order for the state to make necessary changes for compliance. *Clark v. Coye*, 967 F.2d 585 (9th Cir. 1992). The state would only agree to slightly increase its rates (from 50% of the average amount billed by Denti-Cal providers up to 55%), and ignored the magistrate's order to increase rates to 80% of the average amount billed. *V.L.*, No. C 09-04668-CW, 2009 U.S. Dist. LEXIS 116880, at *1. The Ninth Circuit affirmed that the magistrate had the power to determine whether the state's plan complied with federal law, and held that if the magistrate finds the then-existing rates were noncompliant based on updated information, he would be free to reinstate the injunction and require reimbursement at the 80% rate or at whatever other rate is necessary to achieve compliance. *Id.* at *3.

318. See, e.g., *Cal. Med. Ass'n*, 2012 U.S. Dist. LEXIS 12074, at *19. In relevant part:

In this respect, the Court finds significant that the Secretary's approval of SPA 11-009 did not involve a formal adjudication accompanied by the procedural safeguards justifying Chevron deference. Instead, the Secretary issued her interpretation of *Section 30(A)* in a letter to DHCS. This kind of interpretation is of the very type for which the Supreme Court has declined to extend Chevron deference.

Id. In a footnote, the court went on to explain that where HHS rejects a state plan, federal law gives the state the opportunity to petition for reconsideration and then the Secretary of HHS must hold a hearing: "For this reason, Chevron deference is more appropriate for the disapproval of a State Plan Amendment." *Id.* at *21 n.7.

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rate setting because of the deeper concerns raised by this Article: a concern about states' willingness to comply with equal access and quality protections in rate setting, and doubts about HHS's commitment to, and thus effectiveness in, ensuring 30A compliance. Such concerns are justified in light of a history of state noncompliance, federal regulatory failures, and apparent conflict of interest at the federal and state levels that prioritizes immediate reduction in spending over access and quality concerns. Thus, these recent cases can be seen as a warning in the midst of great economic, legal, and regulatory uncertainty for Medicaid patients, providers, and states: a reminder of the importance of not only having access and quality protections in the law, but of the need for effective enforcement mechanisms to ensure compliance and meaningful judicial review by federal courts.

CONCLUSION

As this Article was in the editing process, the Supreme Court issued its decision in *Douglas v. Independent Living Center*.³¹⁹ *Douglas* represented the consolidation of several suits challenging cuts in California's Medi-Cal reimbursement for a wide range of health care services.³²⁰ The Ninth Circuit affirmed lower court decisions halting the cuts because they were found to violate 30A's equal access provision; at issue, were legislative attempts to make across-the-board cuts in 2008 and 2009, without any consideration of 30A factors and exclusively for budgetary reasons.³²¹ The Supreme Court did not take up the issue of whether the cuts actually violated this requirement; rather it granted certiorari to decide whether patients and providers had a right to challenge such cuts in federal court using the Supremacy Clause.³²²

319. 132 S. Ct. at 1204.

320. *Id.* at 1209.

321. *See* *Indep. Living Ctr. v. Maxwell-Jolly*, 572 F.3d 644, 649 (9th Cir. 2009) (noting that the California Assembly passed Assembly Bill 5 (AB 5) on February 16, 2008 which reduced "payments under the Medi-Cal fee-for-service program to physicians, dentists, pharmacies, adult health care centers, clinics, health systems, [hospitals not under contract with the state for inpatient services] and other providers by ten percent"); *Managed Pharm. Care v. Maxwell-Jolly*, 2009 U.S. Dist. LEXIS 33692, at *2 (C.D. Cal. Apr. 3, 2009) (noting that the California legislature passed AB 1183 to replace the cuts under AB 5 which would have terminated early in 2009 and were partially enjoined by the court; as of March 1, 2009, AB 1183 would have cut Medi-Cal reimbursement by one percent or five percent, depending on the type of provider).

322. *See Douglas*, 132 S. Ct. at 1207-08.

Interestingly, the Court never answered this question.³²³ In a five-to-four decision, the Court reframed the question and remanded it back to the Ninth Circuit for briefing by the parties because of what the Court viewed as a potentially significant change in legal posture which occurred during litigation: CMS approved the cuts.³²⁴ The practical effect of delaying the decision is that it preserves plaintiffs' rights to sue. The majority declined to follow the dissent's approach, which would have held that the Supremacy Clause cannot be used regardless of CMS approval.³²⁵

The new question presented is whether private citizens can use the Supremacy Clause to challenge state cuts *after* CMS has approved them,³²⁶ and the most interesting part of the decision is the Court's explanation for why it reframed the question for remand in this way. First, the Court suggested that CMS action may be subject to judicial review under the Administrative Procedure Act, making the Supremacy Clause unnecessary for challenges in federal court.³²⁷ This is significant because it indicates that the Court is unwilling to foreclose plaintiffs' ability to challenge payment cuts in federal court.

But the Court's decision also raised an important question about the legal significance of CMS approval, particularly in terms of how much deference courts must give to agency approval. Despite the apparent win for plaintiffs, some viewed this aspect of the majority's opinion as foreshadowing a more favorable rule for states.³²⁸ The majority does emphasize the deference typically afforded to agency action under the APA, and suggests that such deference might be warranted in this case because of CMS approval.³²⁹ However, the de-

323. *See id.* at 1213 (dissent criticizing the majority's failure to answer the original question presented).

324. *See id.* at 1207-08. While litigation was pending in the lower courts, CMS reviewed the SPA and in November 2010 disapproved the rate cuts for failure to comply with 30A. *Id.* at 1209. Subsequently, California DHCS resubmitted its SPA with the proposed cuts with the access analysis requested by CMS. These cuts were recently approved by CMS, but have been temporarily enjoined by a district court in three separate cases. *See supra* Part IV.C.2.

325. *Douglas*, 132 S. Ct. at 1213-14.

326. *Id.* at 1207.

327. *Id.* at 1210 ("For one thing, the APA would likely permit respondents to obtain an authoritative judicial determination of the merits . . .").

328. See Brietta Clark, *The (In)decision of Douglas v. ILC: The Relevance of CMS Approval in Challenges to Medicaid Payment Cuts*, available at http://healthcarejusticeblog.org/2012/02/us_supreme_cour.html#more (quoting recent commentary describing the decision as favorable to states).

329. For example, the Court raises questions about the difference between judicial review under the APA and the level of review courts apply in Supremacy Clause actions. It emphasized the importance of deference in light of 30A's broad statutory factors that seem to depend on

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cision does not clearly favor states or demand *unqualified* deference because it also reiterates the limits on this deference: agency action must be set aside where shown to be arbitrary, capricious, an abuse of discretion, or otherwise not in accordance with law.³³⁰ Thus, what was initially a focus on the viability of the Supremacy Clause for enforcement of spending clause conditions has morphed into an inquiry about the kind of judicial review that federal regulatory action should receive in these disputes – an inquiry that implicates the concerns illuminated in this Article. Indeed, the three recent California cases described above, especially when considered against the history of state noncompliance and federal regulatory failures identified in Parts III and IV, illustrate why deference is not always warranted, even under the APA.

Despite Medicaid expansion and increased regulatory activity, the current administration is, unfortunately, undermining its stated commitment to improving access. The promise of expanded access under Medicaid reform depends on the extent to which federal regulators are willing to develop and enforce robust criteria for ensuring meaningful access reviews, apply the same level of oversight to state proposals to cut rates as those that propose rate increases, and use its enforcement power to deny state plan amendments that clearly violate the law and do not make credible assurances of 30A compliance. By these measures, the federal government's commitment to enforcing 30A access and quality protections does not look very promising. Courts should continue to be troubled by evidence of arbitrary, capricious, and inconsistent decision making by state and federal officials, and to be willing to take a hard look at agency action to determine whether deference is warranted. Medicaid payment suits provide a critical check on illegal cuts that have significant health consequences and undermine the legal promises of equal access and quality.

agency expertise. It also speculated that CMS approval might lead the Ninth Circuit on remand to find that the rates are valid because of this deference. *Id.* at 1210-11.

330. *Id.* at 1210.

Section 1557 of the Affordable Care Act: Civil Rights, Health Reform, Race, and Equity

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INTRODUCTION

The Patient Protection and Affordable Care Act (ACA or “Affordable Care Act”) provisions expanding access to affordable health insurance offer a critical tool to improve minority access to health insurance and reduce inequities both in the health care system and among communities. Lack of health insurance is the biggest barrier to receiving timely and affordable health care services,¹ and people of color are more likely than white Americans to be uninsured.² Although people of color make up just thirty-five percent of the U.S.

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1. See COMM. ON HEALTH INS. STATUS & ITS CONSEQUENCES, BD. ON HEALTH CARE SERVS., INST. OF MED., AMERICA'S UNINSURED CRISIS: CONSEQUENCES FOR HEALTH AND HEALTH CARE XI (2006) (stating that from 2001 to 2004 that the Institute of Medicine (IOM) issued six reports that concluded: “being uninsured was hazardous to people’s health”).

2. COMM. ON UNDERSTANDING & ELIMINATING RACIAL & ETHNIC DISPARITIES IN HEALTH CARE, INST. OF MED., UNEQUAL TREATMENT: CONFRONTING RACIAL AND ETHNIC

population, they comprise more than half—fifty-four percent—of the uninsured.³ People of color are less likely to have private insurance because, not only are they less likely to work in jobs that offer health insurance, but they also tend to be sicker and poorer than white Americans and thus are shut out or priced out of the individual health insurance market.⁴ While Medicaid has been a particularly important source of health insurance for children of color who are more likely to live in poverty, gaps in Medicaid coverage for adults have left most poor minority adults with no place to turn for health insurance.⁵

The ACA's new programs that make insurance more affordable for low- and moderate-income individuals and families who do not have access to employer-sponsored health insurance will particularly help people of color. Of the forty-one million Americans newly eligible for health insurance because of the ACA, 22.7 million, fifty-four percent are people of color.⁶ Sixty percent of the twenty-two million Americans newly eligible for Medicaid are people of color.⁷ Half of the nineteen million uninsured individuals newly eligible for federal tax credits and subsidies to purchase private insurance through the new Health Insurance Exchanges (Exchanges) are people of color.⁸ This means that the design and structure of the ACA's newly expanded Medicaid offerings and Exchange-offered policies are of particular importance to people of color.

DISPARITIES IN HEALTH CARE 83 (Brian D. Smedley, Adrienne Y. Stith & R. Alan Nelson eds. 2003) [hereinafter *UNEQUAL TREATMENT*].

3. U.S. CENSUS BUREAU, HEALTH INSURANCE: CURRENT POPULATION SURVEY (CPS) tbl. H101, http://www.census.gov/hhes/www/cpstables/032011/health/h01_000.htm; see also KAISER FAMILY FOUND., HEALTH REFORM AND COMMUNITIES OF COLOR: IMPLICATIONS FOR RACIAL AND ETHNIC HEALTH DISPARITIES 3 (2010) [hereinafter *COMMUNITIES OF COLOR*].

4. See *UNEQUAL TREATMENT*, *supra* note 2, at 84-87 (stating “African Americans are less likely to possess private or employment-based health insurance relative to white Americans” and Hispanics’ disparities in health insurance “largely results from the lack of job-based insurance.”); see also U.S. DEP’T OF HEALTH & HUMAN SERVS., AGENCY FOR HEALTHCARE RESEARCH & QUALITY, 2010 NATIONAL HEALTHCARE DISPARITIES REPORT 4 (2011) (stating in core measures that Hispanics received worse care in sixty percent of core measures and blacks, American Indians, and Alaska Natives received worse care in forty percent of core measures).

5. See KAISER COMM’N ON MEDICAID & THE UNINSURED, KAISER FAMILY FOUND., EXPANDING HEALTH COVERAGE FOR LOW-INCOME ADULTS FILLING THE GAPS IN MEDICAID ELIGIBILITY 1 (2009) (stating that parent eligibility levels are below poverty in thirty-four states and could be an “effective” and “efficient” tool for expanding coverage) [hereinafter *EXPANDING COVERAGE*].

6. See *id.* at 4, 6 (comparing and combining the number of Americans and people of color who will be newly covered by Medicaid and private insurance).

7. *COMMUNITIES OF COLOR*, *supra* note 3, at 8.

8. *Id.* at 6.

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Attending to issues of race and equity in this time of health insurance expansion and reform is critical because, in America, health insurance and health care remain racially and ethnically segregated with one health care system serving disproportionately white patients with private insurance and a different “safety net” system serving minority patients with Medicaid and the uninsured.⁹ Private health insurers and health care providers rely on a variety of business practices that operate to segregate and exclude minority patients from mainstream medical care.¹⁰ These policies may not have the intent of discriminating on the basis of race and ethnicity – in fact, most are motivated by economic and profit maximization concerns – but they operate to disproportionately exclude and segregate people of color.¹¹ For example, health insurers avoid selling private plans in minority neighborhoods because residents tend to be sicker, less educated, poorer, and thus, they are more risky to insure.¹² Health care providers avoid locating in minority neighborhoods due to the higher percentages of uninsured residents.¹³ Health insurers offer one set of plans and networks to privately insured patients and a different set for those with Medicaid.¹⁴ Most private physicians either refuse outright to treat Medicaid patients or restrict the number of Medicaid patients they accept.¹⁵

Because the ACA continues the tradition of Medicaid for the poor and a variety of private insurance offerings for wealthier Americans, it has the potential to perpetuate America’s dual track medical care with one system serving mostly white patients with private insurance and a different system for poorer, mostly minority patients with Medicaid. In fact, the ACA may exacerbate this two-tier system by creating a third tier of moderate-income Americans, half of whom are people of color, who obtain their health insurance through the new Exchanges using federal tax credit subsidies. By maintaining multiple sources of health insurance, the ACA may serve to reinforce and further segregate patients along racial lines. Similarly, the ACA’s commitment to expanding the number and capacity of community health

9. See UNEQUAL TREATMENT, *supra* note 2, at 110.

10. *Infra* text accompanying notes 83-86.

11. *Id.*

12. *Id.*

13. *Id.*

14. *Infra* text accompanying note 76.

15. See Sara Rosenbaum et al., *Civil Rights in a Changing Health Care System*, 16 HEALTH AFF. 90, 94 (1997) (discussing how market industry practices, including refusing to care for Medicaid enrollees, has perpetuated discrimination).

centers and other alternative providers may reinforce the racial segregation that has emerged over the last thirty years in which special “safety net” providers serve minority neighborhoods while mainstream providers operate in more affluent white communities.¹⁶

The Act contains an important new provision specifically aimed at documenting racial disparities, including racial segregation in health insurance and health care delivery.¹⁷ The ACA requires that federally funded health insurers and health care providers collect and report data about the race, ethnicity, and language of the patients they serve.¹⁸ While data collection is necessary—and long overdue—to document the extent of racial segregation in health insurance and delivery, reporting alone is unlikely to eliminate racial and ethnic segregation in health care, even when combined with the ACA’s new health insurance coverage provisions and workforce initiatives.¹⁹

16. See Patient Protection and Affordable Care Act (ACA), Pub. L. No. 111-148, § 10503, 124 Stat. 119 (2010) (codified as amended at 42 U.S.C. § 18001 (2006)) (establishing a fund that provides \$11 billion over the next five years to expand community health centers); see also KAISER FAMILY FOUND., COMMUNITY HEALTH CENTERS: OPPORTUNITIES AND CHALLENGES OF HEALTH REFORM 3 (2010) (explaining that health centers are important in serving uninsured and low-income patients). The ACA also provides for expanded loan repayment programs, training grants, and expansions of the National Health Service Corp to recruit primary care providers, nurses, mental health professionals, dentists and dental hygienists, and public health workers to medically underserved areas. ACA § 5207.

17. See ACA § 4302(a).

18. The ACA also requires the establishment of uniform categories to be used in the collection of race, ethnicity, sex, and primary language for federally funded health care and health-related activities. *Id.* The law also requires, to the extent practical, that all federally funded population surveys collect enough data to allow for reliable reporting of racial and ethnic subgroups. *Id.* The provisions will greatly improve the ability to document racial and ethnic disparities, especially among some of the smaller population groups who are typically either excluded from survey findings or grouped as “Other.” See SUBCOMM. ON STANDARDIZED COLLECTION OF RACE/ETHNICITY DATA FOR HEALTHCARE QUALITY IMPROVEMENT, BD. ON HEALTH CARE SERVS., INST. OF MED., RACE, ETHNICITY, AND LANGUAGE DATA: STANDARDIZATION FOR HEALTH CARE QUALITY IMPROVEMENT xi-xii (explaining the shortcomings of previous data collection and reporting and recommending many of the provisions that are included in the ACA).

19. Since 2003, the Agency for Healthcare Research and Quality has produced, under a Congressional mandate, a National Healthcare Disparities Report, which shows that as far as access to health care, the gap between whites and people of color is growing. AGENCY FOR HEALTHCARE RESEARCH & QUALITY, U.S. DEP’T OF HEALTH & HUMAN SERVS., NAT’L HEALTHCARE DISPARITIES REPORT 1 (2010). There was no improvement shown on 70% of its core measures and 40% were getting worse. *Id.* at 6. In 2010, the Agency for Healthcare Research and Quality (AHRQ) reported that blacks, American Indians, and Alaska Natives received worse care than whites for about forty percent of the agency’s list of core measures, including timely mammography screenings and recommended hospital care for heart attack patients. *Id.* at 4. The disparities were even greater for Hispanics and Latinos who received worse care than non-Hispanic whites for about sixty percent of the core measures. *Id.* AHRQ concludes that overall health care disparities are improving, but the improvements are very slow and not uniform. *Id.* at 28. Since 2007, inpatient care for people with heart failure has actually grown worse for Hispanics or Latinos, Native Americans, and Alaskan Natives. *Id.* at 77.

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Civil rights protections provide a unique mechanism for identifying and redressing racial and ethnic segregation in American health care. In the language of civil rights law, much of the health care segregation along racial lines results from “facially neutral policies and practices that have a disproportionate adverse racial and ethnic impact.”²⁰ The practices and policies that exclude minority patients are “facially neutral” because they do not mention race. Nevertheless, they have a disproportionate racial impact, because the policies impact racial and ethnic minorities differently than other groups.

The ACA includes a broad new health care specific civil rights mandate: Section 1557 prohibits health insurers and health care providers from discriminating on the basis of race and ethnicity along with gender, disability, and age.²¹ This new antidiscrimination protection prohibits not only intentional discrimination but also facially neutral policies and practices that have an unjustified disproportionate racial impact, including those that segregate along racial lines.²² While Title VI of the 1964 Civil Rights Act has long prohibited federally funded health care providers and Medicaid from using facially neutral policies that have a disproportionate adverse racial impact, Section 1557’s antidiscrimination mandate reaches many more health insurance, health care, and public health activities.²³ It offers an important new antidiscrimination tool for identifying and dismantling health care segregation.

Part I of this Article explains the reach of Title VI and its role in health care. The history of Title VI in the health care context, particularly how Title VI was used to desegregate the nation’s hospitals at the time of the creation of Medicare, offers an important lesson about how combining civil rights initiatives with health insurance expansions provides a powerful tool to create more equitable health care delivery systems. However, the history of Title VI in other areas of health care offers some cautionary tales about why civil rights protections can fall short.

Part II examines Section 1557 of the ACA to show how this new provision expands civil rights protections in the health insurance and health care arenas. Section 1557 extends civil rights coverage to pri-

20. Sidney D. Watson, *Reinvigorating Title VI: Defending Health Care Discrimination—It Shouldn’t Be So Easy*, *FORDHAM L. REV.* 942 (1990) [hereinafter Watson, *Reinvigorating*].

21. ACA § 1557(a).

22. *Id.*

23. *Id.*; see also *infra* text accompanying notes 105-07.

vate insurers and the new Health Insurance Exchanges, filling in gaps in Title VI coverage and removing the fear that enforcing civil rights mandates will push providers out of Medicare and Medicaid. Part III concludes by offering recommendations on how to implement Section 1557's anti-discrimination provisions so that minority Americans are guaranteed more equitable access to health insurance and health care.

The Department of Health and Human Services (HHS) should convene an interagency task force that draws on expertise across HHS's many agencies and involves providers, insurers, and minority communities in formulating specific compliance standards for Section 1557. Broad statements prohibiting facially neutral policies and practices that have an unjustified disparate racial impact do not give health insurers, health care providers, the agency, or courts sufficient guidance on how to strike the proper balance between equity concerns and economic and profit motives. HHS needs to begin an iterative process aimed at producing policy statements, reports, and technical assistance to help the new Exchanges, private insurers, and Medicaid create new insurance products and delivery systems that reduce segregation along racial and ethnic lines. Creating clear, strong, civil rights guidance via Section 1557 is a critical component of implementing the ACA in a way that increases health care equity across racial lines.

I. TITLE VI: THE LIMITS OF PRE-ACA CIVIL RIGHTS REMEDIES IN THE HEALTH CARE ARENA

Prior to the passage of the 1964 Civil Rights Act, hospitals, physicians, and other health care providers openly discriminated against African Americans.²⁴ Most white doctors and dentists refused to treat black patients.²⁵ Hospitals also barred African Americans or segregated them on wards where only African American physicians and support staff provided care.²⁶ Nursing homes, too, were racially segregated.²⁷ Federal policies supported this segregation through awards of federal Hill Burton Act hospital and nursing home construction money to segregated facilities.²⁸

24. See DAVID BARTON SMITH, *HEALTH CARE DIVIDED: RACE AND HEALING A NATION* 132 (1999).

25. See Peter B. Bach et al., *Primary Care Physicians Who Treat Blacks and Whites*, 351 *NEW ENG. J. MED.* 575, 575 (2004).

26. SMITH, *supra* note 24, at 27.

27. *Id.*

28. See David Barton Smith, *Racial and Ethnic Health Disparities and the Unfinished Civil Rights Agenda*, 24 *HEALTH AFF.* 317, 319 (2005); see also *Simkins v. Moses H. Cone Mem'l*

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Congress passed Title VI of the 1964 Civil Rights Act, in part, to ensure that federal money could no longer be used to support segregated health care.²⁹ Its operative section provides, “No person in the United States shall, on the ground of race, color, or national origin, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.”³⁰

Title VI prohibits discrimination in any “program or activity” that receives “[f]ederal financial assistance.”³¹ Title VI defines “program or activity” broadly so that Title VI generally prohibits discrimination throughout an entire public agency, business, or corporation if “any part” receives federal financial assistance.³² The purpose of Title VI is to ensure that these recipients of federal money do not discriminate in providing services, money, or goods to the ultimate beneficiaries of the programs.³³ It does not apply to employment practices, except where a primary objective of the federal financial assistance is to provide employment.³⁴ However, the prohibition against discriminatory conduct applies to all persons served by the recipient, regardless of who pays for a particular service.³⁵

“Federal financial assistance” includes direct aid such as grants, loans, and advances of federal funds, as well as indirect aid such as

Hosp., 323 F.2d 959, 969 (4th Cir. 1963) (en banc) (stating that segregated facilities were eligible to receive federal funding as long as they certified that there was a “separate but equal” facility).

29. See 110 Cong. Rec. 1661 (1964); see also SMITH, *supra* note 24, at 101-05.

30. 42 U.S.C. § 2000d (2006).

31. A “recipient” is any public or private entity that receives this federal financial assistance, either directly from the federal government or through another recipient, but does not include the ultimate beneficiaries of the programs that receive federal financial assistance. See 42 U.S.C. § 2000d-4a (defining programs and activity considered to be prohibited from receiving federal financial assistance). For example, state governments that receive federal Medicaid dollars are recipients of federal financial assistance for purposes of Title VI, as are managed care companies and providers who accept state Medicaid payments that include such federal dollars, but not the low-income patients enrolled in Medicaid. *Id.*

32. See 42 U.S.C. § 2000d-4a. For state and local governments only, the department or agency that receives the aid is covered. Where one entity of a state or local government receives federal aid and distributes it to another department, both entities are covered. *Id.* The Supreme Court narrowly interpreted of “program or activity” holding that Title IX did not prohibit discrimination in all educational programs and activities, but only programs and activities specifically receiving federal financial assistance. *Grove City Coll. v. Bell*, 465 U.S. 555, 556 (1984). The Civil Rights Restoration Act of 1988 overturned the Supreme Court’s decision in *Bell*, in which the court limited the reach of the law to only those programs or activities within an institution that directly received the federal funds. See Civil Rights Restoration Act, Pub. L. No. 100-259, § 382, 102 Stat. 28, 28-29 (1988).

33. See 45 C.F.R. § 80.13 (2012) (stating the purpose of Title VI).

34. 42 U.S.C. § 2000d-3.

35. See 42 U.S.C. § 2000d-4a.

Medicare and Medicaid payments.³⁶ While Title VI defines federal financial assistance in very broad terms to include federal money awarded through grants, loans, or contracts, the statutory language exempts federal “contracts of insurance or guaranty.”³⁷

Title VI does not define prohibited discrimination, but its implementing regulations prohibit both intentional acts of discrimination and activities that are neutral on their surface but have a discriminatory effect.³⁸ The regulations prohibit recipients of federal funds from

36. See 45 C.F.R. § 80.13(f) (“[Federal financial assistance includes] (1) grants and loans of Federal funds, (2) the grant or donation of Federal property and interests in property, (3) the detail of Federal personnel, (4) the sale and lease of, and the permission to use (on other than a casual or transient basis), Federal property or any interest in such property without consideration or at a nominal consideration, or at a consideration which is reduced for the purpose of assisting the recipient, or in recognition of the public interest to be served by such sale or lease to the recipient, and (5) any Federal agreement, arrangement, or other contract which has as one of its purposes the provision of assistance.”). The regulations also include a non-exclusive list of more than fifty types of health care and public health grant programs that receive federal financial assistance for purposes of Title VI coverage including primary care, mental health and substance abuse treatment funding, loans and loan guarantees for hospitals and other medical facilities, and research and education grants. See 45 C.F.R. § 80 app. A; see also Dep’t of Health & Human Servs., Guidance to Federal Financial Assistance Recipients Regarding Title VI Prohibition Against National Origin Discrimination Affecting Limited English Proficient Persons, 68 Fed. Reg. 47,311 (Aug. 8, 2003) [hereinafter HHS Guidance on LEP]. See generally 42 C.F.R. § 438.100(d) (2002) (implying that Title VI is applicable to Medicaid managed care plans). Courts have consistently found that health care providers who accept Medicaid or Medicare Part A payments are recipients of federal financial assistance. See *Bowen v. Am. Hosp. Ass’n*, 476 U.S. 610, 624 n.9 (1986) (affirming that the hospital was the recipient of “financial assistance” through its participation in Medicare and Medicaid programs); *Fobbs v. Holy Cross Health Sys. Corp.*, 29 F.3d 1439, 1447 (9th Cir. 1994) (explaining that the entity is required to show that it is receiving federal financial assistance); *United States v. Harris Methodist Fort Worth*, 970 F.2d 94, 100 (5th Cir. 1992) (finding that the anti-discrimination provisions of Title VI apply to staff privileges at the hospital receiving federal funds); *Frazier v. Bd. of Trs. of Nw. Miss. Reg’l Med. Ctr.*, 765 F.2d 1278, 1289 (5th Cir. 1985); *United States v. Baylor Univ. Med. Ctr.*, 736 F.2d 1039, 1046 (5th Cir. 1984) (discussing cases where the courts have concluded that hospitals receiving Medicare must abide by discrimination statutes); *Rackley v. Bd. of Trs. of Orange Burg Reg’l Hosp.*, 238 F. Supp. 512, 519-20 (E.D.S.C. 1965) (holding that state or private hospitals receiving federal funds are bound by Title VI).

37. 42 U.S.C. § 2000d-1; see also § 2000d-4 (“[Title VI] shall [not] add to or detract from any existing authority with respect to any program or activity under which Federal financial assistance is extended by way of a contract of insurance or guarantee.”). Implementing regulations define federal financial assistance. See 45 C.F.R. § 80.13(f) “[Federal financial assistance includes] (1) grants and loans of Federal funds, (2) the grant or donation of Federal property and interests in property, (3) the detail of Federal personnel, (4) the sale and lease of, and the permission to use (on other than a casual or transient basis), Federal property or any interest in such property without consideration or at a nominal consideration, or at a consideration which is reduced for the purpose of assisting the recipient, or in recognition of the public interest to be served by such sale or lease to the recipient, and (5) any Federal agreement, arrangement, or other contract which has as one of its purposes the provision of assistance.”).

38. See 34 C.F.R. § 100.3(b)(2) “[one may not use] criteria or methods of administration which have the effect of subjecting individuals to discrimination because of their race, color, or national origin, or have the effect of defeating or substantially impairing accomplishment of the objectives of the program as respect individuals of a particular race, color, or national origin.”).

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subjecting persons to segregation or separate treatment on the basis of race or from establishing facility locations with discriminatory effects. The regulations also require recipients of federal funds to take affirmative action to overcome the effects of prior discrimination.³⁹ While the Supreme Court has held that Title VI itself forbids only intentional discrimination, the Court has also held that these regulations prohibiting neutral policies with an unjustified disparate impact are valid and enforceable by federal agencies.⁴⁰

Unlike the other titles of the 1964 Civil Rights Act, Title VI relies primarily on administrative action rather than judicial enforcement and only provides expressly for administrative remedies.⁴¹ The Supreme Court has held that individuals have an implied private right of action to pursue judicial claims of intentional discrimination, but only the agency can enforce claims of disparate impact.⁴²

The Health and Human Services Office for Civil Rights (HHS/OCR) has primary responsibility for ensuring that federally funded health care providers comply with Title VI.⁴³ The federal agencies that award federal financial assistance may refuse to grant funds or terminate funding to any recipient found in violation of Title VI regulations after an opportunity for an administrative hearing.⁴⁴ While a recipient of federal funds may not discriminate in any of its activities, the administrative sanction for a violation is termination of federal funds, only to the “particular program, or part thereof, in which such noncompliance has been so found.”⁴⁵

Early on, the Supreme Court ruled that national origin includes discrimination based upon limited English language ability. *See Lau v. Nichols*, 414 U.S. 563, 568 (1974).

39. 34 C.F.R. § 100.3(b)(4) (establishing facility locations for services supported by federal assistance in which discrimination is barred); *Id.* § 100.3(b)(6)(i) (explaining that the recipient who has previously discriminated against persons on prohibited grounds must take affirmative action to overcome the prior effects of discrimination).

40. *See Alexander v. Sandoval*, 532 U.S. 275, 293 (2001) (holding that no private right of action exists to enforce disparate impact claims); *Guardians Ass’n v. Civil Serv. Comm’n*, 463 U.S. 582, 608 n.1 (1983) (discussing that Title VI reaches only intentional discrimination, but the regulations reaching disparate impact claims are valid). For a history of the case law upholding these regulations, see Watson, *Reinvigorating*, *supra* note 20, at 948-55.

41. *See generally* 42 U.S.C. § 2000d-2 (speaking on the remedies for enforcement).

42. *See Alexander*, 532 U.S. at 300 (Stevens, J., dissenting); *Guardians Ass’n*, 463 U.S. at 608-09.

43. *Civil Rights*, U.S. DEP’T OF HEALTH & HUM. SERVS., <http://www.hhs.gov/ocr/civilrights/index.html> (last visited Apr. 11, 2012) (stating that OCR promotes and ensures compliance with civil rights laws).

44. *See* 42 U.S.C. § 2000d-1.

45. *Id.*

When Title VI was signed into law on July 2, 1964, little federal money flowed into health care.⁴⁶ Federal funding was limited to Hill-Burton construction grants and loans to hospitals, nursing homes, academic medical centers, and a few state and local health activities.⁴⁷ One year later, in 1965, Congress enacted Medicare and Medicaid, creating massive new federal financial assistance for health care.⁴⁸

The Johnson Administration decided to use Title VI along with the sudden infusion of substantial and new federal Medicare dollars to desegregate the nation's hospitals.⁴⁹ In the four-month period between March 4, 1966 and July 1, 1966, more than 6,500 hospitals—over ninety-two percent of American hospitals—integrated.⁵⁰ Not only were the visible signs of segregation removed, such as the “white only” signs, but hospital waiting rooms, operating rooms, wards, and beds were integrated in fact, as well as in theory.⁵¹ Patients could no longer be asked upon admission whether they minded being assigned to a room with a patient of another race, and admissions officials were required to assign patients in a race-blind way.⁵²

This transformation came about through the efforts of a small, interagency task force working alongside community leaders and grass-roots organizations.⁵³ The initiative was led by a small staff in the former Office for Equal Health Opportunity of the old U.S. Department of Health, Education, and Welfare (HEW) supplemented by volunteers from other parts of the department.⁵⁴ At the community level, chapters of the NAACP, the National Medical Association, and local coalitions served as the local eyes and ears of the effort.⁵⁵

The Title VI hospital desegregation campaign's success can be attributed to the confluence of a number of factors. First, the financial incentives were clear and strong.⁵⁶ The new federal Medicare payments were generous and thus essential to the future of these hospi-

46. See SMITH, *supra* note 24, at 243.

47. *Id.* at 106-110, 115.

48. *Id.* at 110-15.

49. *Id.* at 141.

50. *Id.*

51. *Id.* at 137.

52. *Id.* at 320.

53. See *id.*

54. Smith, *supra* note 28, at 319.

55. *Id.* at 320.

56. Sidney D. Watson, *Race, Ethnicity and Quality of Care: Inequalities and Incentives*, 27 AM. J.L. & MED. 203, 215 (2001) [hereinafter Watson, *Race, Ethnicity and Quality of Care*].

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tals.⁵⁷ Second, the government's civil rights demands were unambiguous and easily verifiable.⁵⁸ Therefore, "hospitals understood what was expected of them and compliance monitors did not have to work hard to ensure integration."⁵⁹ Third, the "effort was entirely forward-looking." Participation in the new Medicare program was conditioned on compliance with new civil rights certification.⁶⁰ "No questions were asked about past behavior," but the federal money did not start flowing until compliance was verified.⁶¹

While the hospital desegregation campaign profoundly changed American health care, the Johnson Administration's decisions to ignore other aspects of health care segregation have left a lasting legacy, which contributes to today's racial and ethnic disparities in health care. First, the Johnson Administration gave both nursing homes and physicians who accepted Medicaid a pass on Title VI compliance.⁶² As long as nursing homes and physicians signed statements stating they would not discriminate and did not flaunt their discriminatory practices, the agency made no effort to monitor actual compliance.⁶³ Even as HHS insisted that hospitals desegregate, it did not question nursing homes that excluded black patients altogether or segregated them in separate rooms or wings.⁶⁴ Neither did the agency confront Medicaid physicians who refused outright to treat black patients, racially segregated their practices, or restricted their Medicaid patients in a way that screened out black patients.⁶⁵

Second, HEW took a particularly hands-off approach with other physicians: the agency opted to exempt from Title VI altogether private physicians who accepted only Medicare but not Medicaid.⁶⁶ The HEW Office for Civil Rights concluded that Medicare Part B was a "contract of insurance" with seniors rather than a grant of federal financial assistance to providers as are Medicare Part A and Medicaid.⁶⁷ The American Medical Association (AMA) lobbied

57. See SMITH, *supra* note 24, at 214-15 (addressing the strategy of the Johnson Administration for getting hospitals to desegregate and stop discriminating through the Medicare program).

58. *Id.* at 216.

59. *Id.*

60. *Id.* at 215-16.

61. *Id.*

62. Smith, *supra* note 28, at 322.

63. SMITH, *supra* note 24, at 159-60.

64. *Id.* at 159-61.

65. *Id.* at 162.

66. Smith, *supra* note 28, at 322.

67. *Id.* Title VI specifically excludes "contracts of insurance or guaranty" from federal financial assistance. *Id.* This language was specially included to exempt federal bank deposit

vigorously for HEW to adopt this analysis, and HEW's original decision is best explained as politically motivated rather than well reasoned.⁶⁸ The agency concluded that Medicare Part B operated as indemnity insurance with the patient paying the doctor and then seeking repayment from Medicare.⁶⁹ HEW's reasoning ignored the fact that even in the early days of Medicare Part B, physicians could opt to get paid directly by Part B rather than via the patient, and it certainly ignores the reality of today's Medicare Part B in which almost all physicians who participate in Medicare get paid directly just like hospitals.⁷⁰

These early Title VI non-enforcement decisions have cast a long shadow contributing to continuing racial segregation in America's health care delivery system. Nursing homes still tend to be racially identified as either white or black.⁷¹ Physician care continues to be more racially separate than hospital care, and contributes to persistent racial disparities regarding who gets referred for diagnostic and specialty procedures.⁷² African Americans and Hispanics, regardless of insurance coverage, are almost twice as likely as whites to get outpatient physician care from safety net providers like hospital-based clinics and emergency rooms.⁷³ These hospital-based providers tend to be characterized by rotating physicians and lack of continuity of care.

insurance because some southern senators were concerned that Title VI might be used to block mortgages for racially discriminatory housing. *Id.* ("The Fair Housing Act of 1968 rendered this concession irrelevant."). Similar language, excluding "contracts of insurance or guaranty," is included in Section 504 of the Rehabilitation Act of 1973, the Age Discrimination Act, and Title IX of the Education Amendments of 1972. 42 U.S.C. § 6103(a)(4) (2006); 20 U.S.C. § 1682 (2006); 29 U.S.C. § 794 (2006); *see also* 42 U.S.C. § 2000d-4 (defining programs or activities for purposes of federal financial assistance).

68. *See, e.g.,* Smith, *supra* note 28, at 322 (noting that HEW's decision "makes no sense in today's context").

69. *Id.*

70. Daniel J. Gottlieb et al., *Prices Don't Drive Regional Medicare Spending Variations*, 29 HEALTH AFF. 537, 538 (2010). Nevertheless, HHS still maintains that Medicare Part B payments are not federal financial assistance for purposes of Title VI. *See* HHS Guidance on LEP, *supra* note 36, at 47,000,313. While the continuing exclusion of Medicare Part B from Title VI federal financial assistance is less important today because of the recent growth in Medicare Advantage plans, this reach of Title VI to most physician practices is a very new occurrence. Vernellia R. Randall, *Perspective: Title VI, Healthcare Reform and the Need for a State Antidiscrimination Law*, in HEALTHCARE DISPARITIES AT THE CROSSROADS WITH HEALTHCARE REFORM 313, 315 (Richard Allen Williams ed., 2011).

71. Rudqaiijah Yearby, *Striving for Equality, But Settling for the Status Quo in Health Care: Is Title VI More Illusory Than Real?*, 59 RUTGERS L. REV. 429, 454 (2007).

72. *See* Bach et al., *supra* note 25, at 575 (stating that minorities are significantly more likely to report problems accessing specialty care).

73. HOLLY MEAD ET AL., THE COMMONWEALTH FUND, RACIAL AND ETHNIC DISPARITIES IN U.S. HEALTH CARE: A CHARTBOOK 48 (2008), available at http://www.commonwealthfund.org/usr_doc/mead_raceethnicdisparities_chartbook_1111.pdf.

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This means that minority patients are less likely to have an ongoing relationship with a primary care provider who can serve as an advocate to ensure patients receive specialty care, to help patients negotiate the intricacies of insurance pre-approval requirements, or simply to understand patients' treatment preference.⁷⁴

The advent of Medicaid managed care offered the potential for reducing health care segregation along racial and ethnic health lines because private insurers began organizing networks of providers that could serve both their privately insured and Medicaid patients.⁷⁵ However, health insurers created multiple networks, segmenting their plans to offer different networks of providers to privately insured and Medicaid enrollees.⁷⁶ Insurers also acted quickly to keep their private insurance offerings outside the reach of Title VI by creating separate corporate entities to sponsor Medicaid managed care.⁷⁷

Moreover, a whole array of business practices that have become standard operating procedures for providers and insurers have a disproportionate adverse impact on minority patients and tend to segregate treatment on the basis of race.⁷⁸ Many of these policies are rooted in providers' economic decision to avoid treating the uninsured and lower paying Medicaid patients.⁷⁹ Others arise from insurers' attempts to avoid those who are likely to be sicker.⁸⁰

74. UNEQUAL TREATMENT, *supra* note 2, at 154-55.

75. See Rosenbaum et al., *supra* note 15, at 98.

76. See, e.g., *UnitedHealthcare Dual Complete (HMO SNP)*, UNITED HEALTHCARE, <http://www.uhccommunityplan.com/plan/details/MO/166/MEDICARE/plan-details> (last updated Nov. 18, 2011) (outlining health insurance offerings for those claiming dual eligibility under Medicare and Medicaid to enroll, including eligible Missouri counties and a link to Benefit details); see also KAISER COMM'N ON MEDICAID & THE UNINSURED, KAISER FAMILY FOUND., EXPANDING HEALTH COVERAGE FOR LOW-INCOME ADULTS FILLING THE GAPS IN MEDICAID ELIGIBILITY 1 (2009); cf. *Health Plans*, UNITED HEALTHCARE, http://www.uhc.com/employers/health_plans/group_coverage/choice_plus.htm (last visited Apr. 11, 2012) (listing Missouri's United Healthcare private group health plan options—all with different names, coverage areas, and prices than the dual eligible insurance plan). Medicaid policy's focus on maintaining access to traditional safety net providers is important to avoid disrupting long-standing treatment relationships and to avoid segmenting networks; offering different networks to privately and publicly insured patients reinforces the long-standing segregated patterns of healthcare where one set of providers tends to serve white patients, and a different set tends to serve minority patients. KAISER COMM'N ON MEDICAID & THE UNINSURED, KAISER FAMILY FOUND., *supra*.

77. *Id.*

78. See UNEQUAL TREATMENT, *supra* note 2, at 8 (suggesting that the manner in which health systems are organized, financed, and their availability of services particularly affect minorities).

79. *Id.* at 397.

80. See Kenneth J. Arrow, *Uncertainty and the Welfare Economics of Medical Care*, 53 AM. ECON. REV. 941, 961 (1963).

Physicians and hospitals both tend to avoid minority neighborhoods because residents tend to be poorer and more likely to be either uninsured or covered by Medicaid.⁸¹ Physicians tend to avoid Medicaid patients primarily, but not exclusively, because reimbursement rates are often lower than for privately insured and Medicare patients.⁸²

Health plans tend to avoid selling their private insurance products to minorities who are likely to be sicker and therefore riskier to insure.⁸³ Insurers designate their service areas to avoid inner city areas with high concentrations of minority patients in favor of suburban areas with lower proportions of minority residents.⁸⁴ They also avoid advertising in minority areas to avoid attracting minorities.⁸⁵ Health plans have also discriminated against minority physicians and other providers who have traditionally served minority patients by either refusing to contract with them altogether or admitting them to their Medicaid network but not to the network serving privately insured patients.⁸⁶

The hotly debated—and still unresolved—Title VI issue is the extent to which such economically motivated policies and practices should be allowed to justify policies that have an adverse impact on minority patients.⁸⁷ Title VI regulations prohibit policies and practices that have a discriminatory effect, but not every practice that tends to exclude minority patients violates Title VI. There is no Title VI violation even if a health care provider or insurer's neutral policy has a disparate racial impact when the policy has a "manifest relation-

81. HEALTHY, WEALTHY, AND FAIR: HEALTH CARE AND THE GOOD SOCIETY 79 (James A. Morone & Lawrence R. Jacobs eds., 2005).

82. PETER CUNNINGHAM & JESSICA MAY, CTR. FOR STUDYING HEALTH SYS. CHANGE, MEDICAID PATIENTS INCREASINGLY CONCENTRATED AMONG PHYSICIANS 1 (2006), available at <http://www.hschange.com/CONTENT/866/866.pdf>.

83. See Rosenbaum et al., *supra* note 15, at 94-95.

84. *Id.* Such redlining is typically motivated by a desire to avoid minority populations because they tend to have more health problems and thus need more healthcare, making them financially more risky for health plans to insure, but it has a disproportionate racial impact on minorities' access to health insurance. See *id.*

85. *Id.* (demonstrating no evidence of this behavior); see *id.* at 96. Just as health insurers advertise their insurance in health clubs and other locations where they are likely to capture younger, healthier enrollees, they avoid advertising in neighborhoods where sicker individuals likely live; cf. *id.*

86. *Id.* at 98.

87. See Watson, *Reinvigorating*, *supra* note 20, at 964-66.

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ship” to program objectives, meaning the policy is vitally necessary and there is no less discriminatory means to achieve its objective.⁸⁸

However, HHS/OCR does not routinely collect data on minority health care access and treatment to monitor the extent of racial segregation or individual providers’ or insurers’ Title VI compliance.⁸⁹ For two decades, during the Reagan and first Bush Administrations, HHS/OCR limited its enforcement efforts to respond to individual complaints of discrimination and pursued only claims of intentional discrimination.⁹⁰ While HHS/OCR now investigates complaints of disparate impact discrimination, the regulatory standards provide only general standards, which means that individual compliance actions can be protracted affairs with much wrangling over how the regulations are to be interpreted in practice.⁹¹ Without the guidance that comes from more specific compliance directives, HHS/OCR does not have the resources to pursue large numbers of compliance actions because they require detailed factual investigations and an unstructured analysis of the competing financial and equity considerations.⁹²

As the health care delivery system and health insurance have evolved over the last forty-five years, HHS has generally failed to provide the kind of clear, specific compliance instructions that set the tone and expectations for the 1966 hospital desegregation campaign and that would provide guidance on how to balance Title VI’s nondiscrimination mandate with economic considerations. Without clear standards, Title VI compliance has languished, and the health care delivery and insurance system has evolved into a fragmented, racially segregated system.

With the passage of the ACA, the nation stands, like it did in 1965, on the verge of a new era. The ACA authorizes the creation of new entities in 2014 that will make health insurance available to all and bring a massive new influx of federal money into health insurance

88. *See id.* at 955-57 (explaining that (1) the plaintiff must identify a particular racially neutral policy or practice that has a statistically significant adverse effect on a protected racial or ethnic group, and (2) if plaintiff establishes a prima facie case, defendant must establish a legitimate, nondiscriminatory reason for the policy or practice).

89. *See* UNEQUAL TREATMENT, *supra* note 2, at 21-22; *see also* Madison-Huges v. Shalala, 80 F.3d 1121, 1123 (6th Cir. 1996) (alleging that HHS/OCR violated Title VI by failing to require health care providers to routinely report race and ethnicity data).

90. *See generally* COMMITTEE ON GOV’T OPERATIONS, INVESTIGATION OF THE OFFICE FOR CIVIL RIGHTS IN THE DEPARTMENT OF HEALTH AND HUMAN SERVICES (1987).

91. *See* Watson, *Race, Ethnicity, and Quality of Care*, *supra* note 56, at 219-21.

92. *See generally* SMITH, *supra* note 24 (discussing discrimination in healthcare and strategies for ending such discrimination).

and care. This new federal authority and new federal dollars create the opportunity for the Administration to provide the same kind of bold leadership that the Johnson Administration showed in 1965 when it placed clear demands on hospitals to change old patterns of segregation. Just as importantly, the ACA creates new civil rights tools that reach more areas of health care and health insurance.

II. SECTION 1557: THE ACA'S ANTI-DISCRIMINATION PROVISION

Section 1557 of the ACA creates a new health-specific anti-discrimination prohibition that reaches further than Title VI, prohibiting discrimination not only in federally funded health programs but also federally administered health programs and new ACA-authorized entities like Exchanges.⁹³ Section 1557 does not merely extend Title VI to additional health programs; it creates a new civil right and remedy while leaving in place Title VI and other existing civil rights laws.⁹⁴ Section 1557 relies on familiar language from Title VI and other federal civil rights statutes that have established legal meanings, which is evidence of the Congressional intent that this new civil rights statute is to prohibit both intentional and disparate impact discrimination.⁹⁵

Section 1557, like many sections of the ACA, is not a model of drafting clarity. It provides in total:

Section 1557: Nondiscrimination

(a) IN GENERAL.—Except as otherwise provided for in this title (or an amendment made by this title), an individual shall not, on the

93. ACA, 42 U.S.C. § 18116 (2006).

94. Part (b) provides as follows:

(b) CONTINUED APPLICATION OF LAWS.—Nothing in this title (or an amendment made by this title) shall be construed to invalidate or limit the rights, remedies, procedures, or legal standards available to individuals aggrieved under title VI of the Civil Rights Act of 1964 (42 U.S.C. 2000d et seq.), title VII of the Civil Rights Act of 1964 (42 U.S.C. 2000e et seq.), title IX of the Education Amendments of 1972 (20 U.S.C. 1681 et seq.), section 504 of the Rehabilitation Act of 1973 (29 U.S.C. 794), or the Age Discrimination Act of 1975 (42 U.S.C. 611 et seq.), or to supersede State laws that provide additional protections against discrimination on any basis described in subsection (a).

Id.

95. *Id.* § 1557(b).

Nothing in this title (or an amendment made by this title) shall be construed to invalidate or limit the rights, remedies, procedures, or legal standards available to individuals aggrieved under title VI of the Civil Rights Act of 1964 (42 U.S.C. 2000d et seq.), title VII of the Civil Rights Act of 1964 (42 U.S.C. 2000e et seq.), Title IX of the Education Amendments of 1972 (20 U.S.C. 1681 et seq.), section 504 of the Rehabilitation Act of 1973 (29 U.S.C. 794), or the Age Discrimination Act of 1975 (42 U.S.C. 611 et seq.), or to supersede State laws that provide additional protections against discrimination on any basis described in subsection (a).

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ground prohibited under title VI of the Civil Rights Act of 1964 (42 U.S.C. 2000d et seq.), title IX of the Education Amendments of 1972 (20 U.S.C. 1681 et seq.), the Age Discrimination Act of 1975 (42 U.S.C. 6101 et seq.), or section 504 of the Rehabilitation Act of 1973 (29 U.S.C. 794), be excluded from participation in, be denied the benefits of, or be subjected to discrimination under, any health program or activity, any part of which is receiving Federal financial assistance, including credits, subsidies, or contracts of insurance, or under any program or activity that is administered by an Executive Agency or any entity established under this title (or amendments). The enforcement mechanisms provided for and available under such title VI, title IX, section 504, or such Age Discrimination Act shall apply for purposes of violations of this subsection.

(b) CONTINUED APPLICATION OF LAWS.—Nothing in this title (or an amendment made by this title) shall be construed to invalidate or limit the rights, remedies, procedures, or legal standards available to individuals aggrieved under title VI of the Civil Rights Act of 1964 (42 U.S.C. 2000d et seq.), title VII of the Civil Rights Act of 1964 (42 U.S.C. 2000e et seq.), title IX of the Education Amendments of 1972 (20 U.S.C. 1681 et seq.), section 504 of the Rehabilitation Act of 1973 (29 U.S.C. 794), or the Age Discrimination Act of 1975 (42 U.S.C. 611 et seq.), or to supersede State laws that provide additional protections against discrimination on any basis described in subsection (a).

(c) REGULATIONS.—The Secretary may promulgate regulations to implement this section.⁹⁶

Section 1557's textual density is the byproduct of its tendency to cross reference to Title VI and three other existing civil rights laws: Title IX, which prohibits sex discrimination in federally funded school activities;⁹⁷ the Age Discrimination Act of 1975, which prohibits age discrimination in federally funded programs;⁹⁸ and Section 504 of the Rehabilitation Act, which prohibits disability discrimination in federally funded programs.⁹⁹ These other three civil rights statutes are modeled on Title VI, and courts have interpreted the terms they have in common, *in pari materia*, as having the same legal meaning.¹⁰⁰

96. *See id.* § 1557.

97. 20 U.S.C. § 1681(a) (2006).

98. 42 U.S.C. § 6101 (2006). This provision should not be confused with the Age Discrimination in Employment Act which prohibits discrimination in employment for persons over the age of forty. Age Discrimination in Employment Act of 1967, 29 U.S.C. § 631(a) (2006).

99. 29 U.S.C. § 794(a).

100. *See, e.g.,* Alexander v. Sandoval, 532 U.S. 275, 280 (2001) (noting that Title IX was modeled on Title VI and parallel language in the two statutes are to be interpreted similarly).

While the House version of health reform legislation would have created a sweeping antidiscrimination mandate prohibiting discrimination on any ground other than “need for medical care,” ACA Section 1557 is more firmly grounded in existing civil rights laws adopting, adapting, and expanding upon Title VI, Title IX, Age Discrimination Act, and Section 504’s protected classes, anti-discrimination language, covered programs and activities, and remedies.

Section 1557 prohibits discrimination based not only on race, ethnicity, and national origin, but also sex, age, or disability.¹⁰¹ The inclusion of sex in Section 1557 is particularly important because while Title VI, Section 504, and the Age Discrimination Act already prohibit race, disability, and age discrimination in federally funded health programs, Title IX only prohibits sex discrimination in federally-funded school activities and does not reach federally funded health programs.¹⁰²

Section 1557 does not define prohibited discrimination but does adopt language from Title VI that is mirrored in Title IX, Section 504, and the Age Discrimination Act, providing that an individual shall not, on the grounds prohibited by the statute be “*excluded from participation in, be denied the benefits of, or be subjected to discrimination under*” any health program or activity.¹⁰³ The use of this familiar language seems to evidence an intent that Section 1557’s anti-discrimination mandate is to be interpreted consistently with that of Title VI, Title IX, Section 504, and Age Discrimination Act, all of which have implemented regulations that prohibit both disparate impact, as well as intentional discrimination.¹⁰⁴

In terms of covered activities, Section 1557 reaches beyond Title VI to prohibit discrimination in three types of health programs and activities: (1) those in which any part is receiving Federal financial assistance, including credits, subsidies, or contracts of insurance, (2)

101. ACA §1557(a) (referencing Title VI, which covers race, color, and national origin; Title IX which covers sex; The Age Discrimination Act of 1975 which covers age; and Section 504 of the Rehabilitation Act which covers disability).

102. Title VII’s prohibition on employment discrimination only reaches sex discrimination in the distribution of employee benefits like health insurance; it does not reach discrimination by providers or non-employer sponsored health insurance. See Mary Crossley, *Discrimination Against the Unhealthy in Health Insurance*, 54 U. KAN. L. REV. 73, 88-94 (2005).

103. See 42 U.S.C. § 12132 (2006); accord 42 U.S.C. § 2000h-2, 29 U.S.C. § 701, 42 U.S.C. § 2000d-2.

104. UNIV. OF CAL., BRIEFING REPORT FOR THE COMMITTEE ON EDUCATIONAL POLICY, RACE, SEX AND DISPARATE IMPACT 3-6 (2008), available at <http://www.universityofcalifornia.edu/regents/regmeet/may08/e2attach.pdf>.

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those administered by an Executive Agency, and (3) those established under Title I of the ACA.¹⁰⁵

Under the first prong, Section 1557 reaches “any health program or activities, *any part of which* is receiving Federal financial assistance.”¹⁰⁶ By adopting the specific language used in Title VI, as well as Title IX, Section 504, and the Age Discrimination Act, Section 1557 indicates that its non-discrimination requirement reaches an entire public agency or institution if any part receives Federal financial assistance.¹⁰⁷

However, the first prong of Section 1557 also provides a more expansive statutory definition of “[f]ederal financial assistance” than does Title VI and its companion civil rights statutes, defining federal financial assistance to include, rather than exclude, “credits, subsidies or contracts of insurance.”¹⁰⁸ This inclusion of “contracts of insurance” makes clear that Section 1557 reaches physicians and other health care providers who accept Medicare Part B insurance, making irrelevant HHS’s specious conclusion that Medicare is an excluded “contract of insurance” for purposes of Title VI.¹⁰⁹ Moreover, Section 1557’s specificity that federal financial assistance includes “credits” and “subsidies” unequivocally establishes that Section 1557’s antidiscrimination mandate covers private insurance companies, physicians, and other providers who will be receiving new federal tax credits and subsidies authorized by the ACA.¹¹⁰

The ACA provides that individuals with incomes between 133% and 400% of the federal poverty level (FPL) will be eligible for federal tax credits that will subsidize premium costs and that those with incomes between 133% and 200% FPL will be eligible for additional tax credits to reduce their out-of-pocket costs.¹¹¹ The federal government will pay the tax credits to qualified insurance plans, and the in-

105. *See* ACA § 1557(a).

106. *See id.*

107. *Id.* This language was added to Title VI, Title IX, Section 504, and the ADA of 1975 by the Civil Rights Restoration Act to overturn a Supreme Court decision narrowly interpreting the reach of Title VI. *See* Civil Rights Restoration Act of 1987, Pub. L. No. 100-259, 102 Stat. 28 (1988).

108. *See* ACA § 1557(a).

109. *See id.*

110. MARY YODELMAN, NAT’L HEALTH LAW PROGRAM, THE ACA AND LANGUAGE ACCESS 4 (2011), *available at* <http://familiesusa2.org/conference/health-action-2012/toolkit/content/pdfs/ACA-language-access.pdf>.

111. *See* ACA §§1401-1412.

surer will reduce the individual's premium and cost sharing by the amount of the federal payment.¹¹²

These new ACA-authorized federal private insurance tax credits and subsidies operate similarly to federal funding for private Medicaid managed care plans, Medicare Advantage plans, or private plans participating in the State Children's Health Insurance Program (SCHIP).¹¹³ In these programs, the private insurer receives federal financial assistance that the insurer then passes along to the providers.¹¹⁴ Under existing Title VI regulations and case law, both the private insurance companies and providers who accept such insurance payments are recipients of federal financial assistance for purpose of Title VI.¹¹⁵ Section 1557's explicit language simply makes clear that this analysis extends to the new federal private insurance tax credits and subsidies the ACA authorizes for purposes of Section 1557 coverage.

The second prong of Section 1557 prohibits discrimination in any health program or activity "administered by an Executive Agency" and is broader than Title VI, which extends only to recipients of federal financial assistance and which courts have interpreted as not reaching federal agencies administering their own programs, like Medicare and Social Security.¹¹⁶ The "administered by an Executive

112. ACA § 1412(a)(3)-(c), (c)(B)(i)-(ii). The ACA makes very clear that these premium tax credits and cost sharing subsidies are payments to private insurance plans and not to the individual. Section § 1415 of the ACA provides:

(1) any credit or refund allowed or made to any individual by reason of [the premium tax credit authorized by ACA Section 1401]. . . shall not be taken into account as income and shall not be taken into account as resources for the month of receipt and the following 2 months; and (2) any cost sharing reduction payment or advance payment of credit [for cost sharing authorized by ACA §1402 and 1412] shall be treated as made to the qualified health plan in which an individual is enrolled and not to that individual.

Id. § 1415.

113. Compare FAMILIES USA, LOWER TAXES, LOWER PREMIUMS: THE NEW HEALTH INSURANCE TAX CREDIT 6 (2010), available at <http://www.familiesusa.org/assets/pdfs/health-reform/Premium-Tax-Credits.pdf>, with CTRS. FOR MEDICARE & MEDICAID SERVS., MEDICARE & YOU, 26-27 (2012), available at <http://www.medicare.gov/Publications/Pubs/pdf/10050.pdf> [hereinafter MEDICARE & YOU] (both outlining their structure so that financing goes first to the insurance company).

114. See MEDICARE & YOU, *supra* note 113, at 26-27 (outlining structure by which federal financing goes first to the insurance company).

115. See MARA YODELMAN, THE ACA AND APPLICATION OF § 1557 AND TITLE VI OF THE CIVIL RIGHTS ACT OF 1964 TO THE HEALTH INSURANCE EXCHANGE, NATIONAL HEALTH LAW PROGRAM 3-4 (2011), available at http://www.healthlaw.org/index.php?option=com_content&view=article&id=511:health-reform-short-papers&catid=51.

116. See *Soberal-Perez v. Heckler*, 717 F.2d 36, 38-39 (2d Cir. 1983) (concluding that Title VI does not apply to programs directly administered by the federal government but only those where federal funding is given to a non-federal entity which, in turn, provides financial assistance to the ultimate beneficiary); see also *Maloney v. Soc. Sec. Admin.*, 517 F.3d 70, 76 (2d Cir. 2008)

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Agency” language in Section 1557 is similar to that found in Section 504 of the Rehabilitation Act that covers both federally funded programs and activities “conducted by any Executive agency.”¹¹⁷ In the Section 504 context, HHS has interpreted “federally conducted program[s]” or activities to include “anything a Federal agency does” including employment, activities involving general public contact as part of ongoing agency operations and activities directly administered by the agency for program beneficiaries and participants, like Medicare.¹¹⁸

Thus, Section 1557’s “administered by an Executive Agency” prong extends anti-discrimination protection not only to federal Medicare, National Institutes of Health (NIH), and the Food and Drug Administration (FDA) activities but to two private health insurance programs administered by the federal Office of Personnel Management (OPM): (1) the existing Federal Employees Health Benefit Program (FEHBP), which insures federal employees, retirees and their dependents,¹¹⁹ and (2) the new Multi-State Qualified Health Plans, authorized by Title I of the ACA, which will be offered nationwide through the new Exchanges.¹²⁰ OPM plays a similar role in both programs negotiating with private plans and administering the programs.¹²¹ The FEHBP is not covered under Title VI because it is a federal agency administering its own program, and therefore, it is not considered to be a recipient of federal funding. However, OPM is now covered under the Section 1557’s second prong.

(holding that similar language in the Age Discrimination Act requires the same holding as *Heckler*).

117. 29 U.S.C. § 794 (2006).

118. HHS defines activities involving general public contact as those that involve communication with the public through telephone contacts, office walk-ins, or interviews and the public’s use of the agency’s facilities. HHS defines “directly administered by the federal government for program beneficiaries and participants” as programs that provide federal services or benefits. See Enforcement of Nondiscrimination on the Basis of Handicap in Programs or Activities Conducted by the Department of Health and Human Services, 53 Fed. Reg. 25,595, 25,596 (July 8, 1988) (providing a “Section-by-Section Analysis” of 45 C.F.R. § 85.65 (2011)).

119. The FEHBP provides federal employees, retirees, and their dependents with a choice of competing private health plans with different premiums and the largest employer sponsored health insurance system in the country. Sidney D. Watson, Yolonda Campbell & Timothy McBride, *Creating Multi-State Qualified Health Plans in Health Insurance Exchanges: Lessons for Rural and Urban America from the Federal Employees Health Benefit Plan*, 5 ST. LOUIS U. J. HEALTH L. & POL’Y 103, 104 (2011).

120. ACA, Pub. L. No. 111-148, § 1334, 124 Stat. 119 (2010).

121. See *id.*

The third prong of Section 1557 reaches “any entity established” under Title I of the ACA.¹²² Title I of the ACA contains the provisions that reform the private insurance market creating new rules for private health insurance plans and new entities to offer and market private insurance.¹²³ Title I creates at least two new entities that do not receive ongoing federal financial assistance but are still subject to Section 1557 through this third prong.

First, Title I establishes new Health Insurance Exchanges, to provide one-stop shopping for those who use the individual and small group insurance.¹²⁴ The Exchanges will provide an online web portal where individuals and small businesses will be able to see, compare, and purchase private health insurance.¹²⁵ The Exchanges will also set standards for qualified health plans to meet for benefits and premiums, marketing, provider networks, quality improvement activities, and accreditation.¹²⁶ Exchanges are also the place where low- to middle-income Americans, those earning between 133% and 400% of the federal poverty level (\$29,726 to \$89,400 for a family of three in 2011) will apply for and obtain federal premium assistance tax credits and cost-sharing subsidies and only policies bought through an exchange will be eligible for tax credit support.¹²⁷ The Exchanges are predicted to become a major gateway to private insurance coverage with twenty-four million Americans purchasing health insurance through the new Exchanges, including nineteen million using premium tax credits.¹²⁸

122. ACA § 1557(c). This provision also reaches any amendments to Title I, which would include the Reconciliation Act and any subsequent amendments to the provisions of Title I. See Health Care and Education Reconciliation Act of 2010, Pub. L. No. 111-152, 124 Stat. 1029.

123. See ACA tit. I.

124. See ACA § 1311; Timothy Jost, *Implementing Health Reform: Health Insurance Exchanges*, HEALTH AFF. BLOG (July 12, 2011, 10:29 AM), <http://healthaffairs.org/blog/2011/07/12/implementing-health-reform-health-insurance-exchanges/>.

125. See Jost, *supra* note 124.

126. See ACA § 1311. For a detailed discussion of these provisions, see Sidney D. Watson, *Mending the Fabric of Small Town America: Health Reform & Rural Economics*, 113 W. VA. L. REV. 1, 22-29 (2010).

127. See ACA § 1402(b)(2); Sarah Kliff, *The Health Insurance Income Gap*, WASH. POST, Feb. 7, 2012, http://www.washingtonpost.com/blogs/ezra-klein/post/the-health-insurance-income-gap/2012/02/07/gIQAVCn5wQ_blog.html; *The 2011 HHS Poverty Guidelines: One Version of the [U.S.] Federal Poverty Measure*, U.S. DEP'T OF HEALTH & HUM. SERVS., <http://aspe.hhs.gov/poverty/11poverty.shtml> (last visited Oct. 24, 2011).

128. Letter from Douglas W. Elmendorf, Dir., Cong. Budget Office, to Nancy Pelosi, Speaker, U.S. House of Representatives (Mar. 20, 2010), available at <http://www.cbo.gov/ftpdocs/113xx/doc11379/Amendreconprop.pdf> [hereinafter Elmendorf Letter]; *id.* at tbl. 4.

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The new Exchanges will take a variety of forms.¹²⁹ By January 1, 2014, each state may establish one or more Exchanges that is either a state governmental agency or nonprofit entity.¹³⁰ If a state opts not to establish an exchange, the Secretary of HHS has authority to create and operate an Exchange within that state.¹³¹ While Title I provides start-up grants to assist states that wish to establish public or private Exchanges, assessments on health insurance issuers, not federal funding, will cover ongoing costs.¹³² The third prong of Section 1557 makes clear that whatever form these Exchanges take—federal or state, public or not-for-profit—their activities are subject to Section 1557's new anti-discrimination provision.¹³³

Second, Title I also creates new nonprofit, member-run health issuers called Consumer Operated and Oriented Plans (COOPS) that will offer qualified health plans in the individual and small group markets.¹³⁴ These new COOPs were created to give consumers more options for insurance offered by not-for-profit entities.¹³⁵ While Title I of the ACA provides for loans to help COOPs with start up costs and grants to assist COOPs in meeting state solvency requirements, the Act generally requires that loans be repaid within five years and grants within fifteen years and does not provide ongoing federal funding for the operating costs of COOPs.¹³⁶ While it is likely that most

129. See ACA §1311.

130. States may establish one exchange for the individual market and a separate Small Business Options Program (SHOP) for the small group market, or operate one exchange for both. States also have the option to establish multiple exchanges to serve different geographic areas of the state or to offer multi-state Exchanges in cooperation with other states. See *id.*

131. *Id.*

132. See *id.*

133. The Exchanges are also likely to be subject to the ADA, either places of public accommodation or public programs. See Sara Rosenbaum, Joel B. Teitelbaum & Katherine Hayes, *Crossing the Rubicon: The Impact of the Affordable Care Act on the Content of Insurance Coverage for Persons with Disabilities*, 25 NOTRE DAME J.L. ETHICS & PUB. POL'Y 527, n. 153 (2011)

A related question is whether coverage purchased through an exchange is considered a public program. One could argue that it is, since exchanges operate under the authority of public law, even though their products are private health insurance products. In this regard, the civil rights provision of the Act appears to classify tax subsidies as federal financial assistance for purposes of applying Section 504 of the Rehabilitation Act. See ACA § 1557. The statute is inconclusive as to whether exchanges themselves are considered a public program for purposes of the ADA, although in their establishment, exchanges receive federal grants and are operated as programs with public accountability under state and federal law.

Id.

134. ACA §1322(a)(2).

135. Timothy Jost, *Implementing Health Reform: CO-Ops, MEWAS, and Medicare Data*, HEALTH AFF. BLOG (Dec. 12, 2011, 12:07 PM), <http://healthaffairs.org/blog/2011/12/12/implementing-health-reform-co-ops-mewas-and-medicare-data/>.

136. ACA §1322(b)(3).

COOPs will receive federal premium tax credits or cost-sharing subsidies and thus be covered by the first prong of Section 1557,¹³⁷ the third prong of Section 1557 makes clear that all COOPs, as “entit[ies] created by Title I,” are subject to Section 1557.¹³⁸

Finally, Section 1557 also expressly provides for enforcement. It states: “The enforcement mechanisms provided for and available under such title VI, title IX, section 504, *or* such Age Discrimination Act shall apply for purposes of violations of this subsection.”¹³⁹ Section 1557’s use of the connector “or” to describe the available enforcement mechanisms is significant because the Age Discrimination Act provides for different enforcement mechanisms than do Title VI, Title IX, and Section 504.¹⁴⁰ The Age Discrimination Act expressly creates a private right of action in federal court after exhausting administrative remedies, while Title VI, Title IX, and Section 504 rely primarily on administrative remedies.¹⁴¹

Title VI, Title IX, and Section 504 provide expressly for only administrative enforcement.¹⁴² A letter of complaint from an aggrieved individual can prompt agency enforcement, but it is the agency and not the individual complainant who has standing to pursue administrative enforcement.¹⁴³ Courts have inferred a private right of action for claims on intentional discrimination but not claims of disparate impact discrimination.¹⁴⁴ Because Title VI, Title IX, and Section 504 do not provide a mechanism where individuals can actively participate in the administrative process and obtain individual relief, judicial claims of intentional discrimination do not have to exhaust administrative rem-

137. *Id.* §1557(a).

138. *Id.*

139. *Id.* (emphasis added).

140. *Id.*

141. Compare 42 U.S.C. § 2000d-1(1) (2006), 20 U.S.C. § 1682 (2006), and 29 U.S.C. § 794(a) (2006), with 42 U.S.C. § 6104(e)(1) (providing “(1) [w]hen any interested person brings an action in any United States district court”); see also *Long v. Fulton Cnty. Sch. Dist.*, 807 F.Supp. 2d 1274, 1287 (N.D. Ga. 2011) (noting that Title VI and Title IX are enforceable through an implied right of action while the Age Discrimination Act has an express right of action).

142. See 42 U.S.C. § 2000d-1(1); 20 U.S.C. § 1682; 29 U.S.C. § 794(a).

143. 28 C.F.R. § 50.3 (2012).

144. See *Guardians Ass’n v. Civil Serv. Comm’n of New York*, 463 U.S. 582, 584 (1983); see also *Alexander v. Sandoval*, 532 U.S. 275, 293 (2001). The remedy provisions of Title VI, Title IX, and Section 504 have been interpreted *in pari materia*, as having the same legal meaning, in terms of their remedies.

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edies.¹⁴⁵ Moreover, plaintiffs proving intentional discrimination may recover money damages.¹⁴⁶

In contrast, the Age Discrimination Act provides expressly for both administrative enforcement and a private right of action in federal court to review agency adjudication.¹⁴⁷ Individuals have a right to agency mediation, and if that fails, adjudication, enabling them to obtain individualized relief from the agency.¹⁴⁸ The statute also requires that plaintiffs exhaust administrative remedies, unless futile or inadequate¹⁴⁹ and provide thirty-days notice before filing a lawsuit.¹⁵⁰ There is little case law interpreting the Age Discrimination Act, but it would appear that because implementing regulations prohibit both disparate impact and intentional discrimination and provide individuals with an opportunity for agency adjudication of both types of claims, that judicial review is available for claims of both disparate

145. See *Neighborhood Action Coal. v. City of Canton*, 882 F.2d 1012, 1015 (6th Cir. 1989); see also *Freed v. Consol. Rail Corp.*, 201 F.3d 188, 194 (3d Cir. 2000); *Doe ex rel. Doe v. St. Joseph's Hosp. of Fort Wayne*, 788 F.2d 411, 425-26 (7th Cir. 1986), *overruled on other grounds* by *Alexander v. Rush N. Shore Med. Ctr.*, 101 F.3d 487, 488 (7th Cir. 1996); *Chowdhury v. Reading Hosp. & Med. Ctr.*, 677 F.2d 317, 321 (3d Cir. 1982).

146. See generally *Gebser v. Lago Vista Indep. Sch. Dist.*, 524 U.S. 274 (1998) (requiring actual knowledge of discrimination for monetary damages to become available in a Title IX case); *Franklin v. Gwinnett Cnty. Pub. Sch.*, 503 U.S. 60 (1992) (holding that compensatory damages are available in a Title IX action alleging intentional discrimination); *Guardians Assoc.*, 463 U.S. at 582 (holding that compensatory relief in a Title VI action is only available upon a showing of intentional discrimination).

147. See 42 U.S.C. § 6104(a), (e), (f) (stating that an agency head may seek compliance by terminating or refusing to grant federal funds, and interested persons may bring an action in federal court after exhausting administrative remedies).

148. See 42 U.S.C. § 6105(b).

149. See *id.* § 6104(f) (deeming administrative remedies to be exhausted 180 days after filing of an administrative complaint); see also *Parker v. Bd. of Supervisors Univ. of La.-Lafayette*, 296 Fed. App'x 414, 417 (5th Cir. 2008); *D.A. v. Hous. Indep. Sch. Dist.*, 716 F. Supp. 2d 603, 620-21 (S.D. Tex. 2009), *aff'd sub nom.*, 629 F.3d 450 (5th Cir. 2010); *Harris v. New York State Educ. Dep't*, 419 F. Supp. 2d 530, 535 (S.D.N.Y. 2006).

150. 42 U.S.C. § 6104(e)(1). No such action shall be brought if at the time the action is brought, the same alleged violation by the same defendant is the subject of a pending action in any court of the U.S., or administrative remedies have not been exhausted. 42 U.S.C. § 6104(e)(2); see also 42 U.S.C. § 6104(f) (explaining how one may exhaust administrative remedies). In actions for relief, "administrative remedies shall be deemed exhausted upon the expiration of 180 days from the filing of an administrative complaint . . . [if the] agency makes no finding . . . or . . . [the] agency issues a finding in favor of the recipient of financial assistance, whichever occurs first." *Id.*; see also § 6104(e)(1), which provides:

(1) When any interested person brings an action in any United States district court for the district in which the defendant is found or transacts business to enjoin a violation of this Act . . . such interested person shall give notice by registered mail not less than 30 days prior to the commencement of that action to the Secretary of [HHS], the Attorney General of the United States, and the person against whom the action is directed.

Id. Such person may be awarded reasonable attorneys' fees as the prevailing party. *Id.*

impact and intentional discrimination.¹⁵¹ However, a majority of the few courts that have considered the issue have concluded that the Age Discrimination Act's statutory language specifically authorizing court review for injunctive relief and attorneys' fees does not authorize courts to award monetary damages.¹⁵²

Given that Section 1557 provides that the enforcement mechanisms available under Title VI, Title IX, Section 504 or the Age Discrimination Act are available to redress violations of Section 1557, plaintiffs asserting a violation of Section 1557 appear to have their choice of process: either direct access to federal court for claims of intentional discrimination as provided by Title VI, Title IX, and Section 504, or an agency hearing with an opportunity for judicial review for claims of both disparate impact and intentional discrimination as the Age Discrimination Act provides. The enforcement choice would determine whether a damage remedy was available for claims of intentional discrimination.

Section 1557 creates a far-reaching new civil rights remedy. For the first time, federally funded health programs will be prohibited from discriminating on the basis of sex. Private insurers and health care providers who do not accept federal financial assistance will be prohibited from discriminating on the basis of race, sex, disability, and age.¹⁵³ Federal government health programs and activities will also be prohibited from discriminating as will new health care entities, like the

151. See 49 C.F.R. § 21.5 (2012) (prohibiting intentional and disparate impact discrimination); see also *NAACP v. Med. Ctr., Inc.*, 657 F.2d 1322, 1324 (3d Cir. 1981) (allowing judicial review of disparate impact claim).

152. See *Long v. Fulton Cnty. Sch. Dist.*, 807 F. Supp. 2d 1274, 1287 (N.D. Ga. 2011) (collecting the cases holding that monetary relief is not available under Age Discrimination Act claims); see also 42 U.S.C. § 6104(e)(1). In relevant part,

[W]hen any interested person brings an action in any United States district court for the district in which the defendant is found or transacts business to enjoin a violation of this Act . . . [s]uch interested person may elect, by a demand for such relief in his complaint, to recover reasonable attorney's fees

Id. For an excellent overview of Age Discrimination Act litigation in the health care context, see Phoebe Weaver Williams, *Age Discrimination in the Delivery of Health Care Services to Our Elders*, 11 MARO. ELDER'S ADVISOR 1, 29-33 (2009).

153. See *supra* text accompanying notes 104-06. The Americans with Disabilities Act already reaches physicians as places of public accommodation. The ADA's coverage of contents of private insurance policies has been less clear. See *Doe v. Mut. of Omaha Ins. Co.*, 179 F.3d 557, 562-64 (7th Cir. 1999) (finding that the ADA does not reach contents of individual health insurance policies); *Winslow v. IDS Life Ins. Co.*, 29 F. Supp. 2d 557, 561-64, 567 (D. Minn. 1998) (finding that insurer's policy of denying coverage to any applicant treated for a mental condition within the past year violated the ADA). *But see Chabner v. United of Omaha Life Ins. Co.*, 225 F.3d 1042, 1046-47 (9th Cir. 2000) (holding that discrimination in premium charged based on disability did not violate the ADA).

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Health Insurance Exchanges that Title I of the ACA authorizes.¹⁵⁴ Moreover, Section 1557 reaches both intentional discrimination and policies and practices that have a disparate impact in minorities and provides for a private right of action to enforce claims of both intentional and disparate impact discrimination.

III. SECTION 1557 AND HEALTH
REFORM IMPLEMENTATION

Passage of the ACA's Medicaid and private insurance credits and subsidies, along with the creation of new entities like the Exchanges, COOPs, and Multi-State Qualified Health Plans (MSQHPS) in tandem with Section 1557, offers a unique opportunity to combine a dramatic expansion of federal funding for new insurance options and new mechanisms for purchasing insurance with civil rights remedies. The Johnson Administration used such an opportunity to de-segregate the nation's hospitals.¹⁵⁵ That effort succeeded because the civil rights expectations were clear and easily verified. The hospitals knew what was expected of them and knew they had to both dismantle segregation and also put into place new policies before the new federal Medicare dollars would begin to flow. An inter-governmental taskforce, supplemented by local community members, served as the eyes and ears of the federal level effort.

Much can be gleaned from the language of Section 1557 because it uses familiar civil rights language that has established legal meaning. However, implementing regulations are needed.

Given that Section 1557 cross-references to Title VI and its companion civil rights statutes, HHS may be tempted to make a health policy and civil rights misstep, and promulgate Section 1557 regulations that closely track Title VI implementing regulations. The Title VI regulations in force today were originally developed in 1965.¹⁵⁶ An interagency taskforce crafted very general Title VI regulations so that all twenty-two agencies that award a wide range of federal financial assistance to a huge variety of programs and activities could use the same set of implementing regulations.¹⁵⁷ This meant that the Title VI

154. *See supra* text accompanying notes 119-40.

155. *See supra* text accompanying notes 49-52.

156. Watson, *Reinvigorating*, *supra* note 20, 947-48.

157. Linda R. Singer et al., Comment, *Title VI of the Civil Rights Act of 1964—Implementation and Impact*, 36 GEO. WASH. L. REV. 824, 846 (1968).

regulations were and remain, very general, and in many ways quite vague.

Section 1557 is not a general civil rights remedy; it is health-specific. Implementing regulations need to be not only health-centric but activity specific, providing guidance for health care providers, insurers, public health agencies, medical research, and other types of health entities. The Section 1557 regulation-drafting project will require something more than merely repeating the general Title VI, or Title IX, Section 504, or Age Discrimination Act regulations.

As the ACA not only retains but tries to strengthen an American health care financing system that relies on multiple insurers and market competition, the pressures for health insurers to avoid more costly patients and for health care providers to seek out higher paying insurers and avoid others will remain. This frenzy of market competition may exacerbate long-standing racial divides in health insurance and health care. Section 1557 will be effective as a civil right's antidote only if standards are clear and the balance between markets and equity are clearly stated.

Hopefully, HHS will take a tip from the Johnson Administration and develop clear, unambiguous compliance standards for Section 1557. Such standards will be particularly important for the new health entities that emerge as the ACA is implemented: the Exchanges and the qualified health plans that will be offered through them, the CO-OPs, the nationally available MSQHPs, and the new Medicaid Managed Care plans designed to serve expansion populations.

HHS has tasked their Office of Civil Rights (OCR) with the job of drafting proposed regulations for Section 1557,¹⁵⁸ but this effort, like the hospital desegregation campaign, requires cross-agency expertise and community involvement. Figuring out how to ensure that the new health insurance offerings and delivery system models the ACA and does not perpetuate and deepen racial and ethnic health care disparities requires the civil rights expertise of OCR. It also requires the operational expertise of the Centers for Medicare and Medicaid Services (CMS), which run Medicare and Medicaid and are creating the regulations that will govern the new Exchanges. Likewise, it requires input from the Health Resources and Services Administration

158. See DEP'T OF HEALTH & HUMAN SERVS., FISCAL YEAR 2012, OFFICE FOR CIVIL RIGHTS, JUSTIFICATION OF ESTIMATES FOR APPROPRIATIONS COMMITTEES 20 (2012), available at http://www.hhs.gov/about/budget/fy2012/ocr_cj_fy2012.pdf.

(HRSA), which administers the safety-net programs upon which minority patients disproportionately rely.¹⁵⁹ Also needed is guidance from units like the Office for Minority Health and Agency for Healthcare Research and Quality (AHRQ) that have generated important new studies about the extent and causes of racial and ethnic disparities in care.¹⁶⁰ Providers and community members need to be part of the ongoing conversation, not merely commentators on proposed regulations.

The hospital desegregation campaign offers one model for this kind of interactive, specific, forward-looking civil rights enforcement, but HHS can turn to more recent examples as well. The HHS/OCR formulation of standards of conduct for programs and entities serving persons with limited English proficiency (LEP) is another.¹⁶¹ The LEP Guidance is an interesting example of bipartisan effort that originated in 2000 during the Clinton administration and was revised in 2003 during the Bush presidency.¹⁶² The LEP Guidelines give providers of different sizes who serve different numbers of people with LEP both a broad general standard requiring “meaningful access” but also provide specific guidance, including detailed information about the kinds of documents that need to be translated and the languages that should be available, to meet general standards compliance.¹⁶³ The LEP Guidelines also include legal safe harbors, providing that written translations that meet the safe harbor recommendations will be considered strong evidence of compliance.¹⁶⁴ As Sara Rosenbaum and Joel Teitelbaum have noted, this use of specific standards and legal safe harbors has been used extensively for enforcing health care antitrust and fraud and abuse statutes.¹⁶⁵ It is a style of legal guidance that health insurers, health care providers, and their lawyers are famil-

159. See Sara Rosenbaum & Joel Teitelbaum, *Civil Rights Enforcement in the Modern Healthcare System: Reinvigorating the Role of the Federal Government in the Aftermath of Alexander v. Sandoval*, 3 YALE J. HEALTH POL’Y L. & ETHICS 215, 233-34 (2003).

160. See, e.g., JENNIFER K. BENZ ET AL., OFFICE OF MINORITY HEALTH, TRENDS IN U.S. PUBLIC AWARENESS OF RACIAL AND ETHNIC HEALTH DISPARITIES (1999-2010), at 1 (2010), available at <http://minorityhealth.hhs.gov/assets/pdf/checked/1/2010StudyBrief.pdf>; José A. Pagan et al., *Racial and Ethnic Disparities in Awareness of Genetic Testing for Cancer Risk*, 37 AM. J. PREV. MED. 524, 529 (2009).

161. See DEP’T OF HEALTH & HUMAN SERVS. FISCAL YEAR 2012, *supra* note 158, at 20.

162. See HHS Guidance on LEP, *supra* note 36, at 47,311.

163. See *id.* at 47,323.

164. *Id.* at 47,319.

165. See generally Sara Rosenbaum & Joel Teitelbaum, *Addressing Racial Inequality in Health Care*, in POLICY CHANGES IN MODERN HEALTH CARE 135 (David Mechanic et al. eds., 2005) (exploring dilemmas and disparities in America’s health care system).

iar with and comfortable using.¹⁶⁶ This kind of specificity reduces the need for protected administrative compliance proceedings that have arisen under vague Title VI regulations.

Another example of a cross-agency civil rights enforcement effort is the HHS response to *Olmstead v L.C.*, where the Supreme Court ruled that medically unjustifiable institutionalization of people with disabilities violated the Americans with Disabilities Act (ADA) and that states should take steps to move to community integration “at a reasonable pace.”¹⁶⁷ Following that decision, HHS convened an interagency working group to help federally financed programs move closer to the goals of the community integration goals of the ADA. The group systematically worked to identify and address inadequate and flawed federal standards. Through three Presidential administrations, the work group has produced a series of policy statements, reports, technical assistance efforts, and other activities that show federal fund recipients how to move more people with disabilities into the community.¹⁶⁸ The Supreme Court’s general standard was important, but it was the interagency workgroup’s specific guidance through technical assistance projects, best practices, and standard setting that moved the effort forward.

CONCLUSION

The ACA’s expansions of private insurance and Medicaid create foundational building blocks that will improve minority access to health insurance and health care. However, as long as health insurance and health care remain segregated along racial lines with one system serving disproportionately higher-income white patients and another safety net system attending to lower-income minority patients, the nation risks deepening the dual track health care that contributes to racial inequities in health care and health.

Section 1557 of the ACA is a broad new civil rights protection that will reach most (if not all) of America’s health insurers and health care providers prohibiting them from discriminating on the basis of race, ethnicity, gender, disability and age. HHS should move quickly to convene an interagency task force that involves providers, insurers and minority communities in formulating specific compliance stan-

166. *See id.*

167. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 584 (1999).

168. *See Rosenbaum & Teitelbaum, supra* note 165, at 247.

Section 1557 of the Affordable Care Act

dards for Section 1557. Broad statements prohibiting policies and practices that have a disparate racial impact do not give sufficient guidance to health insurers and health care providers of their civil rights obligations in this new era in which ACA guarantees affordable health care for all. As the Medicare hospital desegregation campaign shows, implementing new health insurance programs in tandem with new civil rights protections offers a unique opportunity to dismantle old patterns of segregation and reshape American health care along new models of equality.

Global Health Law Norms and the PPACA Framework to Eliminate Health Disparities

GWENDOLYN ROBERTS MAJETTE*

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*“Health is a universal human aspiration and a basic human need. The development of society, rich or poor, can be judged by the quality of its population’s health, how fairly health is distributed across the social spectrum, and the degree of protection provided from disadvantage as a result of ill-health. Health equity is central to this premise”*¹

INTRODUCTION

The existence of health disparities for racial and ethnic minorities is a longstanding problem in the United States. According to the Institute of Medicine (IOM), a health disparity is the “difference in health or clinical outcomes that is not attributable to clinical appropriateness or patient preferences.”² Health disparities have multiple causes³ including barriers to access to care. Some of the barriers encountered by people of color include: financing health care and the lack of health insurance, a shortage of institutional and individual providers, difficulties in communications because of cultural insensitivity and language differences, stereotyping, and discrimination.⁴

The consequence of encountering numerous barriers to health care means that racial and ethnic minorities have a disproportionately worse health status. People of color have “higher infant mortality, premature death rates and disease burden, and lower quality of health care when compared with the national average.”⁵ The magnitude of

1. COMM’N ON SOC. DETERMINANTS OF HEALTH, INTERIM STATEMENT (2007) (Commission’s Vision and Mission Statement), *available at* http://www.who.int/social_determinants/resources/csdh_media/csdh_interim_statement_07.pdf.

2. INST. OF MED., FUTURE DIRECTIONS FOR THE NATIONAL HEALTHCARE QUALITY AND DISPARITIES REPORT 44 (Cheryl Ulmer et al. eds., 2010) [hereinafter IOM FUTURE DIRECTIONS OF NHQR & NHDR]. The focus of the Institute of Medicine (IOM) analysis is two-fold: “(1) the operation of healthcare systems and the legal and regulatory climate” governing the systems; and (2) “discrimination at the individual, patient-provider level.” INST. OF MED., UNEQUAL TREATMENT: CONFRONTING RACIAL AND ETHNIC DISPARITIES IN HEALTH CARE 4 (Brian D. Smedley et al. eds., 2003) [hereinafter IOM, UNEQUAL TREATMENT].

3. Other causes include determinants of health like the social and physical environment, biology and genetics, and human behavior. David Satcher & Eve J. Higginbotham, *The Public Health Approach to Eliminating Disparities in Health*, 98 AM. J. PUB. HEALTH 400, 400 (2008).

4. Gwendolyn Roberts Majette, *Access to Health Care: What a Difference Shades of Color Make*, 12 ANNALS HEALTH L. 121, 123-39 (2003) [hereinafter Majette, *Access to Health Care*] (discussing the common barriers to care for people of color and proposing an interdisciplinary approach to eliminate those barriers that relies on the work of lawyers, physicians, business leaders, and health economists); *see* IOM, UNEQUAL TREATMENT, *supra* note 2, at 1. The IOM’s non-legal definition of discrimination is “the differential and negative treatment of individuals on the basis of their race, ethnicity, gender, or other group membership.” *Id.* at 95. A cause of discrimination is bias or prejudice. *Id.* at 127.

5. Satcher & Higginbotham, *supra* note 3, at 400.

the problem is reflected in a startling statistic which estimated that 886, 202 deaths could have been avoided if mortality rates between white and black individuals were equal in the United States.⁶

The Department of Health and Human Services first recognized that there were significant health and health care disparities for people of color in 1985 when it released the Report of the Secretary's Task Force on Black and Minority Health (Heckler Report).⁷ Thereafter, in 1998, President Clinton announced the Presidential Initiative to Eliminate Racial and Ethnic Disparities in Health.⁸ This national initiative sought for the first time to eliminate, not simply reduce, disparities in health in six areas: (1) cancer screening and management, (2) cardiovascular disease, (3) diabetes, (4) HIV/AIDS, (5) immunization rates, and (6) infant mortality.⁹ In 2000, elimination of health care disparities became a goal of Healthy People 2010, the nation's health-promotion and disease-prevention agenda.¹⁰

Despite these and other initiatives, in 2010, former Surgeon General David Satcher wrote, "not much progress has been made, to date, in moving toward the reduction and ultimate elimination of disparities in health."¹¹ Additionally, current Assistant Secretary for Health, Howard K. Koh concluded that "the goal of eliminating disparities remains unmet."¹² A major cause of the failure to eliminate health care disparities for racial and ethnic minorities is the lack of commitment of resources.¹³

6. This estimate is based on a nine-year period from 1991–2000. Michael G. Marmot & Ruth Bell, *Action on Health Disparities in the United States: Commission on Social Determinants of Health*, 301 J. AM. MED. ASS'N 1169, 1170 (2009).

7. Howard K. Koh et al., *Reducing Racial and Ethnic Disparities: The Action Plan from the Department of Health and Human Services*, 30 HEALTH AFF. 1822, 1822 (2011).

8. *President Clinton Announces New Racial and Ethnic Health Disparities Initiative*, U.S. DEP'T HEALTH & HUM. SERVICES (Feb. 21, 1998), <http://archive.hhs.gov/news/press/1998pres/980221.html>.

9. David Satcher & Eve J. Higginbotham, *supra* note 3, at 400; David Satcher, *Our Commitment to Eliminate Racial and Ethnic Health Disparities*, 1 YALE J. HEALTH POL'Y L. & ETHICS 1, 2 (2001); David Satcher, *The History of the Public Health Service and the Surgeon General's Priorities*, 54 FOOD & DRUG L.J. 13, 19 (1999).

10. Howard K. Koh, *A 2020 Vision for Healthy People*, 362 NEW ENG. J. MED. 1653, 1653 (2010).

11. Edward J. Sondik et al., *Progress Toward the Healthy People 2010 Goals and Objectives*, 31 ANN. REV. PUB. HEALTH 271, 280 (2010).

12. Koh, *supra* note 10, at 1653, 1656.

13. Sondik et al., *supra* note 11, at 271. At least one scholar, Professor Ruqaiijah Yearby, argues that a major cause of the persistence of health disparities for people of color is "the failure to meaningfully acknowledge and address the root cause of racial disparities: racial discrimination." Ruqaiijah Yearby, *Does Twenty-Five Years Make a Difference in "Unequal Treatment"? The Persistence of Racial Disparities in Health Care Then and Now*, 19 ANNALS HEALTH L. 57, 58 (2010).

In 2010, Congress passed the Patient Protection and Affordable Care Act (PPACA), which President Obama signed into law on March 23, 2010.¹⁴ Passage of this piece of legislation provides the United States with a significant opportunity to eliminate health care disparities. Elimination of health disparities for people of color is not simply a national concern; it is also of international concern. Health and human rights norms impose obligations on countries to address discrimination and inequality.¹⁵ Both the World Health Organization and the United Nations Special Rapporteur for Health recognize the inequitable treatment of disadvantaged groups across the world as an issue of international concern.¹⁶ Additionally, Professor Vernellia Randall argues that, “persistent discrimination in U.S. health care contributes to continuing health disparities . . . [in] violation of the U.S. obligations under [the International Convention for the Elimination of Racial Discrimination].”¹⁷

This Article analyzes how PPACA constitutes framework legislation that complies with global health law norms protecting a right to health in its approach to the reduction of health care disparities for racial and ethnic minorities in the United States. Part I identifies the

14. Patient Protection and Affordable Care Act (PPACA), Pub. L. No. 111-148, 124 Stat. 119 (2010), *amended by* Health Care and Education Reconciliation Act of 2010, Pub. L. No. 111-152, 124 Stat. 1029.

15. Paul Hunt, *Missed Opportunities: Human Rights and the Commission on Social Determinants of Health*, Address at the Closing the Gap in a Generation: Health Equity Through Action on the Social Determinants of Health Conference (Nov. 6-7, 2008), in *GLOBAL HEALTH PROMOTION*, Apr. 8, 2009, at 36, 37, available at http://ped.sagepub.com/content/16/1_suppl/36.full.pdf+html [hereinafter Hunt, *Missed Opportunities*].

16. In a report of the Special Rapporteur for Health, Paul Hunt notes that health care systems must be accessible to “all disadvantaged individuals and communities.” Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, *Economic, Social and Cultural Rights*, ¶ 6, at 5, Comm’n on Human Rights, Econ and Soc. Council, U.N. Doc. E/CN.4/2006/48 (Mar. 3, 2006) (by Paul Hunt) [hereinafter ECOSOC Special Rapporteur Report]; see also WHO, *Engaging for Health: Eleventh General Programme of Work, 2006–2015: A Global Health Agenda*, at 15 (May 2006), available at http://whqlibdoc.who.int/publications/2006/GPW_eng.pdf. Additionally, the U.N. Charter requires countries to pledge the “promotion of universal respect for and observance of human rights and fundamental freedoms” for all without distinction as to race, sex, language, or religion. Universal Declaration of Human Rights, G.A. Res. 217 (III) A, U.N. Doc. A/RES/217(III), at pmb., art. 2 (Dec. 10, 1948) [hereinafter UDHR].

17. Vernellia R. Randall, *Racial Discrimination in Health Care in the United States as a Violation of the International Convention on the Elimination of All Forms of Racial Discrimination*, 14 U. FLA. J.L. & PUB. POL’Y 45, 50 (2002). Professor Randall analyzes the existence of persistent racial discrimination in the United States health care system up to the new millennium; she argues that institutional racism contributes to health disparities and violates ICERD articles 2(1)(a), 2(1)(c), 2(1)(d), and 5(e)(iv). *Id.* at 68; see also Ruqaiyah Yearby, *Is It Too Late for Title VI Enforcement?—Seeking Redemption of the Unequal United States’ Long Term Care System Through International Means*, 9 DEPAUL J. HEALTH CARE L. 971, 978 (2005) (examining the United States’ disregard for elderly African Americans’ right to equality).

global health laws that impose a duty on the United States to eliminate health disparities for people of color. Part II analyzes the legislative framework that PPACA creates to protect the right to health and eliminate health care disparities. Finally, Part III concludes with my recommendations on future efforts to reduce and eliminate health care disparities for people of color in the United States.

I. GLOBAL HEALTH LAWS THAT IMPOSE A DUTY ON THE UNITED STATES TO REDUCE OR ELIMINATE HEALTH DISPARITIES

Global health law is a field that encompasses the legal norms, processes, and institutions needed to create the conditions for people throughout the world to attain the highest possible level of physical and mental health. The field seeks to facilitate health-promoting behaviour among the key actors that significantly influence the public's health, including international organizations, governments, businesses, foundations, the media, and civil society.¹⁸

There are several global health laws that impose a duty on the United States to reduce or eliminate health disparities for people of color including global health governance documents by the World Health Organization (WHO); the International Convention on the Elimination of Racial Discrimination (ICERD); and non-binding, aspirational laws and documents such as the International Covenant on Economic, Social and Cultural Rights (ICESCR), and reports by the United Nations Special Rapporteur for Health.

The United States is a member of the World Health Organization whose constitution includes a provision to protect the right to health.¹⁹ Health is defined as a “state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.”²⁰ The WHO Constitution provides that health is a fundamental right. It states that, “[t]he enjoyment of the highest attainable standard of

18. Lawrence O. Gostin & Allyn L. Taylor, *Global Health Law: A Definition and Grand Challenges*, 1 *PUB. HEALTH ETHICS* 53, 55 (2008) (“The mechanisms of global health law should [(1)] stimulate investment in research and development, [(2)] mobilize resources, [(3)] set priorities, [(4)] coordinate activities, [(5)] monitor progress, [(6)] create incentives, and [(7)] enforce standards.”). The guiding principle of global health law is social justice. *See id.*

19. *See* World Health Organization [WHO], *Constitution of the World Health Organization*, pmbl., at 1 (July 22, 1946), available at <http://apps.who.int/gb/bd/PDF/bd47/EN/constitution-en.pdf>.

20. *Id.*

health is one of the fundamental rights of every human being without distinction of race, . . . economic or social condition.”²¹

A. The Right to Health Under the International Covenant on Economic, Social and Cultural Rights (ICESCR), General Comment 14, and Reports of the Special Rapporteur for Health

While Presidents Carter and Clinton have recommended ratification of the International Covenant on Economic, Social and Cultural Rights, the United States Senate has not ratified this treaty.²² ICESCR contains the most comprehensive article on the right to health in human rights law. Like the WHO Constitution, this covenant recognizes “the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.”²³ A country like the United States fully realizes that right when it addresses the “reduction of the stillbirth-rate and of infant mortality” and promotes the healthy development of the child; prevents, treats and controls “epidemic, endemic, occupational and other diseases;” and creates conditions to “assure to all medical service and medical attention in the event of sickness.”²⁴ In the context of a health care system, the right to health is the “right to an effective and integrated health system, encompassing health care and the underlying determinants of health, which is responsive to national and local priorities, and accessible to all.”²⁵ If the health care system in the United States was accessible to all,²⁶ this would help reduce health disparities for people of color.

21. *Id.*

22. Eleanor D. Kinney, *Recognition of the International Human Right to Health and Health Care in the United States*, 60 RUTGERS L. REV. 335, 347-48 (2008) [hereinafter Kinney, *Recognition of RTH in the U.S.*].

23. United Nations, Econ. & Soc. Council, Comm. on Econ., Soc. & Cultural Rights, Substantive Issues Arising in the Implementation of the International Covenant on Economic, Social and Cultural Rights, General Comment No. 14, ¶ 2, U.N. Doc. E/C.12/2000/4 (Aug. 11, 2000) [hereinafter General Comment 14] (internal quotation marks omitted).

24. International Covenant on Economic, Social, and Cultural Rights, art. 12(2)(a), (c), (d), Dec. 16, 1966, 1966 U.S.T. 521, 993 U.N.T.S. 3 [hereinafter ICESCR]. Article 12(2)(b) requires governments to improve “all aspects of environmental and industrial hygiene.” *Id.*

25. ECOSOC Special Rapporteur Report, *supra* note 16, ¶ 4; *see also* General Comment 14, *supra* note 23, ¶ 4 (explaining that the right to health includes a number of socioeconomic factors).

26. A health care system is accessible to all when health care and its underlying determinants are geographically, economically, and informationally accessible on a non-discriminatory basis. *See* General Comment 14, *supra* note 23, ¶ 12(b). As discussed in the introduction, people of color disproportionately encounter significant barriers to care and adverse social and economic determinants of health. *See* discussion *supra* Introduction. In 2010, people of color represented a disproportionate percentage of the uninsured in the United States: Hispanics

B. The International Convention on the Elimination of Racial Discrimination

In contrast to ICESCR, the United States has ratified the International Convention on the Elimination of Racial Discrimination (ICERD).²⁷ This treaty explicitly addresses the rights of people of color. ICERD not only condemns racial discrimination and segregation, but it encourages countries to promote understanding among all races.²⁸

1. Treaty Requirements and Prohibitions

ICERD prohibits countries from engaging in racial discrimination; requires countries to take “effective measures” to review, amend, rescind, and nullify policies and laws that have the “effect of creating or perpetuating racial discrimination;” and requires countries to prohibit and end “racial discrimination by any persons, group, or organization.”²⁹ It further requires that countries take “special and concrete measures to ensure the adequate development and protection of certain racial groups . . . for the purpose of guaranteeing them the full and equal enjoyment of human rights and fundamental freedoms.”³⁰ Moreover, countries must “guarantee the right of everyone, without distinction as to race, colour, or national or ethnic origin, to equality before the law . . . [in e]conomic, social and cultural rights, . . . [like t]he right to public health, [and] medical care.”³¹

(32%), American Indians (30%), African Americans (22%), and Asians (19%). See KAISER FAMILY FOUND., THE UNINSURED: A PRIMER 7 fig.5 (2011), available at <http://www.kff.org/uninsured/upload/7451-07.pdf>. In contrast, whites were only 14% of the uninsured population. *Id.*

27. The United States ratified the treaty with three reservations, one understanding, and one declaration. For an in-depth analysis of the history of the United States adoption of ICERD, the effect of its reservations, and the expected impact of adoption, see Gay J. McDougall, *Toward a Meaningful International Regime: The Domestic Relevance of International Efforts to Eliminate All Forms of Racial Discrimination*, 40 HOW. L.J. 571 (1997).

28. International Convention on the Elimination of All Forms of Racial Discrimination, art. 2(1), (3), Dec. 21, 1965, S. EXEC. DOC. C, 95-2 (1978), 660 U.N.T.S. 195 [hereinafter ICERD].

29. *Id.* art. 2(1)(a), (c), (d).

30. *Id.* art. 2(2). Special measures must be of a limited duration and must end when the objectives for which they were adopted have been achieved. *Id.*

31. *Id.* art. 5(e)(iv).

2. United States' Report and Recommendations to the United States from the Committee on the Elimination of Racial Discrimination

To monitor compliance with ICERD, countries are required to file reports every two years and whenever the Committee on the Elimination of Racial Discrimination (CERD Committee) requests.³² These reports should identify the “legislative, judicial, administrative or other measures” adopted to give effect to the treaty.³³ In both the United States' initial and subsequent reports to the CERD Committee, it acknowledged the existence of significant disparities in health status and access to care for racial and ethnic minorities.³⁴ Based on the last report filed by the United States in 2007,³⁵ the CERD Committee identified some positive aspects of governmental efforts to address the health care needs of racial and ethnic minorities. The CERD Committee commended the United States Department of Health and Human Services for creation of the “National Partnership for Action to End Health Disparities for Ethnic and Racial Minority Populations” (NPA) in 2007, “as well as the various programmes adopted . . . to address the persistent health disparities affecting low-

32. *Id.* art. 9(1)(b).

33. *Id.* art. 9(1).

34. PERIODIC REPORT OF THE UNITED STATES OF AMERICA TO THE U.N. COMMITTEE ON THE ELIMINATION OF RACIAL DISCRIMINATION CONCERNING THE INTERNATIONAL CONVENTION ON THE ELIMINATION OF ALL FORMS OF RACIAL DISCRIMINATION 86, ¶ 258 (Apr. 2007) [hereinafter U.S. PERIODIC REPORT TO CERD (2007)], available at <http://www.state.gov/documents/organization/83517.pdf>.

35. The United States has only filed two reports with the Committee on the Elimination of All Forms of Racial Discrimination (CERD Committee). The initial report which constituted the first, second, and third report was filed on September 21, 2000. Comm. on the Elimination of Racial Discrimination, Reports Submitted by States Parties Under Article 9 of the Convention 1, 1, U.N. Doc. CERD/C/351/Add.1 (Oct. 10, 2000). The reports were due on November 20, 1995, November 20, 1997, and November 20, 1999. *Id.* The second report contained the fourth, fifth, and sixth periodic reports and was filed as a single document on April 24, 2007. U.S. PERIODIC REPORT TO CERD (2007), *supra* note 34, at 1. This report covered the years from September 2000 to April 2007. *See id.* In response to questions from the CERD Committee, the United States filed a supplemental report to its second report in March 2008. *See generally* QUESTIONS PUT BY THE RAPPORTEUR IN CONNECTION WITH THE CONSIDERATION OF THE COMBINED FOURTH, FIFTH AND SIXTH PERIODIC REPORTS OF THE UNITED STATES OF AMERICA, CERD/C/USA/6 (2008) [hereinafter U.S. RESPONSE TO CERD QUESTIONS], available at <http://www.state.gov/documents/organization/107109.pdf> (providing the United States' answers to the CERD Committee's questions). The CERD Committee has requested that the United States file its next report as single document on November 20, 2011. U.N. Comm. on the Elimination of Racial Discrimination, 72d Sess., *Consideration of Reports Submitted by States Parties Under Article 9 of the Convention: Concluding Observations of the Committee on the Elimination of Racial Discrimination, United States of America*, 13, ¶ 46, U.N. Doc. CERD/C/USA/CO/6 (Feb. 2008) [hereinafter CERD, *Concluding Observations on U.S. Reports*]. The third report, which has not been filed yet, will constitute the seventh, eighth, and ninth report.

income persons belonging to racial, ethnic and national minorities.”³⁶ When the 2007 report was filed, the NPA was a new initiative of the Office of Minority Health.³⁷ It was based on three core principles: “(1) national leadership and community solutions; (2) effective communications; and (3) broad-based partnerships.”³⁸

The CERD Committee also identified several areas of concern. In light of ICERD article 3, which prohibits racial segregation, the Committee was “deeply concerned” about the disproportionate concentration of racial and ethnic minorities, especially Latino and African American persons, in poor residential neighborhoods with numerous problems including “inadequate access to health care facilities.”³⁹ The CERD Committee was concerned about the large number of racial and ethnic minorities that lacked health insurance and encountered “numerous obstacles to access . . . health care.”⁴⁰ These concerns were based on ICERD article 5(e)(iv), which prohibits racial discrimination and guarantees everyone, “without distinction as to race, colour, or national or ethnic origin, . . . equality before the law . . . [in t]he right to public health, [and] medical care.”⁴¹ Additionally, the Committee was troubled about the poor sexual and reproductive health status of racial and ethnic women. Some areas of concern include infant and maternal mortality and the significant disparities in HIV infection.⁴²

The Committee generally recommended that the United States address “persistent health disparities” among racial and ethnic minorities by continuing efforts to reduce barriers to care by increasing access to health insurance; correcting unequal distribution of health care resources; and improving the poor quality of care provided in public health care services.⁴³ It further requested that the United States

36. CERD, *Concluding Observation on U.S. Reports*, *supra* note 35, at 2, ¶ 8.

37. *Id.*

38. U.S. PERIODIC REPORT TO CERD (2007), *supra* note 34, at 88; *see also* U.S. RESPONSE TO CERD QUESTIONS, *supra* note 35, at 85 (discussing how some of the partnerships would include the faith community and private businesses). *See infra* Part II.B.3 for a discussion of the current status of NPA.

39. CERD, *Concluding Observation on U.S. Reports*, *supra* note 35, at 4, ¶ 16.

40. *Id.* at 10-11, ¶ 32.

41. *Id.*; ICERD, *supra* note 28, art. 5(e)(iv).

42. *See* CERD, *Concluding Observation on U.S. Reports*, *supra* note 35, at 11, ¶ 33.

43. *Id.* at 10-11, ¶ 32. In its 2001 Concluding Observations and Recommendations to the United States, the CERD Committee also identified the existence of persistent disparities in public and private health care as an area of concern. U.N. Gen. Assembly, Comm. on the Elimination of Racial Discrimination, Concluding Observations of the Committee on the Elimination of Racial Discrimination: United States of America, ¶ 19, U.N. Doc. CERD/C/59/Misc.17/Rev.3 (2001). While acknowledging generically the “numerous laws, institutions, and measures de-

“collect statistical data on health disparities affecting persons belonging to racial, ethnic and national minorities [that is] disaggregated by age, gender, race, ethnic or national origin, and to include [that information] in its next periodic report.”⁴⁴

C. Report of the United Nations Special Rapporteur for Health on Factors to Strengthen a Health System to Protect the Right to Health

In 2008, the United Nations Special Rapporteur for Health submitted a report to the Human Rights Council that identified seventeen features of a health care system that protects the right to health (RTH-Strengthening Health Systems report).⁴⁵ This report was designed as a resource for countries to use to develop or strengthen their health care systems.⁴⁶ The features were derived from features that existed in health systems, features recognized in international health instruments, or features advocated for in the medical and public

signed to eradicate racial discrimination,” the CERD Committee recommended that the United States “take all appropriate measures, including special measures [pursuant] to article 2, paragraph 2 . . . to ensure the right of everyone without discrimination as to race, colour, or national or ethnic origin to the enjoyment of the rights contained [within] article 5.” *Id.*

44. CERD, *Concluding Observation on U.S. Reports*, *supra* note 35, at 10-11, ¶ 32. The importance of data collection to enforcement of non-discrimination laws and the lack of availability of this information in the United States has been previously recognized by the United States Commission on Civil Rights, civil rights advocacy groups, and legal scholars like Professor Vernellia Randall. See U.S. COMM’N ON CIVIL RIGHTS, *THE HEALTH CARE CHALLENGE: ACKNOWLEDGING DISPARITY, CONFRONTING DISCRIMINATION, AND ENSURING EQUALITY, VOLUME 1, THE ROLE OF GOVERNMENTAL AND PRIVATE HEALTH CARE PROGRAMS AND INITIATIVES* 50-52 (1999); Randall, *supra* note 17, at 63. See generally Madison-Hughes v. Shalala, 80 F.3d 1121 (6th Cir. 1996) (concerning a civil rights advocacy group’s demands for the government to collect more data pertaining to health care and minority groups).

45. Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, *Promotion and Protection of all Human Rights, Civil, Political, Economic, Social and Cultural Rights*, ¶¶ 36-66, U.N. Gen. Assembly, Human Rights Council, U.N. Doc. A/HRC/7/11 (Jan. 31, 2008) (by Paul Hunt) [hereinafter *RTH-Strengthening Health Systems Report*]. The seventeen features include: (1) a people-centered approach; (2) a focus on process and outcome; (3) transparency; (4) participation; (5) equity, equality, and non-discrimination; (6) respect for cultural difference; (7) the provision of medical care coupled with attention to the underlying determinants of health; (8) progressive development of a health care system that protects the right to health in light of resource availability; (9) adherence to the immediate core obligations; (10) an emphasis on the provision of quality care; (11) the provision of primary and secondary care coupled with effective referrals to specialists; (12) the development of a comprehensive integrated system instead of a disease/condition focused approach; (13) coordination of activities between the public and private actors at the national and international level; (14) an emphasis on health as a global public good; (15) making tough policy choices in light of a limited budget through a fair, transparent, and participatory process; (16) monitoring and accountability of conduct, performance, and outcomes of a health system; and (17) an approach to the right to health as a legally binding obligation. See *id.* ¶¶ 37-66.

46. See *id.* at 2.

health literature.⁴⁷ The Special Rapporteur for Health also consulted with a wide range of stakeholders in eight countries.⁴⁸

This important report does not rely heavily on legal authority. In fact, it rarely cites legal authorities.⁴⁹ Instead, it is a forward-looking report targeted to health policy development that incorporates a right to health approach.⁵⁰ There are three features from the RTH-Strengthening Health Systems report that are particularly important to helping the United States reduce health care disparities for racial and ethnic minorities. They are factor 5–Equity, Equality, and Non-Discrimination; factor 7–Medical Care and the Underlying Determinants of Health; and factor 10–Quality.

1. Factor 5–Equity, Equality, and Non-Discrimination

Equity, equality, and non-discrimination are related concepts that emphasize social justice.⁵¹ Equity is a health concept that has an ethical focus.⁵² Equity requires the provision of “health care to all individuals in a manner that does not vary in quality because of personal characteristics such as gender, *ethnicity*, geographic location, and *socioeconomic* status.”⁵³ According to the Institute of Medicine (IOM), equity is a core aspect of quality and should be included in the United States’ “nation[al] quality improvement agenda.”⁵⁴ In the global health context, the WHO has a longstanding policy to achieve health equity through its Health for All policy, which sets a goal “for all citizens of the world” to attain a level of health that “lead[s to] socially

47. *Id.* at 6, ¶ 18.

48. *Id.* at 6 n.5. The eight countries included: the United Kingdom of Great Britain and Northern Ireland, the United States of America, New Zealand, Australia, Switzerland, Italy, and Zimbabwe. *Id.*

49. The report cites the Alma Ata Declaration (most cited); the International Covenant on the Rights of the Child; General Comment 14 (referring to the meaning of progressive realization and immediate core obligations); and makes a brief reference to the U.N. Charter and UDHR in the context of international assistance and cooperation. *Id.* at 12 n.22, ¶ 47, ¶ 51 n.26, ¶ 60, ¶ 90 n.39.

50. See Paul Hunt & Sheldon Leader, *Developing and Applying the Right to the Highest Attainable Standard of Health: The Role of the U.N. Special Rapporteur (2002-2008)*, in *GLOBAL HEALTH AND HUMAN RIGHTS: LEGAL AND PHILOSOPHICAL PERSPECTIVES* 28, 28 (John Harrington & Maria Stuttaford eds., 2010).

51. See *id.* at 47; see also RTH-Strengthening Health Systems Report, *supra* note 45, at 12.

52. See Hunt & Leader, *supra* note 50, at 46; Audrey R. Chapman, *The Social Determinants of Health, Health Equity, and Human Rights*, *HEALTH & HUM. RTS.*, 2010, at 17, 21-22.

53. IOM FUTURE DIRECTIONS OF NHQR & NHDR, *supra* note 2, at 44 (emphasis added) (internal quotation marks omitted).

54. *Id.*

and economically productive li[ves].”⁵⁵ For the WHO, health equity is a tool to “eliminat[e] disparities in health and in health’s major determinants that are systematically associated with underlying social disadvantage within a society.”⁵⁶ Therefore, a health care system that protects the right to health distributes health care by ensuring “equal access to health care according to need.”⁵⁷

Equality is a global health law concept. The concept of equality is reflected in two human rights instruments. Article 7 of the Universal Declaration of Human Rights and article 26 of the International Covenant for Civil and Political Rights both provide that “all are equal before the law and are entitled without any discrimination to equal protection of the law.”⁵⁸ The meaning of equality is often not defined, but merely viewed as the positive equivalent to non-discrimination, a negative concept.⁵⁹ Scholars like Gillian MacNaughton distinguish equality from discrimination.⁶⁰ More specifically, positive equality re-

55. GIAN LUCA BURCI & CLAUDE-HENRI VIGNES, WORLD HEALTH ORGANIZATION 162 (2004) (internal quotation marks omitted). The “Health for All” agenda began in 1977 through passage of a world health resolution. *See id.*

56. WHO, *25 Questions & Answers on Health and Human Rights*, HEALTH & HUM. RTS. PUBL’N SERIES, 2002, at 24, available at http://www.who.int/hhr/activities/en/25_questions_hhr.pdf. “[E]quity in health can be defined as the absence of systematic disparities in health . . . between social groups who have different levels of underlying social advantage/disadvantage.” P. Braveman & S. Ruskin, *Defining Equity in Health*, 57 J. EPIDEMIOLOGY & COMMUNITY HEALTH 254 (2003). Health equity can be assessed at the local, national, and global level.

57. RTH-*Strengthening Health Systems Report*, *supra* note 45, ¶ 43 (internal quotation marks omitted).

58. UDHR, *supra* note 16; International Covenant on Civil and Political Rights, art. 26, Dec. 16, 1966, 999 U.N.T.S. 171 [hereinafter ICCPR]. The preamble to ICERD incorporates the language from the UDHR that all are equal before the law. ICERD, *supra* note 28, pmb.

59. Gillian MacNaughton, *Untangling Equality and Non-Discrimination to Promote the Right to Health Care for All*, 11 HEALTH & HUM. RTS. 47, 47–48 (2009). Non-discrimination is viewed as the negative form of equality because it prohibits different treatment based on expressly stated grounds. *Id.* For example, both the UDHR and ICCPR have separate non-discrimination provisions that identify prohibited distinctions that impair the exercise of covenant rights. *Id.* at 49–50. Article 2 of the UDHR and article 2 of ICCPR both guarantee to individuals the rights under the declaration or covenant “without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth, or other status.” UDHR, *supra* note 16, art. 2; ICCPR, *supra* note 58, art. 2.

60. While the exact meaning of non-discrimination, equality before the law, and equal protection of the law is not clear under UDHR and ICCPR, it is clear that the drafters of UDHR and ICCPR viewed them as distinct concepts. MacNaughton, *supra* note 59, at 47-48, 50. See also General Comment 18 of the ICCPR, which recognizes three protections by stating, “[a]rticle 26 not only entitles all persons to equality before the law as well as equal protection of the law but also prohibits any discrimination under the law” U.N. High Comm’r for Human Rights, General Comment No. 18: Non-Discrimination, U.N. Doc. HRI/GEN/1/Rev.6 (Nov. 10, 1989) [hereinafter General Comment 18]. General Comment No. 18 further clarifies the distinction between the concepts of equality and non-discrimination by noting that “article 26 [equality] does not merely duplicate the guarantee already provided for in article 2 [discrimination] but provides in itself an autonomous right.” General Comment 18, ¶ 12; MacNaughton, *supra* note 59, at 51.

quires “that everyone be treated in the same manner unless some alternative justification is provided.”⁶¹ For health systems, the U.N. Special Rapporteur for Health interprets this to mean that the health system offers the same health facilities, goods, and services to all.⁶²

Non-discrimination is also a global health law concept. Several treaties prohibit discrimination.⁶³ ICERD prohibits racial discrimination.⁶⁴ Racial discrimination is any distinction, exclusion, restriction, or preference based on prohibited grounds (race, color, descent, and national or ethnic origin) with the intent or effect of impairing the enjoyment of a covenant right.⁶⁵ This means that countries like the United States, which provide public health and medical care services, must do so in a non-discriminatory manner. Moreover, ICESCR—which protects the right to health in article 12—also provides that such treaty rights will be provided “without discrimination of any kind as to race, colour, . . . language, . . . or other status.”⁶⁶ Thus, “health facilities, goods, and services must be accessible to all, especially the most vulnerable or marginalized sections of the population, in law and in fact, without discrimination”⁶⁷ based on prohibited grounds. Ensuring access to the most vulnerable or marginalized sections of the population, such as ethnic minorities and indigenous people, includes “outreach and other programmes to ensure that disadvantaged indi-

61. MacNaughton, *supra* note 59, at 47.

62. RTH-*Strengthening Health Systems Report*, *supra* note 45, at 11.

63. Only four human rights treaties explicitly define discrimination: ICERD, CEDAW, ILO Convention Concerning Discrimination in Respect of Employment and Occupation, and UNESCO Convention Against Discrimination in Education (1960). Anne F. Bayefsky, *The Principle of Equality or Non-Discrimination in International Law*, 11 HUM. RTS. J. 1, 8 (1990).

64. ICERD, *supra* note 28, art. 1.

65. *Id.*

66. ICESCR, *supra* note 24, art. 2. The text of ICESCR does not define non-discrimination. However, the Committee on Economic Social and Cultural Rights adopted the non-discrimination language from ICERD in General Comment 20. U.N. Econ. & Soc. Council, Comm. on Econ., Soc. & Cultural Rights, General Comment No. 20: Non-Discrimination in Economic, Social and Cultural Rights (art. 2, para. 2, of the International Covenant on Economic, Social and Cultural Rights), ¶ 7, U.N. Doc. E/C.12/GC/20 (July 2, 2009) [hereinafter General Comment 20].

67. General Comment 14, *supra* note 23, ¶ 12(b). General Comment 14 addresses non-discrimination in several other provisions. Paragraph 43 provides that countries have a core obligation to ensure that access to health facilities, goods, and services are provided in a non-discriminatory way. *Id.* ¶ 43(a). This means that countries must immediately implement this protection instead of progressively incorporating the right over time. Additionally, in a section entitled, “Non-discrimination and equal treatment,” countries are reminded that ICESCR prohibits “discrimination in access to health care and underlying determinants of health, as well as to means and entitlements for their procurement on the grounds of race, colour, . . . language, national or social origin, . . . social or other status” *Id.* ¶ 18.

viduals and groups have the same access as those who are more advantaged.”⁶⁸

2. Factor 7—Medical Care and Underlying Determinants

The right to health is a broad concept. It includes medical care and the underlying determinants of health.⁶⁹ Public health and societal factors constitute underlying determinants of health.⁷⁰ Public health is what a society does to improve population health.⁷¹ It includes conditions that impact population health like access to nutritious food, housing, safe working conditions, and a healthy environment.⁷² Societal factors include statuses that result in exclusion such as gender, race, poverty, etc.

If a country wants to improve the health of its citizens, it must not only provide medical care, but it must address public health. In 2010, the Institute of Medicine reiterated the importance of the United States in focusing its resources and efforts on improving public health

68. RTH-*Strengthening Health Systems Report*, *supra* note 45, at 11. Taking affirmative or outreach measures to ensure that vulnerable or marginalized groups like racial and ethnic people of color have access to care is also consistent with ICERD’s provision authorizing States to take special measures to protect racial groups’ rights to public health or medical care. ICERD, *supra* note 28, art. 2(2).

69. See *supra* Part II.A; PPACA, Pub. L. No. 111-148, 124 Stat. 119 (2010), amended by Health Care and Education Reconciliation Act of 2010, Pub. L. No. 111-152, 124 Stat. 1029; RTH-*Strengthening Health Systems Report*, *supra* note 45, ¶ 45.

70. RTH-*Strengthening Health Systems Report*, *supra* note 45, ¶ 45. More specifically, “[s]ocial determinants of health refers to the social conditions, in which people are born, grow, live, work, and age, that shape their health and disease exposures, vulnerabilities and outcomes.” WHO, PUTTING OUR OWN HOUSE IN ORDER: EXAMPLES OF HEALTH-SYSTEM ACTION ON SOCIALLY DETERMINED HEALTH INEQUALITIES, at xi (2010). The phrase underlying determinants of health, broadly interpreted, is equivalent to the phrase social determinants of health. This Article adopts that broader view, as does the RTH-*Strengthening Health Systems Report* of the Special Rapporteur for Health and General Comment 14. General Comment 14 adopts a broader view when considered in its totality by mentioning underlying determinants of health while simultaneously emphasizing the need for equal access to all and prohibiting discrimination and distinctions based on race, poverty, gender, etc. General Comment 14, *supra* note 23, ¶¶ 4, 10, 12, 18, 19. Paragraph 10 explicitly notes the broader meaning of determinants of health to include, for example, resource distribution and gender exclusion. The benefit of a broad interpretation of underlying determinants of health or social determinants of health is that it links injustice and inequalities with social structures that affect opportunities economically, culturally, and socially. Chapman, *supra* note 52, at 21. Social determinants of health is discussed more fully *infra* Part I.D.

71. Gwendolyn Roberts Majette, *PPACA and Public Health: Creating a Framework to Focus on Prevention and Wellness and Improve the Public’s Health*, 39 J.L. MED. & ETHICS 366, 366 (2011) (providing an insider’s perspective on Congress’s approach to public health during the drafting of the PPACA and analysis of how PPACA shifts the U.S. health care system to focus on prevention, wellness, and public health consistent with IOM and human rights norms) [hereinafter *PPACA and Public Health*].

72. General Comment 14, *supra* note 23, ¶ 4; RTH-*Strengthening Health Systems Report*, *supra* note 45, ¶ 45.

through increased attention on preventing disease and promoting health, and not solely focusing on improving the efficiency and effectiveness of clinical care.⁷³ Health care systems that effectively protect the right to health integrate medical care and public health and are accessible to all.⁷⁴ This integrated approach requires governments to look at the interrelationship between the right to health and other protected human rights like the rights to housing, education, human dignity, non-discrimination, and equality.⁷⁵

3. Factor 10–Quality

An essential element of the right to health is quality.⁷⁶ Health facilities, goods, and services must be scientifically and medically appropriate and of good quality,⁷⁷ which “requires, *inter alia*, skilled medical personnel, scientifically approved and unexpired drugs,⁷⁸ [safe and adequate] hospital equipment, safe and potable water, and adequate sanitation.”⁷⁹ Good quality care also governs how patients are treated.⁸⁰ Patients should be treated with politeness and respect, and not be subjected to the biases of health care providers.⁸¹

73. INST. OF MED., COMM. ON PUB. HEALTH STRATEGIES TO IMPROVE HEALTH, FOR THE PUBLIC’S HEALTH: THE ROLE OF MEASUREMENT IN ACTION AND ACCOUNTABILITY 2 (2011); *PPACA and Public Health*, *supra* note 71, at 367. Majette also recognizes the need for the United States to discontinue its past practice of spending a disproportionate amount of its health care spending on medical care (ninety-six percent) compared to prevention (four percent). *Id.* at 376 n.17.

74. ECOSOC Special Rapporteur Report, *supra* note 16, ¶ 4. For an analysis of how the Patient Protection and Affordable Care Act helps the United States to integrate its medical care and public health systems, see Lorian E. Hardcastle, Katherine L. Record, Peter D. Jacobson & Lawrence O. Gostin, *Improving the Population’s Health: The Affordable Care Act and the Importance of Integration*, 39 J.L. MED. & ETHICS 317, 317 (2011).

75. General Comment 14, *supra* note 23, ¶ 3 (noting the dependency of the right to health on the “realization of other human rights, as contained in the International Bill of Rights, including the rights to food, housing, work, education, human dignity, life, non-discrimination, equality, the prohibitions against torture, privacy, access to information, and the freedoms of association, assembly and movement.”).

76. *Id.* ¶ 12(d).

77. *Id.*

78. Health care systems should have a regulatory system that tests for “substandard, counterfeit, or contaminated drugs.” U.N. Gen. Assembly, *The Right of Everyone to Enjoy the Highest Attainable Standard of Physical and Mental Health*, 15, U.N. Doc. A/58/427 (Oct. 10, 2003).

79. General Comment 14, *supra* note 23, ¶ 12(d); see World Health Org. & the United Nations Human Rights Council, *Human Rights, Health and Poverty Reduction Strategies*, HEALTH & HUM. RTS. PUBL’N SERIES, Dec. 2008, at 23.

80. RTH-*Strengthening Health Systems Report*, *supra* note 45, ¶ 54.

81. *Id.* WHO, *WHO’s Contribution to the World Conference Against Racism, Racial Discrimination, Xenophobia and Related Intolerance: Health and Freedom from Discrimination*, HEALTH & HUM. RTS. PUBL’N SERIES, Aug. 2001, at 9.

Domestically, the Institute of Medicine defines quality of health-care as “the degree to which health services for individuals and populations increase the likelihood of desired healthcare outcomes and are consistent with current professional knowledge.”⁸² Quality healthcare is safe, effective, patient-centered, timely, efficient, and *accessible*.⁸³ Equity is a cross-cutting theme that applies to every aspect of quality assessment.⁸⁴ Quality health care is “doing the right thing for the right patient, at the right time, in the right way to achieve the best possible results.”⁸⁵ Moreover, quality health care “is based on scientific and medical evidence, it takes the specific details of a patient’s life into consideration, and it is aimed at improving the health and life of the patient being treated.”⁸⁶

According to the 2010 National Healthcare Quality Report and the National Healthcare Disparities Report, the quality of care and access to care is “suboptimal” in the United States, “especially for minority and low-income populations.”⁸⁷ Additionally, while “quality is improving; access and disparities are not improving.”⁸⁸

82. COMM. ON QUALITY OF HEALTH CARE IN AM., INST. OF MED., CROSSING THE QUALITY CHASM, A NEW HEALTH SYSTEM FOR THE 21ST CENTURY 232 (2001) [hereinafter CROSSING THE QUALITY CHASM].

83. Safe health care does not harm the patient. Effective care is based on scientific knowledge. Patient-centered health care responds to patient preferences and values. Timely care is delivered in a manner to reduce wait times and delays. Efficient care avoids waste. CROSSING THE QUALITY CHASM, *supra* note 82, at 6, 232. Accessible care is “the timely use of personal health services to achieve the best possible health outcomes.” IOM FUTURE DIRECTIONS OF NHQR & NHDR, *supra* note 2, at 46.

84. Equitable care does not vary because of gender, ethnicity, geography, or socio-economic status. CROSSING THE QUALITY CHASM, *supra* note 82, at 6. In 2011, the IOM expanded the concept of equity to apply across every dimension of quality assessment. IOM FUTURE DIRECTIONS OF NHQR & NHDR, *supra* note 2, at 41-42.

85. NAT’L COMM. FOR QUALITY ASSURANCE, THE ESSENTIAL GUIDE TO HEALTH CARE QUALITY 8, available at http://www.ncqa.org/Portals/0/Publications/Resource%20Library/NCQA_Primer_web.pdf. [hereinafter ESSENTIAL GUIDE TO QUALITY].

86. *Id.*

87. U.S. DEP’T OF HEALTH & HUMAN SERVS., AGENCY FOR HEALTHCARE RESEARCH & QUALITY, 2010 NATIONAL HEALTHCARE DISPARITIES REPORT 2 (2011) [hereinafter AHRQ, NHDR]. This is not the first time that the quality of care generally provided in the United States has been found deficient and barriers to access to care have been identified. The IOM published two seminal reports on quality, TO ERR IS HUMAN (2000) and CROSSING THE QUALITY CHASM (2001). INST. OF MED., COMM. ON QUALITY OF HEALTH CARE IN AM., TO ERR IS HUMAN: BUILDING A SAFER HEALTH SYSTEM (2000); CROSSING THE QUALITY CHASM, *supra* note 82. It also published a seminal report on access barriers for people of color in 2003. IOM, UNEQUAL TREATMENT, *supra* note 2.

88. AHRQ, NHDR, *supra* note 87, at 2. AHRQ’s definition of disparity used in the NHDR differs from the IOM definition provided in IOM Future Directions of the National Healthcare Quality and Disparities Report. IOM, FUTURE DIRECTIONS OF NHQR & NHDR, *supra* note 2, at 44. AHRQ’s definition is a broader concept that focuses on “simple differences.” *Id.*

In the United States, at the federal level, there are five major areas of health care quality initiatives: (1) research, (2) quality measure development, (3) quality data collection and reporting, (4) patient safety improvement, and (5) implementation of health information technology.⁸⁹ The IOM recently identified eight priority areas for quality improvement in the United States.⁹⁰ One of those priorities is “ensur[ing] that care is accessible and affordable for all segments of the U.S. population.”⁹¹ For all eight priority areas, there were “disparities related to race, ethnicity, and socio-economic status.”⁹²

D. Global Health Governance—Commission on Social Determinants of Health

A global infrastructure has been created to advance social determinants of health as a basis to improve health and lower health inequity worldwide. The catalyst for the creation of this infrastructure was the Commission on Social Determinants of Health (SDH Commission).⁹³ The Commission was created in 2005 by the Director General of the WHO, Dr. J.W. Lee.⁹⁴ It was chaired by Dr. Michael Marmot, a pioneer known for his work on the impact of social inequity on health.⁹⁵ The vision of the SDH Commission was to establish a global movement to address health equity.⁹⁶ A task of the SDH Commission

89. See generally New Frontiers in Quality Initiatives: Hearing Before the Subcomm. on Health of the H. Comm. on Ways and Means, 108th Cong. 9-19 (2004) (statement of Carolyn M. Clancy, M.D.) (outlining some federal health care quality initiatives).

90. IOM, *FUTURE DIRECTIONS OF NHQR AND NHDR*, *supra* note 2, at 34. The priority areas are improving patient and family engagement, population health, safety, care coordination, palliative care, and access to care for all. *Id.* It also includes improving the capabilities of the infrastructure of health systems to support quality care and eliminating overuse of services. *Id.*

91. *Id.* As of 2011, two priority areas were improving (palliative care and patient and family engagement); two needed more data (health system infrastructure and care coordination); and three were lagging (access, population health, and safety). AHRQ, NHDR, *supra* note 87, at 2.

92. *Id.*

93. See Ruth Bell, Sebastian Taylor, & Michael Marmot, *Global Health Governance: Commission on Social Determinants of Health and the Imperative for Change*, 38 J.L. MED. & ETHICS 470, 476 (2010) [hereinafter Marmot, *GHG-Comm'n SDH*]. The term “social” as used in the commission’s name is used in its broadest sense to include environmental, economic, political, and cultural conditions. *Id.*

94. *Id.*

95. Chapman, *supra* note 52, at 18. Dr. Marmot is a Professor of Epidemiology and Public Health and the head of the Department of Epidemiology and Public Health at University College London. Marmot, *GHG-Comm'n SDH*, *supra* note 93, at 470. After serving as Chair of the Commission on Social Determinants of Health, he chaired the Review of Health Inequalities in England. *Id.*

96. Marmot, *GHG-Comm'n SDH*, *supra* note 93, at 475.

was to shift global health from a biomedical model to a social model, which includes global social and political conditions.⁹⁷ This shift is important because it recognizes the social gradient in health: “the lower the position in the social hierarchy, the worse the health.”⁹⁸

While the SDH Commission was an initiative of the WHO, it was created as a separate independent organization with twenty commissioners.⁹⁹ The role of the commissioners was to serve as champions of health equity in their own countries, regionally, and globally.¹⁰⁰ The SDH Commission had a four-part structure that focused on knowledge, action, leadership, and advocacy.¹⁰¹ Its core operational elements included subject matter work groups,¹⁰² country partners,¹⁰³ civil society partners, the WHO, and the Commissioners.¹⁰⁴

1. Closing the Gap in a Generation—Recommendations from the SDH Commission’s Final Report

The SDH Commission made three specific recommendations, but could not prioritize them because of the different social, economic, and political needs of countries.¹⁰⁵ One of the recommendations requires countries to improve the daily living conditions of individuals.¹⁰⁶ For health systems, they should provide universal coverage.¹⁰⁷

97. *See id.*

98. *Id.* at 472. Income inequality can adversely affect social conditions that are important for good health. *See* Marmot & Bell, *supra* note 6, at 1170. Among Organization for Economic Co-operation and Development (OECD) countries, the United States has the third highest poverty rate and the fourth highest disposable income inequality. *Id.*

99. *See* Marmot, *GHG-Comm’n SDH*, *supra* note 93, at 476; Chapman, *supra* note 52, at 18. The commission was composed of a diverse group that included “former heads of government, former and current government ministers, national policy makers and international advisors, leaders in international organizations and civil society, and eminent academics.” Marmot, *GHG-Comm’n SDH*, *supra* note 93, at 476.

100. *Id.*

101. *Id.*

102. The formal name of this component is “knowledge networks.” Chapman, *supra* note 52, at 18 (internal quotation marks omitted). The knowledge networks addressed nine topics: “globalization, early childhood development, employment conditions, women and gender equity, social exclusion, health systems, priority public health conditions, urban settings, and measurement and evidence.” *Id.*; Marmot, *GHG-Comm’n SDH*, *supra* note 93, at 476.

103. These countries were the first to implement the ideas of and share their experience with the commission on taking action through initiatives on social determinants of health. *See* Marmot, *GHG-Comm’n SDH*, *supra* note 93, at 477. There were eight country partners: England, Sweden, Canada, Brazil, Chile, Iran, Sri Lanka, and Kenya. *Id.*

104. *Id.* at 476.

105. *See id.* at 477.

106. *See* WHO, Comm’n. on Soc. Determinants of Health, *Closing the Gap in a Generation: Health Equity Through Action on the Social Determinants of Health*, at 202 (2008) [hereinafter Comm’n, *SDH Final Report*]; WHO, *Commission on Social Determinants of Health: Report by the Secretariat*, ¶ 10 (Mar. 16, 2009) [hereinafter *Comm’n SDH Secretariat Report*]. Conditions

Creation of a system with universal coverage should be a priority issue and an action item. The core values of the system should be equity, disease prevention, and health promotion.¹⁰⁸ Quality care should be provided, and equitable financing mechanisms should be employed to ensure that care is provided regardless of the ability to pay.¹⁰⁹

Second, countries must tackle inequitable distribution of power, money, and resources, which constitute the structural drivers of health.¹¹⁰ Countries should include health equity in all policies, systems, and programs.¹¹¹ This can be done by including a health equity impact assessment in all policies.¹¹² Third, countries should measure and understand the problem and assess the impact of action.¹¹³ This means countries must engage in health equity surveillance.¹¹⁴

From a governance perspective, governments must make health equity a priority at the global, national, and local levels.¹¹⁵ The health sector must include social determinants in policy matters.¹¹⁶ Health must be approached from a multi-sectoral point of view. This means that all parts of society will address health, reflecting “health-in-all” policies.¹¹⁷

2. SDH Commissioners’ Advice to the United States on How to Reduce Health Disparities

It is critical that the United States invests significantly in addressing social determinants of health to improve population health and reduce health care disparities. Four SDH commissioners have recom-

of daily living encompasses where people are born, grow, live, work and age. Thus early childhood development should be emphasized; environments should be healthy; work should be available, provide equal pay, and be safe; and social protections that support sufficient income levels should be provided. Comm’n, *SDH Final Report*, *supra*, at 202-03.

107. Comm’n, *SDH Final Report*, *supra* note 106, at 203; *Comm’n SDH Secretariat Report*, *supra* note 106, ¶¶ 10,11(f).

108. See Comm’n, *SDH Final Report*, *supra* note 106, at 203.

109. *Id.*

110. See *id.* at 43, 204; *Comm’n SDH Secretariat Report*, *supra* note 106, ¶¶ 10, 11(f).

111. Comm’n, *SDH Final Report*, *supra* note 106, at 204; *Comm’n SDH Secretariat Report*, *supra* note 106, ¶ 12(b).

112. See Marmot, *GHG-Comm’n SDH*, *supra* note 93, at 477; Comm’n, *SDH Final Report*, *supra* note 106, at 204.

113. See Comm’n, *SDH Final Report*, *supra* note 106, at 206; *Comm’n SDH Secretariat Report*, *supra* note 106, ¶¶ 10, 13.

114. See Comm’n, *SDH Final Report*, *supra* note 106, at 206; *Comm’n SDH Secretariat Report*, *supra* note 106, ¶ 13.

115. See Marmot, *GHG-Comm’n SDH*, *supra* note 93, at 477; *Comm’n SDH Secretariat Report*, *supra* note 106, ¶ 12(a).

116. See *Comm’n SDH Secretariat Report*, *supra* note 106, ¶ 12(b).

117. *Id.* ¶ 14; see Marmot, *GHG-Comm’n SDH*, *supra* note 93, at 477-78.

mended that the United States incorporates social determinants of health in its policy and legislation that impact health. The former Chair of the SDH Commission, Michael Marmot, and Dr. Ruth Bell, another commissioner, recommended that the United States improve population health, without spending more money on health, by focusing on social determinants of health.¹¹⁸ Throughout the world, for everyone below the top socio-economic position, health inequities exist.¹¹⁹ But these inequities can be reduced through political, social, and economic changes.¹²⁰

SDH Commissioners Marmot and Bell provided three recommendations on how the United States could improve population health in light of the work of the SDH Commission. First, health equity must be a key performance indicator for social and economic policy.¹²¹ Second, working on social and economic policy to address health inequity must be a priority at the highest level of government.¹²² Third, communities across the United States should work on health inequity.¹²³ Commissioners Marmot and Bell also made recommendations on how the United States could help reduce health inequalities worldwide. The United States should take a leadership role in ensuring that the “international community recommit[s] to a more representative multilateral system with fairer participation by all countries and the opportunity to place health equity at the heart of multilateral policy development in areas including trade, finance, responses to climate change, and international security.”¹²⁴

In 2009, two American SDH commissioners, David Satcher, a former Surgeon General, and Gail Wilensky, a former administrator of the Health Care Financing Administration, urged adoption of a health improvement agenda that included addressing social determi-

118. Marmot & Bell, *supra* note 6, at 1171.

119. *See id.* at 1170. Health inequities and disparities exist between countries and within countries. *See id.* at 1169. Life expectancy in Japan is 82.4 years compared to Zambia, which is 41.2 years. *Id.* In life expectancy from birth to age 65, the United States ranks 36th for men and 42nd for women. *Id.* The gap in life expectancy between the most advantaged and least advantaged in the United States is 20 years. Michael Marmot, *Social Determinants of Health Inequalities*, 365 *LANCET* 1099, 1099 (2005). The gradient for life expectancy by socioeconomic deprivation in the United States has worsened for men and women since 1980. Marmot & Bell, *supra* note 6, at 1170. When comparing illness rates and life expectancy of the United States to England, the United States has a higher rate of illness and shorter life expectancy. *Id.* at 1169.

120. *See* Marmot & Bell, *supra* note 6, at 1170.

121. *See id.* at 1171.

122. *See id.*

123. *See id.*

124. *Id.* (internal quotation marks omitted).

nants of health as part of any national health care reform legislation.¹²⁵ They also acknowledged that this approach would likely be far less costly than addressing problems with the health care system.¹²⁶ Commissioners Satcher and Wilensky highlighted the importance of addressing social determinants of health for children and the impact of determinants throughout the child's life. Attention should be paid to childhood development and education, nutrition, the provision of safe and nurturing environments, reduction of substance abuse (including smoking) by young people and pregnant women, and ensuring access to health care (i.e. enrolling in Medicaid or the Children's Health Insurance Program).¹²⁷

E. World Health Organization Initiatives and Resolution on Social Determinants of Health

In addition to helping to create the SDH Commission, WHO took important steps to continue to advance the work on social determinants of health. First, through its strategic plan for 2008-2013, WHO incorporated initiatives to work on social determinants of health.¹²⁸ Thus, its policies and programs would address social determinants of health. It would focus on health equity and approaches that were (1) pro-poor, (2) gender responsive, and (3) human rights focused.¹²⁹ Second, WHO made a commitment to support member states working on social determinants of health by monitoring and developing policies to improve health and lower health inequities.¹³⁰ It also developed partnerships with the United Nations, civil society, and the private sector to improve health and lower health inequities.¹³¹ Third, the World Health Assembly in May 2009 passed a resolution to support action on social determinants of health as a means to reduce

125. *PPACA and Public Health*, *supra* note 71, at 371-72 (describing Dr. Satcher's testimony before the United States Congress on the impact of social determinants of health on population health and the need to adopt a public health approach that includes social determinants of health as part of health care reform legislation); Gail R. Wilensky & David Satcher, *Don't Forget About the Social Determinants of Health*, 28 HEALTH AFF. 2, w194, w194-95, w198 (2009).

126. Wilensky & Satcher, *supra* note 125, at w195.

127. *See id.* at w195-97.

128. Marmot, *GHG-Comm'n SDH*, *supra* note 93, at 477.

129. *Id.*

130. *See id.*; WHO-EUROPE, *Putting Our Own House in Order: Examples of Health-System Action on Socially Determined Health Inequalities*, at 2 (2010), available at http://www.euro.who.int/__data/assets/pdf_file/0004/127318/e94476.pdf.

131. Marmot, *GHG-Comm'n SDH*, *supra* note 93, at 477. The SDH-Commission also recommended that WHO be strengthened so that it could be a leader in global health work with other multilateral agencies. *Id.* at 479.

health inequity.¹³² The resolution included a request to the Director-General to convene a global event in order to discuss future plans to address social determinants of health and report on the progress of social determinants of health at the World Health Assembly in 2012.¹³³

II. CREATING A LEGISLATIVE FRAMEWORK TO PROTECT THE RIGHT TO HEALTH AND ELIMINATE HEALTH DISPARITIES

A. General Comment 14 Urges Governments to Protect the Right to Health Through Policy and Legislative Mechanisms

Pursuant to General Comment 14, governments that have ratified ICESCR must implement a national strategy to ensure that everyone has access to health care facilities, goods, and services.¹³⁴ This strategy should be based on human rights principles and include benchmarks and indicators to monitor progress (or access).¹³⁵ It should also include identification of the available resources to execute the strategy.¹³⁶ Once the strategy is created, governments are encouraged to “adopt[] a framework law to operationalize” it.¹³⁷

In recognition that the government alone cannot protect the health of its population, the government is encouraged to make the private business sector and civil society aware of the importance of the right to health.¹³⁸ The government should also identify potential areas of collaboration with civil society, the private sector, and international organizations.¹³⁹

132. WHO, World Health Assembly, *Reducing Health Inequities Through Action on Social Determinants of Health*, Res. 62.14 62d Sess., WHA Doc. A62/VR8 (May 22, 2009) [hereinafter WHO, *SDH Resolution*]; Marmot, *GHG-Comm'n SDH*, *supra* note 93, at 481-82. The resolution provided that WHO would work with other multilateral agencies to develop measures and to promote policy coherence to reduce health inequity. *Id.* at 482. WHO would also strengthen its internal capacity to work on SDH. *See* WHO, *SDH Resolution*, *supra*, ¶ 4(2). The SDH Commission also made a recommendation that WHO “institutionalize social determinants of health as guiding principle across WHO departments and country programs.” Marmot, *GHG-Comm'n SDH*, *supra* note 93, at 480.

133. *See* WHO, *SDH Resolution*, *supra* note 132, ¶¶ 4(11), 4(13); Marmot, *GHG-Comm'n SDH*, *supra* note 93, at 482.

134. *See* General Comment 14, *supra* note 23, ¶ 53.

135. *See id.*

136. *See id.*

137. *Id.* ¶ 56. Like the national right to health strategy, the framework law should also establish a national monitoring mechanism, which contains targets, timeframes, means, and collaborative opportunities with non-governmental entities. *Id.*

138. *Id.* ¶ 55.

139. *Id.* ¶ 56.

According to Professor Eleanor Kinney, the right to health is not protected in the United States pursuant to an international obligation.¹⁴⁰ As discussed previously, the U.S. has not ratified ICESCR, the seminal treaty creating a human right to health.¹⁴¹ Instead the right to health, to the extent it exists, is protected through a legislative infrastructure created pursuant to federal and state law.¹⁴² This legislative infrastructure includes: (1) legislation that finances health care services to certain vulnerable groups through Medicare, Medicaid, and CHIP; (2) federal and state legislation that regulates private insurance to protect consumer interest (ERISA, HIPPA, state benefit mandates); (3) legislation that provides health care services to covered groups; (4) legislation that protects and promotes public health (public health reporting laws); and (5) legislation that prohibits discrimination in access to health care services (Title VI and the ADA).¹⁴³ The PPACA furthers this legislative focus.

B. Patient Protection and Affordable Care Act's Legislative Framework to Reduce Health Disparities Among People of Color

1. PPACA Makes Health and Health Inequity Priority Issues

PPACA creates a legislative framework that protects the right to health¹⁴⁴ and helps reduce health care disparities for people of color in the United States. PPACA adheres to global health law norms, specifically the SDH Commission, by making health and health inequity priority issues at the highest levels of government. Section 10334 of PPACA elevates these issues through structural changes and accountability mechanisms. First, the Office of Minority Health (OMH) is

140. Kinney, *Recognition of RTH in the U.S.*, *supra* note 22, at 348.

141. *See supra* Part I.A.

142. *See* Kinney, *Recognition of RTH in the U.S.*, *supra* note 22, 364-65.

143. Eleanor D. Kinney, *The International Human Right to Health: What Does This Mean for Our Nation and World*, 34 *IND. L. REV.* 1457 (2001).

144. In another piece presented at the 34th Annual Health Law Professors Conference, I argue that PPACA creates a new governance architecture that protects the right to health even in the absence of an international obligation to do so. That piece uses a 2008 report of the United Nations Special Rapporteur for Health on factors countries can use to strengthen their health care systems to protect the right to health to identify the new governance architecture. Gwendolyn R. Majette, Presentation at the Loyola University Chicago School of Law 34th Annual Health Law Professors Conference: Coherency Within the Patient Protection and Affordable Care Act: A Framework to Create A Health Care System that Protects the Human Right to Health (manuscript on file with the author); *see also* Lance Gable, *The Patient Protection and Affordable Care Act, Public Health, and the Elusive Target of Human Rights*, 39 *J.L. MED & ETHICS* 340 (2011) (“[The PPACA] represents a significant turning point in the evolution of health care law and policy in the United States.”).

moved from the Office of Public Health and Science to the Office of the Secretary.¹⁴⁵ The office will be led by the Deputy Assistant Secretary for Minority Health who reports directly to the Secretary of Health and Human Services.¹⁴⁶ The office is tasked with improving minority health, improving the quality of care for minorities, and eliminating racial and ethnic health disparities.¹⁴⁷ Second, six offices of minority health are created within agencies of the Department of Health and Human Services.¹⁴⁸ Offices are created within the Center for Medicare and Medicaid Services (CMS), the Food and Drug Administration (FDA), the Centers for Disease Control and Prevention (CDC), the Health Resources Services Administration (HRSA), the Substance Abuse and Mental Health Services Administration (SAMHSA), and the Agency for Healthcare Research and Quality (AHRQ).¹⁴⁹ The Director of each of the OMH offices reports to the head of the agency.¹⁵⁰ The final structural change is the elevation of the National Center on Minority Health and Health Disparities at the National Institutes of Health to a National Institute on Minority Health and Health Disparities.¹⁵¹ The Institute shall “plan, coordinate, review and evaluate research and other activities conducted or supported by” the National Institutes of Health on Minority Health and Health Disparities.¹⁵²

PPACA provides for an accountability mechanism by requiring the Secretary of Health and Human Services to provide reports to the United States Congress.¹⁵³ The Secretary must submit the reports on a biannual basis to the congressional committees with jurisdiction over health.¹⁵⁴ The biannual report is based on the reports that each agency head must biannually file with the Deputy Assistant Secretary for Minority Health on its “minority health activities.”¹⁵⁵

Health and health inequity are also prioritized at the highest level of government by the creation of the first department-wide strategic plan to reduce health disparities. In November 2010, the Secretary of

145. PPACA, Pub. L. No. 111-148, § 10334(a), 124 Stat. 119, 971 (2010).

146. *Id.*

147. *Id.*

148. *See id.* § 10334(b)(1)(a).

149. *Id.* § 10334(b)(1)(b).

150. *See id.* § 10334(b)(1)(a).

151. *See id.* § 10334(c)(1)(ii).

152. *Id.* § 10334(c)(2)(C).

153. *See id.* § 10334(a)(1)(A).

154. *Id.* § 10334(a)(3).

155. *See id.*

Health and Human Services charged the agency with developing a plan to reduce disparities.¹⁵⁶ The Health and Human Services Action Plan to Reduce Racial and Ethnic Health Disparities was released in April 2011.¹⁵⁷ It “outlines the goals and actions [that] HHS will take to reduce health disparities among racial and ethnic minorities.”¹⁵⁸

The plan’s vision is “a nation free of disparities in health and health care.”¹⁵⁹ The plan is based upon the Secretary’s five goals for the department: “(I) Transform health care; (II) Strengthen the nation’s Health and Human Services infrastructure and workforce; (III) Advance the health, safety and well-being of the American people; (IV) Advance scientific knowledge and innovation; and (V) Increase the efficiency, transparency, and accountability of HHS programs.”¹⁶⁰

Each goal is supported by specific strategies necessary to its achievement. An important strategy to transform the U.S. health care system is the “reduct[ion] of disparities in the quality of health care.”¹⁶¹ As previously discussed in section I(C)(3), the 2010 NHDR concluded that quality of care for racial and ethnic minorities is suboptimal on core indicators for “preventive care, acute treatment, or chronic disease management.”¹⁶² The plan identifies HHS actions that will remove barriers to timely, patient-centered care and use of evidence-based clinical guidelines.¹⁶³ An important strategy designed

156. U.S. DEP’T OF HEALTH & HUMAN SERVS., HHS ACTION PLAN TO REDUCE RACIAL AND ETHNIC HEALTH DISPARITIES 11 (2011), available at http://minorityhealth.hhs.gov/npa/files/Plans/HHS/HHS_Plan_complete.pdf [hereinafter HHS ACTION PLAN TO REDUCE DISPARITIES].

157. See Press Release, U.S. Dep’t of Health & Human Servs., HHS Announces Plan to Reduce Health Disparities (Apr. 8, 2011), <http://www.minorityhealth.hhs.gov/npa/templates/content.aspx?ID=289> [hereinafter Press Release, HHS Announces Plan to Reduce Health Disparities]; Press Release, U.S. Dep’t of Health & Human Servs., The HHS Action Plan to Reduce Racial and Ethnic Health Disparities (Apr. 4, 2011), available at <http://www.hhs.gov/news/press/2011pres/04/04hdplan04082011.html> (last visited Mar. 24, 2012).

158. Press Release, HHS Announces Plan to Reduce Health Disparities, *supra* note 157.

159. See HHS ACTION PLAN TO REDUCE DISPARITIES, *supra* note 156, at 11.

160. *Id.*

161. *Id.* at 17.

162. See *supra* Part I.C.1; HHS ACTION PLAN TO REDUCE DISPARITIES, *supra* note 156, at 17.

163. HHS ACTION PLAN TO REDUCE DISPARITIES, *supra* note 156, at 17. One action item commanded by PPACA section 1311(g) is to improve the quality of care provided in the health insurance exchange through quality improvement strategies. See PPACA, Pub. L. No. 111-148, § 1311(g)(1), 124 Stat. 119, 173 (2010). These strategies can include the use of financial incentives to promote activities to reduce health disparities. *Id.* § 10104 (amending § 1311(g)). PPACA identifies use of language services, community outreach, and cultural competency trainings as mechanisms health plans may use to reduce disparities. HHS ACTION PLAN TO REDUCE DISPARITIES, *supra* note 156, at 17. The HHS Plan goes beyond PPACA by identifying additional mechanisms that can be used to reduce disparities in chronic conditions. CMS will be the lead agency working on quality in the exchange and may use additional activities to reduce disparities such as “health education, wellness promotion, and evidence-based approaches to

to advance the health, safety, and well-being of the American people is the “reduc[ti]on of] disparities in population health by increasing the availability and effectiveness of community-based programs and policies.”¹⁶⁴ Consistent with health and human rights norms, the HHS Action Plan to Reduce Disparities includes universal and targeted interventions designed “to close the modifiable gaps in health, longevity, and quality of life [for] racial and ethnic minorities.”¹⁶⁵

The HHS Action Plan to Reduce Disparities will be implemented to achieve the Secretary’s overarching priorities. The plan will ensure that each HHS program and policy is assessed to determine its impact on the reduction of disparities.¹⁶⁶ The availability and quality of data necessary to improve the health of minorities will be increased.¹⁶⁷ Measurements and incentives will be used to improve the quality of care provided to minority populations.¹⁶⁸ The Centers for Medicare and Medicaid Services will play a critical role in setting and reviewing quality improvement incentives and participating in “cross-departmental and inter-agency collaborations between CMS, HRSA, AHRQ, SAMHSA, and the Indian Health Service.”¹⁶⁹ HHS will be

manage chronic conditions.” *Id.* The timeline for implementation is 2011–2014. *Id.* Another important quality strategy to reduce disparities for racial and ethnic minorities is to “[d]evelop, implement, and evaluate interventions to prevent cardiovascular diseases and their risk factors.” *Id.* at 18. Cardiovascular disease is one of the leading causes of premature death for racial and ethnic minorities. *Id.* The HHS Action Plan notes this initiative is different because it will use multiple efforts to address prevention of cardiovascular disease—such as quality improvement initiatives, reimbursement incentives, and collaborations with minority and other providers serving minority populations. *See id.*

164. HHS ACTION PLAN TO REDUCE DISPARITIES, *supra* note 156, at 25. This goal focuses on “[c]reating environments that promote healthy behaviors to prevent and control chronic diseases and their risk factors.” *Id.* While the focus is population health, it also targets interventions to vulnerable populations, racial and ethnic minorities. *See id.* This goal also includes initiatives that address social determinants of health. *See id.* HHS will “[i]ncrease education programs, social support and home-visiting programs to improve prenatal, early childhood, and maternal health.” *Id.* at 26. The Agency for Children and Families and HRSA will lead this action beginning in 2011. *Id.*

165. *Id.* at 25.

166. *Id.* at 12.

167. *Id.*

168. *Id.* at 13.

169. *Id.* Improving the quality of care for vulnerable populations requires setting incentives and monitoring chronic disease burdens unique to racial and ethnic minorities such as heart attacks, renal failure, stroke, hypertension and diabetes. The Centers for Medicare and Medicaid Services (CMS) will also review existing measures including hospital value-based purchasing, hospital and home health compare, and Children’s Health Insurance Program Pediatric Quality Measures. *Id.* Existing health disparities projects will be expanded. *Id.* This includes the “CMS initiative to reduce avoidable hospital admissions for [individuals] dually eligible for Medicare and Medicaid, racial and ethnic analyses of CMS Survey and Claims Data, and Quality Improvement Organization Disparities Special Initiatives.” *Id.*

held accountable through monitoring and evaluative efforts of its success in implementing the plan.¹⁷⁰

2. PPACA Ensures that U.S. Health Policy Addresses Health Disparities and Social Determinants of Health

Consistent with the recommendations of the SDH Commission, PPACA also ensures that government policy regarding the U.S. health sector addresses health disparities and social determinants of health. First, PPACA makes reduction of health disparities a priority issue for the National Strategy for Quality Improvement in Health.¹⁷¹ PPACA requires the creation of a comprehensive¹⁷² national quality strategy “to improve the delivery of health care services, patient . . . outcomes, and population health.”¹⁷³ It must be updated annually.¹⁷⁴ The strategy explicitly addresses health care disparities by making the reduction of health disparities a priority focus of the strategy.¹⁷⁵ It also addresses health disparities by mandating that improvement initiatives, especially those designed to improve “health outcomes, efficiency, and patient-centeredness [focus on] all populations, including . . . *vulnerable* populations.”¹⁷⁶ When the actual strategy was released on March 21, 2011, it included several broad aims. The first aim establishes the overall purpose of the strategy: “To improve overall quality, by making health care more patient-centered, reliable, accessible, and safe.”¹⁷⁷ The second aim focuses on social determinants of health. The strategy seeks to “improve the health of the U.S. population by supporting . . . interventions” that improve quality of

170. *Id.* at 14.

171. PPACA, Pub. L. No. 111-148, sec. 399HH(a)(1), § 3011, 124 Stat. 119, 378 (2010).

172. PPACA also mandates that the National Quality Strategy coordinate efforts among agencies within HHS; include agency specific goals and benchmarks; include a process for agency reporting to the Secretary; align public and private payer initiatives on quality and patient safety; and address quality initiatives for health information technology. *Id.* sec. 399HH(b)(2), § 3011. The strategy should also reflect consultation with State agencies that operate Medicaid and the Children’s Health Insurance Program. *Id.* sec. 399HH(a)(2)(D), § 3011.

173. *Id.* sec. 399HH(a)(1), § 3011.

174. *Id.* sec. 399HH (a-c), § 3011.

175. *See id.* sec. 399HH (a)(2)(B)(i), § 3011.

176. *Id.* (emphasis added).

177. U.S. DEP’T OF HEALTH & HUM. SERVS., REPORT TO CONGRESS, NATIONAL STRATEGY FOR QUALITY IMPROVEMENT IN HEALTH CARE 1 (2011), available at <http://www.healthcare.gov/law/resources/reports/quality03212011a.html>. The initial National Quality Strategy did not include agency specific information, nor did it contain specific measures and short and long term goals. *Id.* All of this information will be included in the next strategy. *Id.* Additionally, all quality measures selected will be capable of electronic collection. *Id.*

care and “address behavioral, social, and environmental determinants of health.”¹⁷⁸

Second, PPACA creates the National Prevention Strategy, which, like the National Quality Strategy, also focuses on elimination of health disparities and promotes health equity. The National Prevention, Health Promotion, Public Health, and Integrative Health Care Strategy is designed to identify effective means to improve population health and lower preventable illness and disability.¹⁷⁹ According to the first annual report of the council responsible for drafting the strategy, because “vast inequities” exist in the U.S. health system, “specific action and metrics” should be used to monitor and eliminate disparities related to race, ethnicity, and socioeconomic status.¹⁸⁰ Elimination of disparities in traditionally underserved populations is a priority in the conception and final draft of the strategy.¹⁸¹ The National Prevention Strategy also seeks to ensure that the private sector works with the government in accomplishing its goals by acknowledging them as partners in the endeavor.¹⁸² Government collaboration with partners complies with health and human rights norms articulated in General Comment 14.¹⁸³

178. *Id.* (emphasis added). The final broad aim is to “reduce the cost of quality health care.” *Id.*

179. PPACA § 4001(g); *PPACA and Public Health*, *supra* note 71, at 373.

180. See NAT'L PREVENTION, HEALTH PROMOTION & PUB. HEALTH COUNCIL, DEP'T OF HEALTH & HUMAN SERVS., 2010 ANNUAL STATUS REPORT 4 (2010) [hereinafter 2010 ANNUAL STATUS REPORT OF THE PREVENTION COUNCIL], available at <http://www.hhs.gov/news/reports/nationalprevention2010report.pdf>.

181. *PPACA and Public Health*, *supra* note 71, at 373; NAT'L PREVENTION, HEALTH PROMOTION & PUB. HEALTH COUNCIL, DEP'T OF HEALTH AND HUMAN SERVS., DRAFT FRAMEWORK NATIONAL PREVENTION STRATEGY 3 (2011) [hereinafter DRAFT PREVENTION STRATEGY FRAMEWORK]; NAT'L PREVENTION COUNCIL, DEP'T OF HEALTH AND HUMAN SERVS., NATIONAL PREVENTION STRATEGY: AMERICA'S PLAN FOR BETTER HEALTH AND WELLNESS 25 (2011) [hereinafter NATIONAL PREVENTION STRATEGY], available at <http://www.healthcare.gov/prevention/nphpphc/strategy/report.pdf>. The National Prevention Strategy contains five recommendations to eliminate health disparities. First, there should be a “strategic focus on communities at greatest risk.” *Id.* at 25-26. Second, the health care system should be reformed to eliminate disparities in access to quality care. *Id.* at 26. Third, the capacity of the prevention workforce to identify and address disparities must be expanded. *Id.* Fourth, research needs to be increased to identify effective strategies to eliminate health disparities. *Id.* Fifth, data must be standardized and collected to identify and address disparities. *Id.* Two important commitments made by the federal government to advance the Prevention Strategy's focus on eliminating health disparities include a commitment to “[s]upport and expand cross-sector activities to enhance access to high quality education, jobs, economic opportunity, and opportunities for healthy living.” *Id.* The federal government also commits to “[i]dentify and map high-need areas that experience health disparities and align existing resources to meet these needs.” *Id.*

182. See 2010 ANNUAL STATUS REPORT OF THE PREVENTION COUNCIL, *supra* note 180, at 4; NATIONAL PREVENTION STRATEGY, *supra* note 181, at 9-10.

183. See *supra* Part II.A.

Third, PPACA gives the Community Preventive Services Task Force (CP Task Force) new duties which also focus on the reduction of health disparities and inclusion of social determinants of health. PPACA makes permanent the Community Preventive Services Task Force.¹⁸⁴ The CP Task Force reviews “the scientific evidence related to the effectiveness, appropriateness, and cost-effectiveness of community preventive interventions for the purpose of developing recommendations, to be published in the Guide to Community Preventive Services.”¹⁸⁵ The CP Task Force shall make recommendations and interventions regarding “social, economic and physical environments that can have broad effects on the health and disease of populations and health disparities among sub-populations.”¹⁸⁶

3. PPACA Adopts a Multi-Sectoral Approach to Health

PPACA also adheres to global health law norms established by recommendations of the SDH Commission by facilitating a multi-sectoral approach to health. A seminal provision that requires non-health governmental agencies to consider the impact of their policies and regulations on health is Section 4001, which creates the National Prevention, Health Promotion and Public Health Council (National Prevention Council).¹⁸⁷ A key responsibility of the National Prevention Council is “to provide leadership on and coordinate public health activities by federal agencies.”¹⁸⁸ The National Prevention Council is composed of health-focused officials, the Surgeon General as Chair, the Secretary of Health and Human Services, and eleven other non-health executive-level leaders like the Secretaries of Agriculture, Education, Transportation, Labor, and Homeland Security.¹⁸⁹ The National Prevention Council is tasked with drafting the National

184. PPACA sec. 4003(b)(1), § 399U(a). The Community Preventive Task Force began in 1996 and operated under the general authority of the Secretary under Title III General Powers and Duties of the Public Health Service. H.R. REP. NO. 111-299, at 704 (2009).

185. PPACA sec. 4003(b)(1), § 399U(a). An example of a community prevention recommendation targeted to a subpopulation to reduce disparities would be to provide “client reminders and small media campaigns promoting breast cancer screening among African-American women” to educate this population of the importance of breast cancer screening to reduce disparities in breast cancer mortality due to late diagnosis. H.R. REP. NO. 111-299, at 705 (2009).

186. PPACA § 4003(b)(1).

187. See *PPACA and Public Health*, *supra* note 71, at 374.

188. *Id.* at 373; PPACA § 4001(g).

189. Other members include the Chairman of the Federal Trade Commission, the Administrator of the Environmental Protection Agency, the Director of the Office of National Drug Control Policy, the Director of the Domestic Policy Council, the Assistant Secretary for Indian Affairs, and the Chairman of the Corporation for National and Community Service. PPACA § 4001(c); *PPACA and Public Health*, *supra* note 71, at 373.

Prevention, Health Promotion, Public Health, and Integrative Health Care Strategy and “provid[ing] recommendations to the President and Congress concerning the most pressing health issues confronting the United States.”¹⁹⁰

Like the National Prevention Council, the Interagency Working Group on Health Care Quality (Interagency Working Group on Quality) exemplifies a multi-sectoral approach to health at the highest level of government. This working group is convened at the request of the President, chaired by the Secretary of Health, and composed of senior agency officials.¹⁹¹ The Interagency Working Group on Quality was created to ensure collaboration, cooperation, and consultation between federal agencies on quality improvement initiatives; to avoid duplication; to streamline quality reporting and compliance; and to align public and private sector quality initiatives.¹⁹² The activities of the working group must adhere to national improvement priorities such as improving the health outcomes, efficiency, and patient-centeredness for vulnerable populations and reduce health disparities across health disparity populations.¹⁹³

Another multi-sectoral approach to health issues is reflected in the Federal Interagency Health Equity Team (FIHET). The work of this existing team is enhanced by passage of the PPACA. FIHET was created by the Office of Minority Health to guide development of the National Stakeholders Strategy for Achieving Health Equity and implement the National Partnership for Action to End Health Disparities.¹⁹⁴ Its vision is “to attain the highest level of health for racial and

190. PPACA § 4001; *PPACA and Public Health*, *supra* note 71, at 373-74.

191. PPACA § 3012(c). The Working Group on Quality is composed of senior level officials from several agencies of HHS (CMS, AHRQ, NIH, CMS, HRSA, FDA, ONC, ACF) and senior-level officials from the Department of Commerce, Office of Management and Budget, the United States Coast Guard, the Federal Bureau of Prisons, the National Highway Traffic Safety Administration, the Federal Trade Commission, the Social Security Administration, the Department of Labor, the United States Office of Personnel Management, the Department of Defense, the Department of Education, the Department of Veterans Affairs, the Veterans Health Administration, and any other federal agency and department with responsibilities to improve health care quality as identified by the President. *Id.*

192. PPACA § 3012(b). The Interagency Working Group on Quality must file an annual report to Congress on its activities and progress, and make the report publically available on the internet. PPACA § 3012(d).

193. PPACA § 3012(b)(1).

194. U.S. DEP'T OF HEALTH & HUMAN SERVS., OFFICE OF THE SEC'Y, OFFICE OF THE ASSISTANT SEC'Y FOR HEALTH, OFFICE OF MINORITY HEALTH, REPORT TO CONGRESS ON MINORITY HEALTH ACTIVITIES AS REQUIRED BY THE PATIENT PROTECTION AND AFFORDABLE CARE ACT, P.L. 111-148, at 62 (2011) [hereinafter REPORT TO CONGRESS ON MINORITY HEALTH ACTIVITIES], available at <http://www.healthcare.gov/law/resources/reports/minorities03252011a.pdf>. NPA is a public-private partnership that has a three-part structure composed of the (1) NPA

ethnic minorities and underserved populations.”¹⁹⁵ This vision explicitly incorporates a global health law norm previously discussed—part of WHO’s definition of health.¹⁹⁶ FIHET is composed of representatives from federal agencies whose missions affect the determinants of health.¹⁹⁷ The federal agencies include the Departments of Health and Human Services, Agriculture, Commerce, Defense, Education, Housing and Urban Development, Homeland Security, Justice, Labor, Transportation, Veterans Affairs, and the Environmental Protection Agency.¹⁹⁸ FIHET not only facilitates communication and implementation of NPA activities within federal agencies, but it also seeks to improve the efficiency and effectiveness of the policies and programs designed to end health disparities sponsored by their respective agencies.¹⁹⁹

One year after the passage of the PPACA, the first National Stakeholder’s Strategy for Achieving Health Equity was announced. It was released simultaneously with the HHS Action Plan to Reduce Racial and Ethnic Health Disparities in April 2011.²⁰⁰ This strategy adheres to global health law norms by including strategies that focus on social determinants of health, recognizing the importance of the work of the SDH Commission, and explicitly referencing the commission’s recommendations in its final report, “Closing the Gap in a Gen-

partners, (2) FIHET, and (3) Regional Equity Councils. See U.S. Dep’t of Health & Human Servs., Nat’l P’ship for Action to End Health Disparities, *Frequently Asked Questions*, MINORITYHEALTH.HHS.GOV, available at <http://minorityhealth.hhs.gov/npa/templates/browse.aspx?lvl=1&lvlid=5#7>. The NPA partners are public, private, and non-profit organizations that work on prevention or social determinants of health to reduce health disparities. *Id.* These organizations agree to undertake one significant project per year. *Id.* The Regional Councils are responsible for developing recommendations for state and local governments based on the NSS. *Id.* There are ten regional councils composed of leaders and change agents working on disparities reduction. See U.S. Dep’t of Health & Human Servs., Nat’l P’ship for Action to End Health Disparities, *Establishment of Regional Health Equity Councils*, MINORITYHEALTH.HHS.GOV, available at <http://minorityhealth.hhs.gov/npa/templates/browse.aspx?lvl=1&lvlid=42>. While the ten regions correspond to the ten HHS regions, the Regional Equity Councils are not advisors to OMH, HHS, the federal government, or the NPA partners. *Id.*

195. See U.S. Dep’t of Health & Human Servs., Nat’l P’ship for Action to End Health Disparities, Fed. Interagency Health Equity Team, MINORITYHEALTH.HHS.GOV, available at <http://minorityhealth.hhs.gov/npa/templates/browse.aspx?lvl=1&lvlid=36> (last visited Apr. 12, 2012) [hereinafter NPA Federal Interagency Health Equity Team].

196. See *supra* Part I (“[WHO defines health as] a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity.”).

197. HHS ACTION PLAN TO REDUCE DISPARITIES, *supra* note 156, at 9.

198. REPORT TO CONGRESS ON MINORITY HEALTH ACTIVITIES, *supra* note 194, at 62.

199. NPA Federal Interagency Health Equity Team, *supra* note 195; See REPORT TO CONGRESS ON MINORITY HEALTH ACTIVITIES, *supra* note 194, at 62.

200. Press Release, HHS Announces Plan to Reduce Health Disparities, *supra* note 157.

eration: Health Equity Through Action on Social Determinants of Health.”²⁰¹

The National Stakeholder Strategy is a “comprehensive, community-driven approach to reduce health disparities.”²⁰² Its vision is to “promote systematic and systemic change to improve the health of the nation and its most vulnerable populations.”²⁰³ The strategy has five goals which target twenty strategic areas. The goals are: (1) increasing awareness about disparities; (2) developing leadership to work on eliminating health disparities; (3) improving the health system and individual’s life experiences “to improve the health and health care outcomes for racial, ethnic, and underserved populations”; (4) diversifying the health care work force and “improv[ing] cultural and linguistic competency”; and (5) “improv[ing] data availability and the coordination, use[], and diffusion of research.”²⁰⁴ A few of the strategic areas under the goal to improve health systems and life experiences focus on quality and social determinants of health.²⁰⁵ In looking at access to care, the National Stakeholders Strategy reiterates the need to “incentivize health service providers to adhere to quality improvement standards.”²⁰⁶

The final example of a multi-sectoral approach to health is reflected in the HHS Action Plan to Reduce Disparities in which HHS announced that beginning in 2012, it will work on disparities by “engaging other key federal departments, the private sector, and community-based organizations to adopt a ‘health in all policies’ approach, including a health impact assessment for key policy and program decisions.”²⁰⁷ Health in all policies requires all sectors of the government to focus on health and well-being.²⁰⁸ HHS will also test and evaluate

201. U.S. DEP’T OF HEALTH AND HUMAN SERVS., NAT’L P’SHIP FOR ACTION TO END HEALTH DISPARITIES, NATIONAL STAKEHOLDER STRATEGY FOR ACHIEVING HEALTH EQUITY 8, available at <http://minorityhealth.hhs.gov/npa/templates/content.aspx?lvl=1&lvlid=33&ID=286> [hereinafter NATIONAL STAKEHOLDER STRATEGY].

202. HHS ACTION PLAN TO REDUCE DISPARITIES, *supra* note 156, at 1.

203. NATIONAL STAKEHOLDER STRATEGY, *supra* note 201, at 2.

204. *Id.*

205. Examples of targeted social determinants of health include meeting the social and physical environmental needs of at-risk children, improving the high school graduation rates by working at every level to tie educational attainment to life-time health benefits, and implementing policies that create “social, environmental, and economic conditions required to realize healthy outcomes.” *Id.* at 6.

206. *Id.* at 121.

207. HHS ACTION PLAN TO REDUCE DISPARITIES, *supra* note 156, at 28.

208. See DEP’T OF HEALTH, GOV’T OF S. AUSTRALIA, IMPLEMENTING HEALTH IN ALL POLICIES: ADELAIDE 2010, at 14 (2010), available at <http://www.who.int/sdhconference/resources/implementinghiapadel-sahealth-100622.pdf>. The concept of health-in-all policies has evolved over

health disparity impact assessments for selected national programs.²⁰⁹ The health disparity impact assessment will assess the “likely impacts of proposed policies and programs on health and healthcare disparities among racial and ethnic minorities.”²¹⁰ These initiatives will be led by the Office of Minority Health and all agencies will participate.²¹¹ HHS will also collaborate in a pilot program with national foundations to evaluate health disparity impact assessments.²¹²

4. PPACA Makes Universal Coverage, a Key Aspect of Universal Health Care, a Priority Issue

PPACA complies with the global health law norm of providing universal coverage as recommended by the SDH Commission and the CERD Committee. As previously discussed, in 2008, the CERD Committee recommended that the United States comply with ICERD article 5(e)(iv) and address the large number of uninsured racial and ethnic minorities.²¹³ PPACA expands access to care by increasing access to insurance through creation of insurance exchanges,²¹⁴ the provision of federal subsidies to individuals whose incomes are at or below 400% of the federal poverty line,²¹⁵ and expanding Medicaid coverage to non-elderly, non-pregnant individuals below 133% of the federal poverty line.²¹⁶ PPACA also expands access to preventive care by eliminating copayments for preventive services approved by the United States Preventive Services Task Force.²¹⁷ Eliminating eco-

a thirty-year period. *Id.* at 4. The Alma Ata Declaration of 1978 was a seminal effort that reflects the beginning of an inter-sectoral approach to health. *Id.* The second major evolution of the concept is reflected in the Ottawa Charter of 1986, introducing the healthy public policy concept. *Id.* at 16. It focuses on health, equity, and accountability for determinants of health. *Id.*

209. HHS ACTION PLAN TO REDUCE DISPARITIES, *supra* note 156, at 28.

210. *Id.*

211. *See id.*

212. *Id.*

213. *See supra* Part I.B.2.

214. Section 1311 of the PPACA authorizes the creation of either the American Health Benefit Exchange and/or the Small Business Health Options Exchange for businesses. *See* PPACA, Pub. L. No. 111-148, § 1311 (a)-(b), 124 Stat. 119 (2010). These exchanges will facilitate the purchase of insurance by individuals and small businesses. *See id.* The exchanges will be created by the state or the federal government if the state fails to establish it. *Id.* The exchanges must be operational by January 1, 2014. *Id.* sec. 10104, §1311 (modified by 10104).

215. Premium credits and cost-sharing subsidies are provided in the exchange to make insurance more affordable to individuals at or below 400% of the poverty line. *See id.* sec. 10105, §1401.

216. *Id.* sec. 10201, 1004, 1201, § 2001. This new category does not include individuals otherwise eligible for Medicaid. *Id.*

217. Private health insurance plans must include services with a grade of A or B by the United States Preventive Services Task Force, immunizations as recommended by the CDC Ad-

conomic barriers to preventive care was viewed by some congressional staffers as a mechanism to reduce disparities in mortality rates for racial and ethnic minorities by facilitating early diagnosis and treatment of diseases.²¹⁸

5. PPACA Requires the U.S. Government to Monitor Social Determinants of Health and Health Equity

Health and human rights norms articulated in General Comment 14 and the recommendations of the SDH Commission both encourage countries to monitor their progress in protecting human rights and in addressing determinants of health that create health inequities. Through the creation of the National Quality Strategy discussed previously, PPACA requires the Secretary of HHS to file annual reports with the health-related congressional committees regarding the short and long-term goals of the strategy and the progress made.²¹⁹ This means that the Secretary must assess the effectiveness of its quality improvement initiatives that are designed to improve the quality of care to vulnerable groups and its initiatives designed to address behavioral, social, and environmental determinants of health that adversely affect health.

Another mechanism to monitor the effectiveness of initiatives designed to reduce health disparities is through the work of the National Prevention, Health Promotion, and Public Health Council. The Council must provide a report to Congress and the President on the prevention, health promotion, and public health initiatives and the national progress on the goals advanced through the initiatives.²²⁰ Given that the National Prevention Strategy drafted by the Council targets elimination of health disparities for racial and ethnic minorities, the Council must evaluate the success of public health and prevention activities designed to reduce disparities based on race and ethnicity, socioeconomic status, or “other characteristics historically linked to discrimination or exclusion.”²²¹

visory Committee on Immunization Practices, and preventive care and screenings for women and children as recommended by the Health Resources and Services Administration. *Id.* §1001. Access to preventive services is also expanded for the Medicare and Medicaid programs. *Id.* §§ 4104-06.

218. This conclusion is based on my personal experience as a Senate Legislative Fellow.

219. PPACA sec. 3011, § 399HH(d)(2). The report must also identify any barriers HHS encounters to achieve the goals articulated in the National Quality Strategy. *Id.*

220. *Id.* § 4001(h)(1); *PPACA and Public Health*, *supra* note 71, at 373-74.

221. NATIONAL STAKEHOLDER STRATEGY, *supra* note 201, at 9. The National Prevention Strategy seeks to reduce disparities for all Americans and give everyone the opportunity to live a

PPACA also facilitates the monitoring of health disparities by requiring data collection and analysis in federally conducted or supported health related programs by race, ethnicity, sex, primary language, and disability status.²²² Data must also be collected from the Medicaid and CHIP programs.²²³ Furthermore, the HHS Secretary must submit a report with recommendations for improving health disparities data collection under Medicaid and CHIP.²²⁴ These provisions enable the United States to meet the 2008 CERD Committee recommendation to provide statistical data disaggregated by race, ethnicity, and national origin in its next periodic report.

The United States can use the National Healthcare Disparities Report (NHDR) and the HHS Health Disparities Reduction Plan, in addition to the PPACA provisions discussed above, to monitor the progress of initiatives designed to eliminate health disparities. The NHDR has been produced since 2003.²²⁵ As required by federal statute, the report addresses disparities in health care delivery that are due to racial and social economic factors.²²⁶ The report not only identifies existing disparities, but it shows how the disparities have changed over time and where is the greatest need to reduce disparities.²²⁷ Pursuant to the HHS Health Disparities Reduction Plan, HHS will monitor its effectiveness in addressing social determinants of health and reduction in health disparities.²²⁸ Each agency within HHS will develop an evaluation plan for its area of responsibility within the HHS Health Disparities Reduction Plan.²²⁹ These plans will work in conjunction with existing monitoring and evaluation systems.²³⁰

“long, healthy, independent, and productive [life], regardless of their race or ethnicity; religion; socioeconomic status; gender; age; mental health; cognitive, sensory, or physical disability; sexual orientation; . . . geographic location; or other characteristics [historically linked to discrimination or exclusion].” DRAFT PREVENTION STRATEGY FRAMEWORK, *supra* note 181, at 2; *see also* NATIONAL PREVENTION STRATEGY, *supra* note 181, at 25.

222. *See* PPACA § 4302.

223. *Id.*

224. *Id.*

225. *See* AHQR, NHDR, *supra* note 87, at 1.

226. *See* 42 U.S.C. § 299a-1(a)(6) (2006).

227. AHQR, NHDR, *supra* note 87, at 1.

228. HHS ACTION PLAN TO REDUCE DISPARITIES, *supra* note 156, at 34.

229. *Id.*

230. *Id.*

C. PPACA's Emphasis on Quality Provides Additional Tools to Reduce and Eliminate Health Disparities

Global health law norms articulated in General Comment 14 and reports of the Special Rapporteur for health require the provision of quality care.²³¹ Specifically, the U.S. health care system should be designed to ensure that patients receive care that is scientifically and medically appropriate given their health condition.²³² In the United States there are significant disparities in the quality of care provided to people of color.²³³ Thus, all the provisions in the PPACA that seek to improve quality should also help reduce disparities in the quality of care.

Some of the PPACA quality provisions specifically mention health disparities. For example, the National Strategy for Quality Improvement requires a focus on vulnerable populations when designing quality strategies to improve health outcomes.²³⁴ Similarly, improvement initiatives of the Interagency Working Group on Health Care Quality must consider vulnerable populations and reduction of health disparities.²³⁵ The Patient-Centered Outcomes Research Institute is tasked with “assist[ing] patients, clinicians, purchasers, and policy-makers in making informed health decisions by advancing the quality and relevance of [clinical] evidence . . . through research and evidence synthesis”²³⁶ The Institute is authorized to seek data from CMS, federal, state, and private organizations to address priority areas like disparities in health care delivery and patient outcomes.²³⁷ Another quality provision that explicitly mentions disparities facilitates the development of quality measures that evaluate equity in health services and health disparities.²³⁸ These measures will be used to assess the

231. See discussion *supra* Part I.C.3.

232. *Id.*

233. See *id.* (discussing the findings of the 2010 National Healthcare Disparities Report).

234. See discussion *supra* Part II.B.2 (discussing the National Quality Improvement Strategy).

235. See discussion *supra* Part II.B.3 (discussing the Interagency Working Group on Health Care Quality).

236. PPACA, Pub. L. No. 111-148, § 6301(a), 124 Stat. 119, 727-28 (2010). The Patient-Centered Outcomes Research Institute is a private, nonprofit, tax-exempt entity. *Id.* Its nineteen-member board includes the directors of the Agency for Health Care Research and Quality and the National Institutes of Health. *Id.*

237. *Id.*

238. See PPACA § 3013(a)(4). The quality measures are “standard[s] for measuring the performance and improvement of population health[.]” health plans, service providers, or clinicians. *Id.*

“performance and improvement of population health,” health plans, service providers, or clinicians.²³⁹

Other provisions generally focus on improving the quality of care provided in the U.S. health care system. For example, the PPACA creates the Center for Quality Improvement and Patient Safety inside of AHRQ.²⁴⁰ This center is important because it will identify best practices for quality improvement in health care delivery and identify health care providers that consistently deliver “high-quality, efficient health care . . . and [use] best practices that are adaptable . . . [for] diverse health care settings”²⁴¹ The Center will also translate the information for use in practice and create strategies for quality improvement.²⁴² Of particular relevance to reduction of health care disparities among racial and ethnic minorities is the Center’s authority to provide grants to organizations to provide technical assistance to poor performers and health care providers and suppliers “for which there are disparities in care among subgroups of patients”²⁴³

The final general quality provision that will likely positively impact the health of racial and ethnic minorities is the provision governing identification of clinical practice guidelines developed using best practices identified by the Institute of Medicine. Today, while many clinical practice guidelines exist, they are of poor quality.²⁴⁴ Section 10303(c) corrects this problem by authorizing the Secretary of Health to enter into a contract with the Institute of Medicine to identify existing and newly-created clinical practice guidelines that were developed using best practices.²⁴⁵ These guidelines can be used to establish the standard of care for various treatments. The standards can then serve as a mechanism of positive equality to ensure that racial and ethnic minorities receive the care recommended in the clinical practice guideline.²⁴⁶ This puts the burden on the health care provider

239. *Id.*

240. *Id.* §3501.

241. *Id.* The center will also identify processes or system designs that “reliably result in intended health outcomes, improve patient safety, and reduce medical errors” *Id.*

242. *See id.*

243. *Id.*

244. *See* Barry R. Furrow, *Regulating Patient Safety: The Patient Protection and Affordable Care Act*, 159 U. PA. L. REV. 1727, 1736 (2011). Existing clinical practice guidelines are often not based in good science and “serve primarily as self-protective shields created by insurers and medical societies.” *Id.*

245. PPACA § 10303(c).

246. *See* M. Gregg Bloche, *Race and Discretion in American Medicine*, 1 YALE J. HEALTH POL’Y L. & ETHICS 95, 114 (2001) [hereinafter Bloche, *Race and Discretion*]; discussion *supra* Part I.C.1.

to justify or explain why he or she deviated from the clinical practice guideline.

III. MY RECOMMENDATIONS ON FUTURE EFFORTS TO REDUCE AND ELIMINATE HEALTH DISPARITIES FOR PEOPLE OF COLOR IN THE UNITED STATES

Elimination of health care disparities is a complex problem demanding a multifaceted solution. The nature of this issue highlights the importance of viewing health law problems through the lens of the emergent logic perspective created by Professor Gregg Bloche. This approach rejects the single big theory,²⁴⁷ or one unifying theme for health law, and the narrow case-by-case approach, which focuses on one discrete problem.²⁴⁸ Instead emergent logic considers the interrelationship between the players and the parts of the health care system.²⁴⁹ The players include the patients, providers, third-party payors, and the multitude of regulators (e.g. courts, agencies, and accreditors). The health care system has three parts: the financing of health care (coverage), the delivery system, and the public health, prevention, and wellness system. Each of these parts significantly impacts the ability of the United States' health care system to reduce health care disparities among racial and ethnic minorities.

Future efforts to reduce health care disparities should include continued advocacy, publicity, and use of a multi-pronged and integrated approach to disparities reduction. In light of the global health law norm reflected in General Comment 14, that countries create national strategies to protect the right to health, my first recommendation for future efforts to reduce health care disparities in the United States is to impose a requirement that the Department of Health and Human Services creates a national strategy to reduce health care disparities on a periodic basis. The strategy would be equivalent to the HHS Action Plan to Reduce Racial and Ethnic Health Disparities released in 2011. A mandate of this nature is not a new idea. A similar idea was proposed by Senator Edward M. Kennedy in the Minority

247. There are four primary big theory approaches to health law: market competition, patient autonomy, professional authority, and public determination. See M. Gregg Bloche, *The Emergent Logic of Health Law*, 82 S. CAL. L. REV. 389, 408 (2009).

248. *Id.*

249. See *id.* at 396. Bloche also argues that the legal governance of health care is an emergent system, which is unguided by one actor. *Id.* at 397. Instead, he finds that it is the sum total of inputs and mutual adjustments by stakeholders and decision-makers. *Id.* at 396.

Health Improvement and Health Disparity Elimination Act of 2007.²⁵⁰

There are several benefits to imposing a mandate on HHS to develop a National Health Care Disparities Strategy. First, it provides a strategic focus for HHS and the elevated Office of Minority Health. Merely having an office tasked with improving minority health, raising the quality of care, and eliminating disparities does not begin the implementation of activities designed to effectively achieve those goals.²⁵¹ Second, it is a means to integrate and coordinate the multitude of existing and new public health and health care activities of HHS, which are designed to reduce health disparities and address social determinants of health. Given the infrastructure created by PPACA, which includes reduction of health disparities and attention to social determinants of health through a multitude of unconnected provisions, there must be a mechanism to ensure that all of the governmental policies, programs, and regulations are coherent, effective, and adhere to similar priorities. Third, the National Health Care Disparities Strategy can serve as a framework for cooperative work between federal and state governments as well as with private non-governmental organizations. Fourth, requiring production of the strategy on a periodic basis helps ensure that HHS continues its public health responsibilities to protect the health of people of color when administrations change or new threats or risks arise that are adverse to the health of people of color.

My second recommendation would focus on strengthening the regulatory structure designed to improve the quality of care provided in the health care delivery system at the individual physician level. PPACA includes several system-wide initiatives to improve quality,

250. Minority Health Improvement and Health Disparity Elimination Act, S. 1576, 110th Cong. § 501 (2007). Senator Edward M. Kennedy introduced the legislation and it had six original co-sponsors: Senators Thad Cochran (MI), Barack Obama (IL), Jeff Bingaman (NM), Hillary Clinton (NY), Sherrod Brown (OH) and Richard Durbin (OH). *Id.* Section 501 required the secretary to “develop and implement a comprehensive Department-wide plan to improve minority health and eliminate health disparities in the United States” *Id.*

251. I recognize that the creation of a strategy does not necessarily ensure that implementation steps will occur. This is especially so if HHS becomes more consumed with creating the strategy than implementing it or never implements it. However, requiring the creation of a strategy on the front end provides an accountability mechanism for interested stakeholders. Congress, people of color, and the public can use the strategy as a standard to evaluate the effectiveness of the department’s implementation of PPACA and other regulatory requirements designed to improve the health of people of color. As the former Special Rapporteur for Health Paul Hunt admonishes, ensuring the availability of effective accountability measures is necessary to protect the right to health. Hunt, *Missed Opportunities*, *supra* note 15, at 39.

such as the creation of the national quality strategy discussed previously and the requirement that insurance companies report on activities designed to improve care²⁵² as part of the medical loss ratio disclosures. PPACA also includes general provisions targeted to improve the quality of care provided by physicians. Each of these general provisions should be revised to include improving the quality of care provided to racial and ethnic minorities. This is consistent with global health law norms of health equity, equality, and non-discrimination articulated in the SDH Commission's recommendations, reports of the Special Rapporteur for Health, ICERD, and ICESCR.

In PPACA section 3007, the Medicare reimbursement policy will be changed in 2015 to include "a value-based payment modifier" focusing on quality and costs.²⁵³ This shifts the Medicare reimbursement structure from a fee-for-service payment methodology—rewarding mere provision of service—to a pay-for-performance model—valuing quality.²⁵⁴ Through rulemaking, CMS could include measures that consider quality initiatives designed to reduce health care disparities. This would be consistent with the priorities established in the national quality strategy that address health care disparities,²⁵⁵ as well as the IOM's recommendation that any national quality

252. PPACA, Pub. L. No. 111-148, § 10101(f), 124 Stat. 119, 883-86 (2010).

253. *Id.* § 3007. In December 2011, CMS announced that it will use data from the Physician Quality Reporting System (PQRS) to create the quality component of this new payment methodology. Payment Policies Under the Physician Fee Schedule and Other Revisions to Part B for CY 2012, 76 Fed. Reg. 73,026, 73,427 (Nov. 28, 2011). For more information on PQRS, see discussion *infra* Part III. Because CMS recognizes the limits of some of its data and the complexity of designing a new payment methodology, it will proceed cautiously. *Id.* at 73,427.

254. Both the Institute of Medicine and the Medicare Payment Advisory Committee (MedPac) have recommended that physician payment methodology be changed to incentivize the provision of quality care. INST. OF MED., REWARDING PROVIDER PERFORMANCE: ALIGNING INCENTIVES IN MEDICARE 1 (2006); MEDICARE PAYMENT ADVISORY COMM'N, REPORT TO CONGRESS: MEDICARE PAYMENT POLICY 196-203 (2005); CROSSING THE QUALITY CHASM, *supra* note 82, at 17-19. Health law scholars have also called for a change in the physician reimbursement methodology under the Medicare program or private managed care plans to improve quality of care. See, e.g., David Hyman, *Health Care Fragmentation We Get What We Pay For*, in THE FRAGMENTATION OF U.S. HEALTH CARE 31 (Einer Elhauge ed., 2010); Timothy Stoltzfus Jost & Lawrence P. Casalino, *Value-based Purchasing Opportunities in Traditional Medicare: A Proposal and Legal Evaluation*, in THE FRAGMENTATION OF U.S. HEALTH CARE 204 (Einer Elhauge ed., 2010); Bloche, *Race and Discretion*, *supra* note 246, at 114-15; Gwendolyn Roberts Majette, *From Concierge Medicine to Patient-Centered Medical Homes: International Lessons and the Search for a Better Way to Deliver Primary Health Care in the U.S.*, 35 AM. J.L. & MED. 585, 617 (2009) [hereinafter Majette, *Concierge Medicine*]; William M. Sage, *Pay for Performance: Will it Work in Theory?* 3 IND. HEALTH. L. REV. 303, 308 (2006); Gwendolyn Roberts Majette, *Changing Payment Policy to Improve Quality & Reduce Fragmentation: The Medical Home Concept*, CONCURRING OPINIONS BLOG (Oct. 12, 2010, 9:56 AM), <http://www.concurringopinions.com/?s=fragmentation>.

255. See discussion *supra* Part II.B.2.

improvement initiative includes a focus on the equitable provision of care.²⁵⁶ Care that is equitably provided does not vary because of a patient's personal characteristics like race or ethnicity.

Another incentive mechanism that can be further designed to address health care disparities is PPACA § 3002, which extends the Physician Quality Reporting System (PQRS) under the Medicare program until 2014.²⁵⁷ PQRS began in 2007 and is the largest physician-focused pay-for-performance program in the United States.²⁵⁸ This program provides a small incentive payment to physicians for reporting on designated quality measures.²⁵⁹ PPACA further provides that beginning in 2015, physicians will be penalized 1.5% (increasing to 2% in 2016) of their total Medicare reimbursement for failing to report.²⁶⁰

PQRS has the ability theoretically to improve quality and reduce disparities. However, the full potential of the program has not been realized.²⁶¹ With respect to disparities in particular, PQRS, like many

256. See discussion *supra* Part I.C.1. Professors Gregory Bloche, Timothy Jost, and Sidney Watson have advocated for focusing on quality regulations as a means to reduce racial disparities for racial and ethnic minorities in the United States. See SIDNEY D. WATSON, EQUITY MEASURES AND SYSTEMS REFORM AS TOOLS FOR REDUCING RACIAL AND ETHNIC DISPARITIES IN HEALTH CARE 7 (2005) (urging incorporation of racial and ethnic performance measures into the quality assessment and performance improvement initiatives that apply to Medicaid and Medicare Advantage managed care plans and hospitals that accept Medicare and Medicaid); Bloche, *Race and Discretion*, *supra* note 246, at 114-15 (urging private managed care plans to use more nuanced physician withholding incentives that emphasize “health promotion and disease screening practice, patient satisfaction, measurable treatment success, [and] frugality” to achieve the provision of colorblind care); Timothy Stoltzfus Jost, *Racial and Ethnic Disparities in Medicare: What the Department of Health and Human Services and the Centers for Medicare and Medicaid Services Can, and Should Do*, 9 DEPAUL J. HEALTH CARE L. 667, 704-705 (2005) (urging changes in the accreditation and certification requirements under the Medicare program to expand the quality assessment and performance improvement initiatives (QAPI) to all providers and to modify the QAPI to address access barriers and equity concerns).

257. PPACA § 3002(a).

258. See generally Alex D. Federman & Salomeh Keyhani, *Physicians' Participation in the Physicians' Quality Reporting Initiative and Their Perceptions of Its Impact on Quality of Care*, 102 HEALTH POL'Y 229 (2011).

259. *Id.* The incentive was 1% for 2011 and will be .5 % for 2012–2014. PPACA § 3002(a).

260. PPACA § 3002(b).

261. Physician perceptions on the impact of PQRS to improve quality are mixed, ranging from no impact to little impact. Federman & Keyhani, *supra* note 258. There are three significant factors that likely influenced physicians' perceptions that PQRS does not improve quality. First, the program to date does not provide payment or feedback based on the provision of quality care, but instead only provides for the correct reporting of the quality data. See Payment Policies Under the Physician Fee Schedule and Other Revisions to Part B for CY 2012, 76 Fed. Reg. 73,425-26 (Nov. 28, 2011). However, CMS promulgated recent regulations which provide through a separate program, the Medicare Feedback program, for a limited group of physicians to receive limited feedback on the quality of care provided to Medicare beneficiaries beginning in 2012 based on PQRS. *Id.* at 73,436. PPACA Section 3003 extended the scope of the Feedback program to include feedback on quality in addition to resource use. PPACA § 3003. Second,

other pay-for-performance programs, was not originally designed to impact the reduction of health care disparities.²⁶² After three years of operation, however, CMS began to address disparities.²⁶³ Those initial steps continue as reflected in, the most recent regulations describing PQRS. The 2012 PQRS Program will include measures “that are high impact and support CMS and HHS priorities for improved quality of care to Medicare beneficiaries.”²⁶⁴ One of the priority topics is the elimination of health disparities.²⁶⁵

some of the quality measures are narrowly defined, limited to a few conditions, or are inappropriate. Federman & Keyhani, *supra* note 258, at 231; Chris Silva, *Medicare Pay-for-Reporting Still Gets Bad Grades from Physicians*, AMEDNEWS.COM (Mar. 1, 2010), <http://www.ama-assn.org/amednews/2010/03/01/gvsc0301.htm>. Third, before 2011, there was no published empirical report regarding whether the program actually improved quality. See Letter from Michael D. Maves, MD, Exec. Vice President, CEO Am. Med. Ass’n, to Donald Berwick, MD, Adm’r Ctrs. for Medicare and Medicaid Servs., DHHS (Aug. 24, 2010), available at <http://www.ama-assn.org/resources/doc/washington/2011-physician-fee-schedule-comment-letter.pdf>. CMS reported in the 2009 Reporting Experience Including Trends (2007-2010), that despite the data limitations, it has noticed some improvements in quality since inception of the program. CMS, 2009 REPORTING EXPERIENCE INCLUDING TRENDS (2007-2010), PHYSICIAN QUALITY REPORTING SYSTEM AND ELECTRONIC PRESCRIBING (eRx) INCENTIVE PROGRAM xiii-xiv, 25-31 (2011) [hereinafter CMS, 2009 PQRS REPORTING EXPERIENCES & TRENDS], available at <http://www.cms.gov/pqrs/2009/itemdetail.asp?itemid=CMS1246584>.

262. Medicare Program; Payment Policies Under the Physician Fee Schedule and Other Revisions to Part B for CY 2009; E-Prescribing Exemption for Computer-Generated Facsimile Transmissions; and Payment for Certain Durable Medical Equipment, Prosthetics, Orthotics, and Supplies (DMEPOS), 73 Fed. Reg. 69,726, 69,831 (Nov. 19, 2008) (acknowledging receipt of industry comments addressing “gaps in the PQRI measure set . . . on equity/disparities.”); Alyna T. Chien & Marshall H. Chin, *Incorporating Disparity Reduction into Pay-for-Performance*, 24 J. GEN. INTERNAL MED. 135, 135 (2008); Alyna T. Chien et al., *Pay for Performance, Public Reporting, and Racial Disparities in Health Care: How are Programs Being Designed?*, 64 MED. CARE RES. & REV. 283S, tbl.1 (2007).

263. Medicare Program; Payment Policies Under the Physician Fee Schedule and Other Revisions to Part B for CY 2010, 74 Fed. Reg. 61,738, 61,814 (Nov. 25, 2009) (CMS lists without further detail the “elimination of health disparities” as a consideration that was applied in selecting the “2010 PQRI quality measures”). This change was not mandated by PPACA. In fact, PPACA did not address disparities in PQRS Section 3002. PPACA § 3002.

264. Medicare Program; Payment Policies Under the Physician Fee Schedule, Five-Year Review of Work Relative Value Units, Clinical Laboratory Fee Schedule: Signature on Requisition and Other Revisions to Part B for CY 2012, 76 Fed. Reg. 73,026, 73,340 (Nov. 28, 2011) (to be codified at 42 C.F.R. pts. 410, 414, 415, 495).

265. *Id.* To date PQRS addresses disparities by including measures relevant for diseases where the literature shows disparities exist based on race and ethnicity. For example, measures exist for preventive care items such as the provision of immunizations or screening items like colonoscopy for colon cancer, mammograms for breast cancer, and body mass index to detect obesity. See generally IOM FUTURE DIRECTIONS OF NHQR & NHDR, *supra* note 2. These measures were included to make the areas measured a priority for physicians, which in turn will hopefully lead to better care and a reduction in health disparities. This approach is consistent with best practices on the development of a pay-for-performance program that addresses disparities reduction. Chien et al., *supra* note 262, at 135 (does not discuss PQRS). It is unclear what impact PQRS has had on the actual reduction of health care disparities. The 2009 Reporting Experience, which includes trends from 2007 – 2010 does not address this topic. See generally CMS, 2009 PQRS REPORTING EXPERIENCE & TRENDS. As PQRS continues to evolve, CMS hopes that it will shed light on how doctors address health disparities.

PQRS can be further designed to address the elimination of racial and ethnic disparities by incorporating specific measures that evaluate equity in health services and health disparities that will be developed pursuant to PPACA incentives.²⁶⁶ Furthermore, PQRS can be designed to capture information that evaluates the existence of racial and ethnic disparities within an individual physician's patient population.²⁶⁷ This type of information will enable CMS or newly created PPACA entities²⁶⁸ to provide assistance to those providers to eliminate those disparities.

Not only can physicians be incentivized through reimbursement policy to address health care disparities, they can also be incentivized through public reporting that can affect their professional reputations. PPACA requires the Secretary to develop a "Physician Compare" website for physicians participating in the Medicare program.²⁶⁹ The information for this website will come from the Physician Quality Reporting System.²⁷⁰ The website should ultimately allow patients to compare physicians based on quality and personal experience measures that are scientifically sound.²⁷¹ In keeping with my overall recommendations on physician quality initiatives, the quality and personal experience measures should be designed to capture information that can be used to monitor and reduce racial and ethnic disparities. Personal experience data can help ensure that patients are not subject to the racial bias of an individual physician in keeping with the global health law norms articulated by the Special Rapporteur for

266. See *supra* Part II.C.

267. The program does not currently collect this type of data, and CMS acknowledged that my recommendation would be a good idea. Implementation of this recommendation is even more likely because of the PPACA requirement that federal health related programs collect data on race, ethnicity, and primary language. Patient Protection and Affordable Care Act, Pub. L. No. 111-148, § 4302, 124 Stat. 119, 578-582 (2010); see *supra* Part II.C.

268. See *supra* Part II.C (discussing the Center for Quality Improvement and Patient Safety within AHQR).

269. PPACA § 10331. To encourage beneficiaries to use the Physician Compare website, PPACA allows incentives to be offered beginning in 2019. This is equivalent to what other countries have done. For example, Belgium encouraged patients to use their designated primary care provider who maintained their global health record by providing a 30% reduction in their out-of-pocket cost. See Majette, *Concierge Medicine*, *supra* note 254, at 605.

270. PPACA § 10331(a)(2). The text of PPACA also mentions other criteria such as an "assessment of patient health outcomes and the functional status of patients; . . . continuity and coordination of care and care transitions, including episodes of care and risk-adjusted resource use; . . . efficiency, . . . patient experience and . . . family engagement; . . . safety, effectiveness, and timeliness . . . ; and other information as determined appropriate by the Secretary." *Id.*

271. PPACA § 10331(b)(2)-(3). There are many protections provided to a physician to ensure that the information presents a "robust and accurate portrayal of [the] physician's performance." *Id.* The physician also has an opportunity to review the information before it is made public. *Id.*

health.²⁷² To the extent the Physician Quality Reporting System includes data or measures that are relevant to efforts to eliminate health disparities, this information should also be reflected in the Physician Compare website.²⁷³

My final recommendation is that the Office of Civil Rights within HHS (OCR) should be viewed as an integral partner in the overall HHS health disparities reduction strategy and be encouraged to actively enforce Title VI of the Civil Rights Act of 1964.²⁷⁴ This recommendation helps eliminate health disparities among racial and ethnic minorities that are caused by discrimination in violation of global health law norms articulated in ICERD and ICESCR.

The HHS Office of Civil Rights has repeatedly been criticized for its lack of robust enforcement of Title VI.²⁷⁵ Title VI prohibits discrimination on the basis of race, color, and national origin in programs and activities that receive federal financial assistance.²⁷⁶ Today, intentional discrimination is less common than more subtle forms of discrimination. Because the Office of Civil Rights is the only entity

272. See *supra* Part I.C.3.

273. Use of the Physician Compare website to monitor physician efforts to eliminate health disparities is analogous to the use of report cards to monitor compliance with civil rights laws proposed by Professor David Barton Smith in 1998. See David Barton Smith, *Addressing Racial Inequities in Health Care: Civil Rights Monitoring and Report Cards*, 23 J. HEALTH POL. POL'Y & L. 75, 100 (1998). Creation of the Physician Compare website is also consistent with the Office of Minority Health Culturally and Linguistically Appropriate Services Standard No. 14. This standard is a recommendation by OMH that "health care organizations . . . regularly make available to the public . . . their progress and successful innovations in implementing the CLAS standards" U.S. DEP'T OF HEALTH AND HUMAN SERVS. OFFICE OF MINORITY HEALTH, NATIONAL STANDARDS FOR CULTURALLY AND LINGUISTICALLY APPROPRIATE SERVICES IN HEALTH CARE: FINAL REPORT 109 (2001), available at <http://minorityhealth.hhs.gov/assets/pdf/checked/finalreport.pdf>.

274. OCR's membership on FIHET and the HHS Health Disparity Council discussed *supra*, note 194, possibly suggests that it is viewed as an important contributor to efforts to reduce health disparities.

275. See, e.g., Randall, *supra* note 17, at 64 (arguing that the Office of Civil Rights has not sufficiently prepared its investigative staff to identify and confront discrimination in the context of managed care); Yearby, *supra* note 17, at 975 (arguing that, for example, the Office of Civil Rights does not collect racial data, regulate admission practices, or survey the racial makeup of nursing homes as required by Title VI, and therefore cannot prevent the institutional racism in those homes causing a disparate impact on elderly African Americans). See generally U.S. COMM'N ON CIVIL RIGHTS, *THE HEALTH CARE CHALLENGE: ACKNOWLEDGING DISPARITY, CONFRONTING DISCRIMINATION, AND ENSURING EQUALITY, VOLUME II: THE ROLE OF FEDERAL CIVIL RIGHTS ENFORCEMENT* (1999) (discussing the limitations of Title VI and the resulting inadequate enforcement which has led to continued discriminatory practices); Jost, *supra* note 256 (pointing out that the OCR has never been aggressive or successful in addressing racial disparities in Medicare, and recommending that it undertake enforcement actions and aggressively pursue the complaints it receives).

276. 42 U.S.C. § 2000(d) (2006).

authorized to bring Title VI disparate impact cases,²⁷⁷ its enforcement activity is critical to elimination of discrimination as a cause of health disparities among people of color. OCR enforcement of disparate impact cases is also mandated by ICERD, which requires governments to prohibit conduct that has discriminatory effects.²⁷⁸

To the extent that the HHS Office of Civil Rights has enforced Title VI, it has concentrated its efforts on language discrimination cases, “low hanging fruit,”²⁷⁹ instead of taking a more balanced approach to include traditional Title VI enforcement. In the 2007 report that the United States submitted to the ICERD Committee, all of the cases described were limited English proficiency discrimination cases.²⁸⁰ More recently, when the Chief of Section Three in the Civil Rights Division of OCR spoke at the Symposium on Health Disparities at American University, he noted that, “for the present moment, the enforcement of Title VI” has been primarily limited English proficiency cases.²⁸¹

In light of the multitude of PPACA provisions that can be used to reduce health disparities and HHS’s renewed commitment to this issue, it is curious that recent HHS reports spend insufficient time addressing Title VI. First, the March 23, 2011 Report to Congress on Minority Health Activities, mandated by PPACA, does not mention

277. In *Alexander v. Sandoval*, the United States held that the Title VI statute only prohibits intentional discrimination. *Alexander v. Sandoval*, 532 U.S. 275, 280 (2001). While the Title VI regulations prohibit discrimination based on disparate impact, there is no private right of action to enforce these regulations. *Id.* at 288-89; Majette, *Access to Health Care*, *supra* note 4, at 128.

278. The CERD Committee has repeatedly advised the United States that ICERD prohibits both intentional discrimination and discrimination that results from disparate impact. *See, e.g.*, CERD, *Concluding Observations on U.S. Reports*, *supra* note 35, ¶ 10 (“[The United States should] review the definition of racial discrimination used in the federal and state legislation and in court practice . . . to ensure [compliance with] . . . article 1, paragraph 1, [which] prohibits racial discrimination in all its forms, including practices and legislation that may not be discriminatory in purpose, but in effect.”); U.N. Gen. Assembly, Rep. of the Comm. on the Elimination of Racial Discrimination, Jul. 30-Aug. 17, 2001, ¶¶ 280-407, U.N. Doc. A/56/18; GAOR, 59th Sess., Supp. No. 18 (2001). Article 1(1) defines racial discrimination as conduct that has the purpose or effect of impairing human rights and fundamental freedoms based on race, color, descent, national or ethnic origin. International Convention on the Elimination of All Forms of Racial Discrimination (ICERD) art. 1, Jan 5, 1969, 660 U.N.T.S. 195.

279. In a 2005 article, Professor Jost notes that when he spoke with individuals at HHS about civil rights enforcement, they referred to limited English proficiency cases as “low-hanging fruit.” Jost, *supra* note 256, at 702.

280. U.S. RESPONSE TO CERD QUESTIONS, *supra* note 35, at 89-90.

281. It is entirely possible that the phrase “for the present moment” signals a future change in enforcement policy. *See* Spring Health Law Symposium, *Health Disparities*, HEALTH L. & POL’Y BRIEF, Fall 2010, at 16 (quoting panelist Kenneth D. Johnson, Department of Health and Human Services, Office of Civil Rights, Panel II—State and Federal Perspectives on Health Care Disparities).

racism or Title VI. It references OCR one time as a member of the HHS Health Disparities Council.²⁸² The Health Disparities Council is tasked with coordinating and making cohesive all of the HHS strategies designed to reduce health disparities, as well as implementing the HHS Health Disparities Reduction Plan.²⁸³ Similarly, the HHS Disparities Reduction Plan does not use the word racism and does not mention OCR or Title VI in the main text. The term discrimination is used rarely. In the main text it appears twice. Title VI is only mentioned in appendix A, in the context of a reference to PPACA Section 1557, which expands the applicability of non-discrimination laws like Title VI to private health insurance plans.²⁸⁴

There is one recent document that provides hope that the HHS Office of Civil Rights will begin a more robust enforcement of Title VI. The most comprehensive discussion of Title VI as a mechanism to reduce health disparities for racial and ethnic minorities is contained in the National Stakeholder Strategy. This document explicitly states that racism, as a social determinant of health, is a cause of health disparities for racial and ethnic minorities.²⁸⁵ It explains that Title VI prohibits discrimination based on race, color, or national origin, and that it applies to virtually all hospitals and most health care providers that receive federal funds.²⁸⁶ It lists and provides examples of prohibited discriminatory conduct. Prohibited discriminatory conduct includes: denying a service or other benefit, providing different services or providing services in a different manner, segregating, or separately treating individuals because of their race, color, or national origin.²⁸⁷ Moreover, the National Stakeholder Strategy encourages all participants in the health care system (quality improvement team members,

282. REPORT TO CONGRESS ON MINORITY HEALTH ACTIVITIES, *supra* note 194, at 61. The HHS Health Disparities Council is chaired by the Assistant Secretary for the Office of Minority Health, composed of the Directors of the Offices of Minority Health and a member of the Office of Civil Rights.

283. *Id.* at 62. The Health Disparities Council is also responsible for tracking progress of the HHS Disparities Reduction plan and keeping the agency heads informed of the agency's progress as well as the progress of HHS as a whole. Additionally, the Council must "assure [the] successful implementation" of activities of the National Partnership for Action to End Health Disparities that are aligned with the HHS Disparities Reduction Plan. *Id.*

284. HHS ACTION PLAN TO REDUCE DISPARITIES, *supra* note 156, at 39.

285. NATIONAL STAKEHOLDER STRATEGY, *supra* note 201, at 7. It distinguishes between institutional racism caused by "differential access to the goods, services, and opportunities of society by race" from personally mediated racism. *Id.* at 21. Personally mediated racism is "prejudice and discrimination by individuals toward others." *Id.*

286. *Id.* at 20.

287. *Id.*

clinicians, patient advocates, board members, employees, and health care professionals) to report violations.²⁸⁸

CONCLUSION

The continuing existence of significant health care disparities for people of color is a substantial problem for the United States. The United States has an obligation under its public health and global health law duties to protect population health. These duties are especially important for vulnerable or societally disadvantaged groups. While the United States' commitment to eliminate health disparities is inconsistent, passage of the PPACA helps the United States satisfy its global health law obligations to address the health concerns of racial and ethnic minorities.

The WHO, the Special Rapporteur for Health, ICERD, ICESCR, and General Comment 14 create global health law norms that prohibit discrimination, promote health equity, and require the provision of scientifically and medically appropriate care. Through a multitude of provisions, the PPACA creates a framework to eliminate health disparities for racial and ethnic minorities consistent with these global health law norms.

PPACA not only elevates the issue of disparities reduction to the highest levels of government, by moving the Office of Minority Health to the Office of the Secretary for HHS; it also creates several permanent structures to eliminate health disparities and address social determinants of health. Of particular note is the creation of a permanent inter-sectoral governmental body, the National Prevention, Health Promotion and Public Health Council, to facilitate a health-in-all policies approach to eliminate health disparities and improve the daily conditions in which people live, work, and play. It also requires creation of a national quality strategy that will target improvements in the quality of care provided to racial and ethnic minorities which, to date, is suboptimal.

The commitment of the United States to eliminate health disparities for racial and ethnic minorities is further advanced by the creation of the Health and Human Services Action Plan to Reduce Racial and Ethnic Health Disparities and the National Stakeholders Strategy for Achieving Health Equity released in 2011. Both of these documents

288. *Id.*

provide priorities and standards for cooperative work among government entities and the private sector.

As noted above, elimination of health disparities among people of color is a complex problem that requires a multi-faceted solution. First, a legislative mandate should be imposed on HHS which requires it to create a national strategy to reduce health care disparities on a periodic basis. This facilitates efficiency and coordination. Second, general quality mechanisms targeted to physicians like value-based purchasing, PQRS, and the Physician Compare website should specifically address reduction of racial and ethnic health disparities. Finally, vigorous enforcement of Title VI by the HHS Office of Civil Rights should be a central component of the HHS plan to reduce health disparities for people of color.

The Patient Protection and Affordable Care Act of 2010 and the Requirement to Maintain Minimum Essential Coverage (Individual Mandate): Constitutional Challenges and Potential Impact on Health Policy

PERRY W. PAYNE, JR.*

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INTRODUCTION

In the spring of 2010, the United States Congress, with a Democratic majority in the House and Senate, passed what by all measures was a partisan bill: the Patient Protection and Affordable Care Act (“ACA”), amended on March 30, 2010 by the Health Care and Education Reconciliation Act of 2010.¹ The ACA is a comprehensive health reform law, over 900 pages in length,² which represents the culmination of decades of political battles focused on improving the quality and affordability of health care in America, with the long-term goal of improving the health status of Americans.³ One important,

1. Patient Protection and Affordable Care Act, Pub. L. No. 111-148, 124 Stat. 119 (2010), amended by the Health Care and Education Reconciliation Act of 2010, Pub. L. No. 111-152, 124 Stat. 1029 (2010).

2. Patient Protection and Affordable Care Act (codified as amended at 42 U.S.C. §§ 18001-18121 (2012)).

3. Sheryl Gay Stolberg & Robert Pear, *Obama Signs Health Care Overhaul Bill, With a Flourish*, N.Y. TIMES (Mar. 23, 2010), <http://www.nytimes.com/2010/03/24/health/policy/24health.html>.

The Requirement to Maintain Minimum Essential Coverage

yet controversial component of the ACA amends the Internal Revenue Code by adding 26 U.S.C. § 5000A, “Requirement to Maintain Minimum Essential Coverage.”⁴ This provision has been referred to by politicians and media outlets as “the individual mandate.”⁵ However, this Article will refer to the provision as the “coverage requirement” for reasons that will be discussed later in the Article. The coverage requirement was fiercely debated prior to the passing of the ACA and met immediate legal challenges after the law passed.⁶ States, private citizens, companies, and organizations initiated lawsuits seeking to prevent the requirement from being implemented and enforced, despite predictions that they would not succeed.⁷ The complaints of these various parties focused on the constitutionality of the coverage requirement.⁸ To date, numerous cases have come before federal appellate courts on this issue, resulting in conflicting holdings. As a result, writs of certiorari were filed with the United States Supreme Court by the respective parties, and recently the Court granted a writ of certiorari to review a case from the Eleventh Circuit Court of Appeals.⁹

This Article reviews the various constitutional challenges that were made and focuses on the timely issue of how the upcoming Supreme Court case will likely impact the ACA. This Article reviews the constitutional challenges as the Court heard arguments in March 2012, just before this Article was sent to press. Part I provides an overview of the coverage requirement including its intellectual origin, logic, legislative history, congressional findings, the actual parameters

4. 26 U.S.C. § 5000A (2006).

5. See Michael Cooper, *Conservatives Sowed Idea of Health Care Mandate, Only to Spurn It Later*, N.Y. TIMES, Feb. 15, 2012, at A15; Karen Davenport, *Should Everyone Be Required to Have Health Insurance*, WALL ST. J., Jan. 23, 2012, at R2.

6. See Richard Cauchi, *State Legislation and Actions Challenging Certain Health Reforms, 2011-2012*, NAT'L CONF. ST. LEGISLATURES (Mar. 14, 2012), <http://www.ncsl.org/issues-research/health/state-laws-and-actions-challenging-aca.aspx>.

7. See Timothy S. Jost, *State Lawsuits Won't Succeed in Overturning the Individual Mandate*, 29 HEALTH AFF. 1225, 1226-27 (2010) (discussing state lawsuits that challenge the constitutionality of the individual mandate).

8. Fred Lucas, *27 of 50 States Now Challenging Constitutionality of Obamacare in Court*, CNS NEWS (Jan. 19, 2011), <http://cnsnews.com/news/article/27-50-states-now-challenging-constitutionality-obamacare-court>.

9. See *Florida v. U.S. Dep't of Health & Human Servs.*, 648 F.3d 1235 (11th Cir. 2011), *cert. granted*, 132 S. Ct. 603 (2011); 132 S. Ct. 604 (2011). The Court is also reviewing whether the Anti-Injunction Act bars the lawsuits against the individual mandate and whether Medicaid expansion is constitutional. See Adam Liptak, *Justices to Hear Health Care Case as Race Heats Up*, N.Y. TIMES, Nov. 14, 2011, at A1; Avik Roy, *Finally, Supreme Court Agrees to Hear Obamacare Challenges*, FORBES (Nov. 14, 2011, 12:15 PM), <http://www.forbes.com/sites/aroy/2011/11/14/finally-supreme-court-agrees-to-hear-obamacare-challenges/>.

of the requirement, and enforcement. Part II provides a comparative analysis of the federal circuit courts of appeal's decisions to date. Part III reviews key arguments put forward in the writs of certiorari that were accepted by the Supreme Court. Part IV discusses the possible decisions available to the Supreme Court, and Part V offers predictions of the Supreme Court decision and potential factors that will influence the Justices. Part VI addresses how the Supreme Court decision, whether they hold that the requirement is constitutional or unconstitutional, is likely to impact the ACA and what future health policy challenges will remain after the Supreme Court ruling. The remaining sections predict what the Supreme Court will decide, and discuss the potential policy impact of that decision.

I. OVERVIEW OF THE PATIENT PROTECTION AND AFFORDABLE CARE ACT REQUIREMENT TO MAINTAIN MINIMUM ESSENTIAL COVERAGE

A. Origin of the Coverage Requirement

Although the ACA is often referred to as “Obamacare”¹⁰ by numerous Republicans and other opponents of the law, the most controversial aspect of the law – the coverage requirement – is actually the idea of conservative thinkers. Stuart Butler from The Heritage Foundation, a well-known conservative think tank, is credited with proposing this idea in a 1989 book entitled *A National Health System for America* while future President Barack Hussein Obama was still a student at Harvard Law School.¹¹

In the book, Butler and colleague Edmund Haislmaier, both, policy experts at The Heritage Foundation, state that their book attempts to offer a comprehensive conservative alternative to the “liberals’ health care agenda.”¹² They state that the key element to this reform strategy is to turn the “quasi-market health care system into a true market system.”¹³ They further indicate that one of the “basic elements of a reformed system” is a “legal obligation on all families to

10. Cf. Marc Seigel, Opinion, *ObamaCare, the GOP and You*, FOX NEWS (Jan. 3, 2012), <http://www.foxnews.com/opinion/2012/01/03/obamacare-gop-and/> (opining that patients and doctors refer to the ACA as “Obamacare”).

11. See generally Stuart Butler & Edmund Haislmaier, *Introduction to CRITICAL ISSUES: A NATIONAL HEALTH SYSTEM FOR AMERICA* (Stuart Butler & Edmund Haislmaier eds., 1989) (proposing that healthcare be available to every American through a market model and providing aid to families unable to pay for coverage).

12. *Id.* at vii.

13. *Id.*

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obtain a *minimum level of protection* [i.e. coverage] *against health care costs.*¹⁴ In chapter two of the book, entitled “A Framework for Reform,” the authors state that responsible reform must have three goals, the first of which is: to “give all Americans access to adequate health care services.”¹⁵ Hence, they sought universal access to health care for all Americans.

Further, in a section entitled “Creating a New Health Care System for Americans,” the authors state that the key elements of a consumer-oriented, market-based, comprehensive American health system would include “Element #1: *Every resident* of the U.S. must, by law, be enrolled in an adequate health care plan to cover major health care costs.”¹⁶ This element is quite similar to the coverage requirement of the ACA; except, this element is actually broader in that it includes all U.S. “residents” which would mean that some individuals who would not have to meet the ACA coverage requirement would be required to purchase insurance in the authors’ proposed system. Hence, the purported government takeover of “Obamacare” was actually theorized by a conservative think tank as a much greater government initiative than Democrats pushed for under Obama.

The authors further indicate that this requirement would be based on a pact between the U.S. government and its citizens, which would require the government to create a market-based system that provides access to care and protects families from financial distress due to the cost of an illness.¹⁷ In exchange, individuals would agree to obtain a *minimum level of protection or health insurance.*¹⁸ The authors also note that this would mean that “Americans *with sufficient means* would no longer be able to be ‘free riders’ on society by avoiding sensible health insurance expenditures and relying on others to pay for care in an emergency or in retirement.”¹⁹ The requirement, based on the authors’ views, would require “all households . . . to protect themselves from major medical costs by purchasing health insurance or enrolling in a prepaid health plan.”²⁰ The architects of this coverage requirement also did not label it an individual mandate, just

14. *Id.* (emphasis added).

15. Stuart Butler, *A Framework for Reform*, in *CRITICAL ISSUES: A NATIONAL HEALTH SYSTEM FOR AMERICA* 36 (Stuart Butler & Edmund Haislmaier eds., 1989).

16. *Id.* at 51 (emphasis added).

17. *Id.*

18. *Id.*

19. *Id.* (emphasis added).

20. *Id.*

as Congress did not do so for the ACA. Instead, they labeled it as “mandatory family protection.”²¹ They envisioned tax credits for individuals who purchase insurance in order to decrease the costs for them. These credits mirror the tax credits that will make insurance more affordable for people who buy health insurance through the state exchanges described in the ACA.²²

The authors also state that their insurance requirement would have to be enforced by households providing proof of insurance via their tax returns.²³ Also, insurance companies would notify the government if coverage lapsed and if coverage was not renewed, possibly causing a “fine [to] be imposed.”²⁴ Thus, Butler and Haislmaier laid out the parameters for what would become the ACA coverage requirement over twenty years ago in an effort to make America’s health care system more market-based.

The same market-based reform that was discussed by the Heritage Foundation experts was incorporated into the Massachusetts health reform legislation during the tenure of Governor Mitt Romney who is currently the leading Republican candidate for President.²⁵ Other Republicans have also supported this requirement. The Republican support for the coverage requirement was discussed in a *Washington Post* article by Ezra Klein, which indicated that George H.W. Bush, Mitt Romney, and Newt Gingrich, and about half of Republican senators during the Clinton administration, all supported an individual health insurance mandate at some point in their political careers.²⁶

B. Logic of Coverage Requirement and Congressional Findings

The “42 U.S.C. § 18091 Requirement to maintain minimum essential coverage; findings” section provides the logic behind the coverage requirement and Congressional findings.²⁷ Figure 1 provides a

21. *Id.*

22. See HENRY J. KAISER FAMILY FOUND., EXPLAINING HEALTH REFORM, QUESTIONS ABOUT HEALTH INSURANCE SUBSIDIES 1 (2010), available at <http://www.kff.org/healthreform/upload/7962-02.pdf>.

23. Butler, *supra* note 15, at 51.

24. *Id.*

25. Noam N. Levey, *Massachusetts Health Reform a Double Edged Sword for Romney*, L.A. TIMES, May 12, 2011, at A1.

26. Ezra Klein, *A Lot of Republicans Supported the Individual Mandate*, WASH. POST (May 12, 2011, 2:00 PM), http://www.washingtonpost.com/blogs/ezra-klein/post/a-lot-of-republicans-supported-the-individual-mandate/2011/05/09/AFi26Z0G_blog.html.

27. 42 U.S.C. § 18091(a) (2006).

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diagram of this logic. The coverage requirement arises from the notion that some people are making a decision to forego health insurance even though they need health insurance to pay for health care problems that arise. Accordingly, instead of buying insurance, they self-insure, which creates more risks for their family's finances given that health care costs are unpredictable. One serious emergency or chronic illness could absorb all the money a family allots for health care services, which are usually quite expensive and require them to use funds that were reserved for other activities. As a result, a family could find themselves in a financially disastrous situation.

According to Congress, half of all bankruptcies are partially caused by medical expenses.²⁸ The risk for health providers also increases because they are less likely to receive payment for the services they offer. Congress further noted that the requirement will add millions of Americans to the number of insured people in the country.²⁹ The increase in the number of insured people will decrease the economic loss of \$207 billion that the country suffers as a result of the poorer health and shorter lifespan of the uninsured.³⁰ In order to pay for the \$43 billion of uncompensated care provided in 2008, providers passed on the cost to private insurers, who then passed on the cost to families.³¹ The coverage requirement is meant to increase the number of insured people while also decreasing the amount of uncompensated care and preventing the shifting of costs from uninsured to insured people. In addition, it is also a way to keep premium levels lower for currently insured people since the costs will be spread among a larger pool of people. Aspects of this logic will be challenged throughout this Article.

C. Characteristics of the Coverage Requirement

The coverage requirement section of the ACA indicates that an “applicable individual shall for each month beginning after 2013 ensure that the individual, and any dependent of the individual who is an applicable individual, is covered under minimum essential coverage for such month.”³² At first glance, the requirement appears to require all individuals in the U.S. to purchase at least a minimum level of

28. § 18091(a)(2)(g).

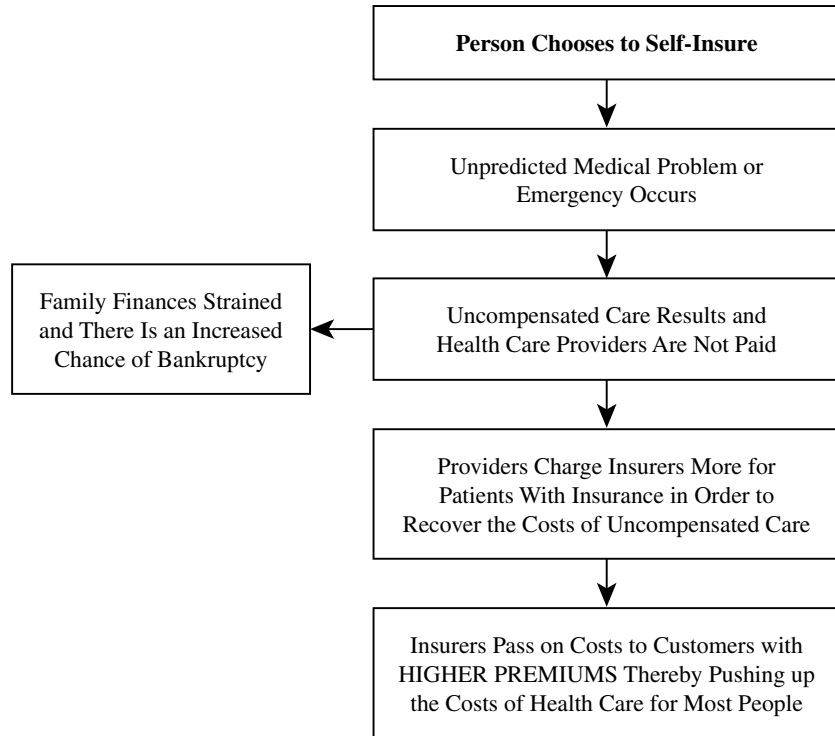
29. § 18091(a)(2)(c).

30. § 18091(a)(2)(e).

31. § 18091(a)(2)(f) (stating that cost shifting increases insurance premiums).

32. 26 U.S.C. § 5000A(a) (2006).

Figure 1 – Diagram of Logic of Coverage Requirement



health insurance beginning on January 1, 2014 just like the mandatory family protection requirement of The Heritage Foundation. However, the ACA coverage requirement is the legislative equivalent of Swiss cheese—it has numerous holes. In other words, there are multiple ways for individuals to avoid adhering to this requirement.³³ This section will discuss the various features of the requirement and the numerous ways that individuals can legally opt out of it.

1. Applicable Individuals and Exemptions

The coverage requirement only applies to applicable individuals and their dependents as stated above. “Applicable individual” is defined in the negative as a person other than individuals who are exempted from the coverage requirement.³⁴

33. § 5000A(d)-(e).

34. § 5000A(d)(1).

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The first exemption is the religious conscience exemption.³⁵ Initially, this exemption may appear to be available to any individual who states that his or her religious beliefs oppose the coverage requirement.³⁶ However, the exemption requires much more. An application must be filed with the IRS indicating that the person wants a religious conscience exemption.³⁷ Through the application, the person must provide evidence of membership with a religious sect or division opposed to accepting benefits of private/public insurance in the event of death, disability, old age, or retirement.³⁸ The person must also provide evidence of adhering to the teachings of the religious sect and a waiver of certain Social Security Act benefits.³⁹ The waiver is given if the IRS finds proof that the teachings of the religious sect oppose insurance benefits, the members of the sect make provisions for their dependent members, and there is an indication that the sect has been in existence since December 31, 1950.⁴⁰

The second exemption is for individuals who are members of a health care sharing ministry (“HCSM”).⁴¹ These ministries are made up of individuals who share their medical expenses.⁴² HCSMs are defined clearly by the legislation.⁴³ One key feature of members is that they retain membership with the organization after acquiring a medical condition.⁴⁴ According to the Alliance of Health Care Sharing Ministries, HCSM serve over 100,000 members.⁴⁵

A third exemption exists for people who are in the U.S. illegally.⁴⁶ This group is defined as someone who is “not a citizen or national of the United States or an alien lawfully present in the United States.”⁴⁷ This group numbers in the millions although the exact number is unknown because there are no good measures of the number of people illegally in the U.S.⁴⁸ Because the requirement is a month-to-

35. § 5000A(d)(2)(A).

36. *Id.*

37. *Id.*; § 1402(g)(1)(A).

38. § 5000A(d)(2)(A); *see* § 1402(g)(1)(B).

39. § 5000A(d)(2)(A); *see* § 1402(g)(1)(B).

40. § 5000A(d)(2)(A); *see* § 1402(g)(1)(B).

41. § 5000A(d)(2)(B).

42. *Id.*

43. *Id.*

44. *Id.*

45. *What is a Health Care Sharing Ministry?*, ALLIANCE HEALTH CARE SHARING MINISTRIES, <http://www.healthcaresharing.org/hcsm/> (last updated Jan. 2, 2012).

46. § 5000A(d)(3).

47. *Id.*

48. *See* Hope Yen, *Number of Illegal Immigrants in US Steady at 11.2 Million*, CNS NEWS (Feb. 1, 2011), <http://cnsnews.com/news/article/number-illegal-immigrants-us-steady-112m> (not-

month requirement, individuals are exempt only for those months when they are not in the U.S. lawfully, but they must adhere to the requirement during those months that they are legal.⁴⁹

The final exemption is for individuals who are incarcerated.⁵⁰ Again, this is a month-to-month requirement,⁵¹ so a person may be exempt for some months of the year and not others. Another provision of the law also indicates that bona fide residents of U.S. territories such as Puerto Rico do not have to satisfy the coverage requirement.⁵² They are deemed as having met the minimum essential coverage requirement by virtue of their residency.⁵³ The logic behind this exception is not clear given that people in territories can go to other states easily, use health care services in those states, and generate uncompensated care costs, continuing the existing problem the coverage requirement seeks to solve based on the congressional findings discussed earlier.

These exemptions prevent the coverage requirement from applying to these people and their dependents because they are not applicable individuals for the purposes of the law.⁵⁴ The exact size of this total exemption group is unknown to date. Although these individuals are not required to have any health insurance coverage like most Americans, hospitals are required to provide them with medical care during an emergency.⁵⁵ The Emergency Medical Treatment and Labor Act requires any hospital that receives Medicare and has an emergency department to stabilize anyone who has an emergency condition.⁵⁶ Therefore, these individuals who are exempt and do not have either private or public health insurance can still shift costs to those who have insurance. This is what Congress sought to prevent by creating the coverage requirement. On the other hand, these individuals may be able to pay cash for their health care, which could actually lead to them being charged more than people with insurance. These

ing that because the Census Bureau does not ask people about their immigration status, the number of illegal immigrants is an estimate).

49. § 5000A(d)(3).

50. *Id.* § 5000A(d)(4).

51. *Id.*

52. *Id.* § 5000A(f)(4).

53. *Id.*

54. *Id.* § 5000A(d)(1).

55. *See generally Overview*, CTRS. FOR MEDICARE & MEDICAID SERVS., <https://www.cms.gov/EMTALA/> (last visited Mar. 21, 2012) (noting that hospitals are required to provide care regardless of an individual's ability to pay).

56. *Id.*

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individuals might help hospitals pay for uncompensated care since they have no insurer bargaining lower prices for them. This is unlikely to be the case for most of these individuals, but some will fall into this category.

2. Types of Insurance Required

The second aspect of the coverage requirement is minimum essential coverage. An applicable individual and his or her dependent must have minimum essential coverage each month.⁵⁷ The ACA lists all the various types of insurance that qualify.⁵⁸ The types of insurance that meet the minimum essential standard are: 1) government sponsored insurance programs including Medicare, Medicaid, state Child Health Insurance Programs, military health plans, veterans' health care programs, and Peace Corps health plans; 2) employer sponsored plans including those paid by government employers; 3) plans in the individual market; 4) grandfathered health plans (those created before the ACA was passed); and 5) other coverage, which includes any other plans that are recognized by the Secretary of Health and Human Services.⁵⁹ Unlike what the Heritage Foundation scholars envisioned for the mandatory family protection requirement, this minimum essential coverage will not be adequate coverage for all individuals. In particular, individuals with more complex, chronic health care needs may not have their needs covered by minimum coverage. However, the minimum essential coverage guarantees that people have some basic coverage for their health care needs—even though the basic coverage will vary. In addition, this minimum, rather than an adequate standard, increases the likelihood that people can actually satisfy the requirement.

An important distinction must be made between minimum essential coverage and essential health benefits, which are also mentioned in the ACA. Minimum essential coverage does not require certain health benefits be covered.⁶⁰ For example, coverage may vary for Medicare and employer sponsored health plans, but both can meet the minimum essential coverage standard. On the other hand, plans that are required to have essential health benefits must all meet a basic

57. § 5000A(f).

58. *Id.* § 5000A(f)(1).

59. *Id.* § 5000A(f)(1)(1)(A)-(E).

60. *Id.* § 5000A(a).

coverage standard.⁶¹ Some of the minimum coverage plans will offer essential health benefits, and some will not. Thus, the minimum essential coverage is a very flexible standard and health plans that may not meet the basic health care needs of individuals can still meet the requirement.

3. Coverage Requirement Penalty and Exemptions

As envisioned by the Heritage Foundation, the Democrats, which controlled U.S. Congress, included a penalty as a means of enforcing the coverage requirement. The penalty is initially referred to in the law as the “shared responsibility payment.”⁶² In general, a person will be assessed a penalty for failing to meet the requirement for one month or more.⁶³ The penalty must be included with the tax return for the year during which the coverage requirement was not met.⁶⁴ If the penalty is not paid, there are no criminal or additional civil penalties.⁶⁵ The lack of payment also does not result in liens or levies by the IRS.⁶⁶ Applicable individuals must pay their penalty and a penalty of any dependents not meeting the requirement.⁶⁷ Also, a married couple filing taxes jointly is jointly responsible for the penalty.⁶⁸ The size of the penalty will be equal to or less than: 1) the sum of monthly penalty amounts (created by Congress) for each month that the requirement is not met or; 2) the national average for premiums that offer a bronze level of coverage to families in health insurance exchanges which are being created by the ACA.⁶⁹ The monthly penalty amount is one-twelfth of the annual penalty, which is \$95 in 2014 then moving to \$325 in 2015, and \$695 in 2016.⁷⁰ After 2016, cost of living adjustments are made to the penalty amount.⁷¹ The graduated approach increases the amount of pressure on individuals to purchase

61. 42 U.S.C. § 18022 (2006) (stating the requirements for essential health benefits).

62. 26 U.S.C. § 5000A(b).

63. *Id.* § 5000A(b)(1).

64. *Id.* § 5000A(b)(2).

65. *Id.* § 5000A(g)(2)(A)-(B) (“In the case of any failure by a taxpayer to timely pay any penalty . . . such taxpayer shall not be subject to any criminal prosecution or penalty with respect to such failure.”).

66. *Id.* § 5000A(g)(2)(B) (stating that the Secretary cannot file notice of a lien or levy any property of a taxpayer that has failed to pay the imposed penalty).

67. *Id.* § 5000A(b)(3)(A).

68. *Id.* § 5000A(b)(3)(B).

69. *Id.* § 5000A(c)(1)(A)-(B).

70. *Id.* §§ 5000A(c)(2)(A), (c)(3)(A)-(C).

71. *Id.* § 5000A(c)(3)(D).

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insurance each year. The penalty is half the stated amounts for individuals under age 18.⁷²

Although these amounts are generally less than the cost of insurance annually, they are in line with the Massachusetts health reform individual insurance requirement.⁷³ However, Massachusetts varies the penalty amount based on income and age.⁷⁴ There is a cap on the size of the total penalty for a household.⁷⁵ The cap is the greatest of 300% of the total monthly penalty amount or a certain percentage of the applicable individual's income.⁷⁶ The income percentage increases each year until 2015.⁷⁷ The cap is useful for large families considering whether to pay the penalty or purchase a minimal coverage. The 300% amount applies to the penalty for a family with two adults (100% for both) and two children (50% for both).⁷⁸ As a result, adults with more than two children do not pay any money for those other children. By contrast, those adults would have to pay more in premiums for these additional children. Thus, larger families have a disincentive to meet the coverage requirement.

There are numerous exemptions to the penalty, which reduces the number of people who have to meet the coverage requirement in the same way that the applicable individual exemptions do. The first exempt group is individuals who cannot afford coverage.⁷⁹ Affordability is defined as 8% of a person's household income for the

72. *Id.* § 5000A(c)(3)(C).

73. *Cf. Find Insurance: Individuals & Families Frequently Asked Questions*, HEALTH CONNECTOR HEALTH INS. FOR MASS. RESIDENTS, <https://www.mahealthconnector.org/portal/site/connector/menuitem.afc6a36a62ec1a50dbef6f47d7468a0c/&fiShown=default#q05> (last visited Mar. 23, 2012) (discussing the tax penalties under Massachusetts' health reform).

74.

The 2011 tax penalties for adults *above* 300% of the federal poverty level are . . . \$72 each month or \$864 for an entire year for individuals aged 18-26 earning more than \$32,496[, and] \$101 each month or \$1,212 for the year for individuals 27 or older earning more than \$32,496.

The 2011 tax penalties for adults *at or below* 300% of the federal poverty level are . . . \$0 for an individual earning up to \$16,248[,] \$19 each month or \$228 for the year for individuals earning between \$16,249 and \$21,660[,] \$38 each month or \$456 for the year for individuals earning between \$21,661 and \$27,084[, and] \$58 each month or \$696 for the year for individuals earning between \$27,085 and \$32,496

Id.

75. § 5000A(c)(2) (“[T]he monthly penalty amount with respect to any taxpayer for any month during which any failure . . . occurred is an amount equal to 1/12 of the greater of the [flat dollar and percentage of income] amounts.”).

76. *Id.* § 5000A(c)(2)(A)(ii).

77. *Id.* § 5000A(c)(2)(B).

78. *Id.* §§ 5000A(b)(1), (c)(3)(C).

79. *Id.* § 5000A(e)(1).

year.⁸⁰ The 8% is indexed over time.⁸¹ One difficulty with this exemption is that an individual's household income may be somewhat unpredictable, especially for people who are self-employed or employed part time. A person may not be able to determine if insurance is affordable or not over time, which may lead to problems implementing this exemption. The second exemption is for taxpayers who have incomes below the filing threshold for any month.⁸² This raises similar issues as the affordability exemption. The third exemption is for members of Indian Tribes.⁸³ The fourth exemption is for short coverage gaps.⁸⁴ This exemption allows people to have one continuous period of no coverage for less than three months.⁸⁵ This exemption is available to all applicable individuals.⁸⁶ The short coverage gaps exemption effectively turns the coverage requirement into a requirement to have insurance at least nine months out of the year instead of twelve months. The final exemption is the most amorphous. It is labeled "hardships."⁸⁷ The definition of hardship is to be determined by the Secretary of Health and Human Services.⁸⁸ If an applicable individual suffers a hardship "with respect to the capability to obtain coverage under a qualified health plan" during any month, the person will not need to meet the coverage requirement.⁸⁹ These exemptions combined with the applicable individual exemptions create numerous outlets for people to avoid the coverage requirement and continue the problem of cost shifting which the individual mandate is meant to stop.

D. Initial Opposition to the Coverage Requirement

Prior to the passing of the ACA and after its approval by Congress and President Obama, opposition came from various corners, led mainly by Republican Attorneys General and Republican legislators in various states. According to the National Conference of State

80. *Id.* § 5000A(e)(1)(A).

81. *Id.* § 5000A(e)(1)(D) ("[T]he percentage the Secretary of Health and Human Services determines reflects the excess of the rate of premium growth between the preceding calendar year and 2013 over the rate of income growth for such period.").

82. *Id.* § 5000A(e)(2).

83. *Id.* § 5000A(e)(3).

84. *Id.* § 5000A(e)(4).

85. *Id.* § 5000A(e)(4)(A).

86. *Id.*

87. *Id.* § 5000A(e)(5).

88. *Id.*

89. *Id.*

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Legislatures, forty-five states proposed legislation opposing or seeking to limit the ACA in some way.⁹⁰ A number of the bills proposed by states focused on preventing the coverage requirement from being applied to their citizens.⁹¹ In addition to legislation, states and other parties filed lawsuits challenging the coverage requirement.⁹² Multiple lawsuits were initiated in federal courts. Five of these cases reached federal circuit courts of appeals.⁹³ They are listed below along with the court that reviewed them.

Case	Federal Circuit Court of Appeals	Date Decided
Thomas More Law Center v. Obama	Sixth	June 29, 2011
Florida v. United States HHS	Eleventh	August 12, 2011
Virginia ex rel. Cuccinelli v. Sebelius	Fourth	September 8, 2011
Liberty Univ., Inc. v. Geithner	Fourth	September 8, 2011
Seven-Sky v. Holder	District of Columbia	September 23, 2011

The remainder of this Article will provide a comparative analysis of the aspects of these cases that focused on the coverage requirement.

II. COMPARATIVE ANALYSIS OF CIRCUIT COURT OPINIONS

In 2011, four U.S. circuit courts of appeals wrote a total of five opinions on the constitutionality of the coverage requirement. They included the Fourth, Sixth, Eleventh, and District of Columbia Circuits. The Fourth Circuit held that Virginia, as a sole, plaintiff had no standing in *Virginia ex rel. Cuccinelli v. Sebelius*⁹⁴ and that the Anti-Injunction Act barred the case in *Liberty University, Inc. v. Geithner*.⁹⁵

90. Cauchi, *supra* note 6.

91. *Id.* (“In at least 16 states, proposed bills aimed to amend state law . . . Virginia became the first to enact a new statute section titled, ‘Health insurance coverage not required.’ . . . Georgia, Idaho, Louisiana, Missouri, Utah and Arizona also each enacted similar statutes.”).

92. *See id.*

93. *Id.*

94. *Virginia ex rel. Cuccinelli v. Sebelius*, 656 F.3d 253, 267 (4th Cir. 2011).

95. *Liberty Univ., Inc. v. Geithner*, No. 10-2347, 2011 U.S. App. LEXIS 18618, at *13 (4th Cir. Sept. 8, 2011).

The Eleventh Circuit, which reviewed the merits of the case, found the coverage requirement unconstitutional but severable from the ACA.⁹⁶ The Sixth and D.C. Circuits held the provision constitutional.⁹⁷ On November 14, 2011, the Supreme Court granted writs of certiorari for the Eleventh Circuit case.⁹⁸ This section will review, compare, and contrast the decisions of the Eleventh, Sixth, and D.C. Circuits, focusing on the aspects of the decisions that dealt with the minimum essential coverage provision. Although all cases will be reviewed, more attention will be given to the Eleventh Circuit opinion.

A. Standing

A preliminary issue for all of the circuit court decisions was standing. In *Virginia ex rel. Cuccinelli v. Sebelius*, the Fourth Circuit held that the State of Virginia, the sole plaintiff, did not have standing to challenge the constitutionality of the coverage requirement and therefore remanded the case with instructions to dismiss for lack of subject matter jurisdiction.⁹⁹ The case was decided at the same time as another challenge to the coverage requirement, *Liberty University, Inc. v. Geithner*.¹⁰⁰

In *Virginia ex rel. Cuccinelli v. Sebelius*, the State of Virginia argued that it had standing because the coverage requirement conflicted with a new Virginia law, the Virginia Health Care Freedom Act (“VHCFA”).¹⁰¹ The Fourth Circuit began its analysis of standing by stating the three requirements of standing: 1) injury in fact; 2) causal connection; and 3) that a favorable judicial ruling will provide redress for the injury.¹⁰² Virginia, as the party invoking federal jurisdiction, had the burden of proof with regard to these requirements. The requirement at issue for the case was “injury in fact.”¹⁰³

In order to meet this requirement, Virginia needed to show that the ACA invaded a legally protected interest in a manner that is concrete and particularized and actual or imminent.¹⁰⁴ The court stated that the coverage requirement imposed “none of the obligations on

96. *Florida v. U.S. Dep’t of Health & Human Servs.*, 648 F.3d 1235, 1327-28 (11th Cir. 2011).

97. *Thomas More Law Ctr. v. Obama*, 651 F.3d 529, 533-34 (6th Cir. 2011).

98. *Seven-Sky v. Holder*, 661 F.3d 1, 4 (D.C. Cir. 2011).

99. *Sebelius*, 656 F.3d at 266.

100. *Geithner*, 2011 U.S. App. LEXIS 18618, at *5.

101. *Sebelius*, 656 F.3d at 266.

102. *Id.* at 268.

103. *Id.*

104. *Id.*

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Virginia” that have provided other states standing to challenge a federal statute.¹⁰⁵ Further the court stated that the coverage requirement did not burden Virginia, commandeer its enforcement officials, or threaten its sovereign territory, as in other cases where a federal statute was challenged.¹⁰⁶

The court further refined its question and decided whether a potential conflict between the coverage requirement and the VHCFA actually inflicts an injury on the State¹⁰⁷ or if the VHCFA is a “smokescreen for Virginia’s attempted vindication of its *citizens’* interests.”¹⁰⁸ The former would lead to a challenge of the coverage requirement but not the latter. Moreover, the court noted that the Constitution, not the coverage requirement, prevents Virginia from enforcing the VHCFA against the federal government.¹⁰⁹ The court also stated that the VHCFA seems to serve only one function: declaring Virginia’s opposition to a federal insurance mandate.¹¹⁰ The court also thought the timing of the law and statements by officials such as Virginia’s governor served as further support that this law was meant to be a declaration of opposition and nothing more.¹¹¹ The court further noted that permitting a state to litigate whenever it enacts a law in opposition to a federal law would transform the federal judiciary into a place “for the vindication of a state’s ‘generalized grievances about the conduct of government.’”¹¹²

Finally, the court indicated that because it held that Virginia lacked standing, it could not analyze the question of whether the Constitution authorizes Congress to enact the coverage requirement.¹¹³ The court stated that the mere existence of a state law did not permit a judicial challenge of a federal statute; but instead, the federal law needed to interfere with the state’s exercise of its sovereign “power to create and enforce a legal code” in order for the law to inflict an injury in fact on the state.¹¹⁴ The VHCFA was not a law focused on a state’s exercise of its power; instead, the law purports to immunize Virginians from a federal law, namely the ACA. This was not an act

105. *Id.*

106. *Id.*

107. *Id.* at 269.

108. *Id.*

109. *Id.* at 270.

110. *Id.*

111. *Id.*

112. *Id.* at 271 (citing *Flast v. Cohen*, 392 U.S. 83, 106 (1968)).

113. *Id.* at 267.

114. *Id.* at 269.

of sovereign power because Virginia lacked the authority to nullify federal law.¹¹⁵

By contrast, the Sixth Circuit also analyzed the issue of standing but came to a different conclusion for the plaintiffs. The plaintiffs in this case included Thomas More Law Center, a public interest law firm and four private individuals who stated that they were being compelled to purchase health insurance, unconstitutionally, by the coverage requirement.¹¹⁶ In regards to standing, the Sixth Circuit stated that one party with standing is sufficient.¹¹⁷ The Sixth Circuit focused on the injury in fact requirement for standing just as the Fourth Circuit did.

The Sixth Circuit stated that two theories of injury exist: “‘actual’ present injury and ‘imminent’ future injury.”¹¹⁸ When applying these theories to the private plaintiffs, Ceci and Steven Hyder, the court reasoned that both theories were satisfied.¹¹⁹ The plaintiffs showed that the future coverage requirement was making them change their present spending and saving habits.¹²⁰ Their future injury is supported by the coverage requirement itself, which will require the plaintiffs to buy insurance after 2014.¹²¹ The court stated that there is no reason to think the law will change without challenges of this nature and thereby the plaintiffs had an injury in fact, and the requirements for standing were met.¹²²

The Eleventh Circuit also considered the issue of standing.¹²³ The plaintiffs before the Eleventh Circuit also included states, just as in *Virginia ex rel. Cuccinelli v. Sebelius*, and private citizens.¹²⁴ Thus, the Eleventh Circuit concluded that whether state plaintiffs had standing was an interesting question.¹²⁵ However, the court also noted that the law is clear that when at least one plaintiff has standing to raise each claim, the court does not need to address whether other plaintiffs

115. *Id.* at 270 (citing *Mayo v. United States*, 319 U.S. 441, 445 (1943)).

116. *Thomas More Law Ctr. v. Obama*, 651 F.3d 529, 533 (6th Cir. 2011).

117. *Id.* at 535.

118. *Id.* at 536.

119. *Id.*

120. *Id.* at 536.

121. *Id.* at 536-37.

122. *Id.* at 539.

123. *Florida v. U.S. Dep’t of Health & Human Servs.*, 648 F.3d 1235, 1242 (11th Cir. 2011).

124. *Id.* at 1235 (“Twenty-six states, private individuals, and organization of independent businesses brought action against federal Health and Human Services (HHS), Treasury, and Labor Departments and their Secretaries, challenging constitutionality of Patient Protection and Affordable Care Act.”).

125. *Id.* at 1243.

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have standing.¹²⁶ Thus, the court acknowledged the private citizens' standing, without addressing whether the state(s) had standing.

B. Anti-Injunction Act

Prior to addressing the merits of the constitutional challenge or in lieu of addressing the constitutional challenge, the circuit courts also reviewed whether the case should be barred by the Anti-Injunction Act ("AIA"). Based on the Act, "no suit for the purpose of restraining the assessment or collection of any tax shall be maintained in any court by any person."¹²⁷ When the Act applies to a suit, it divests federal courts of subject matter jurisdiction.¹²⁸

The Fourth, D.C., and Sixth Circuits reviewed this issue.¹²⁹ Only the Fourth Circuit held that it did not have subject matter jurisdiction over the suit because it "constituted a pre-enforcement action seeking to restrain the assessment of a tax," which is prohibited by the AIA.¹³⁰ As a result, the court vacated the judgment of the district court and remanded the case with instructions to dismiss for lack of subject matter jurisdiction.¹³¹ In its analysis, the Fourth Circuit assessed whether the penalty that enforces the coverage requirement is actually a tax.¹³² The court noted that only taxpayers are subject to the penalty and that the penalty payment must be filed with an applicable individual's regular tax return.¹³³ The court also stated that the ACA authorized the Secretary of the Treasury to assess and collect the penalty payment "in the same manner as an assessable penalty under subchapter B of chapter 68."¹³⁴ The court further indicated that subchapter B of chapter 68 has penalties that the Secretary is "to assess and collect in the same manner as taxes."¹³⁵ The Secretary of Treasury can use all the civil enforcement tools of the Internal Revenue Code except collecting the penalty through a lien on property or a levy on a taxpayer's

126. *Id.*

127. I.R.C. § 7421(a) (West 2000).

128. *Liberty Univ., Inc. v. Geithner*, No. 10-2347, 2011 U.S. App. LEXIS 18618, at *16 (4th Cir. Sept. 8, 2011).

129. *Id.* at *16 (holding that the Fourth Circuit lacked subject matter jurisdiction based on the Anti-Injunction Act, which is contrary to what the D.C. and Sixth Circuits held about their respective jurisdiction).

130. *Id.* at *1.

131. *Id.*

132. *Id.* at *7.

133. *Id.*

134. *Id.* at *8-9.

135. *Id.* at *9.

property.¹³⁶ The Fourth Circuit asked the parties of this suit to file supplemental briefs focused on the AIA because the Secretary argued that Congress' tax power is one source of authority for the coverage requirement.¹³⁷

In these briefs, both parties argued that the AIA does not apply, but the Fourth Circuit disagreed.¹³⁸ The court stated that the Act does not prevent future refund actions, but instead it focuses on pre-enforcement actions.¹³⁹ The court also defined a tax as "an exaction for the support of the government."¹⁴⁰ Further, the court cited Supreme Court precedent for the idea that an exaction can be a tax even when the exaction raises little revenue and furthers a secondary goal of regulation just as the penalty for the coverage requirement does.¹⁴¹ The court stated that the definition of tax, for the purposes of the AIA, is broad because a key aim of the AIA is to ensure prompt collection of lawful revenue by preventing taxpayers from inundating the IRS with pre-enforcement lawsuits.¹⁴² The court pointed out that the definition of tax, for the purposes of analyzing the taxing power of Congress, could be narrower than the definition of tax for the AIA.¹⁴³ More explicitly, the court indicated that the Supreme Court has clearly stated that the term "tax" in the AIA can include penalties that are mere regulatory measures beyond the taxing power of Congress.¹⁴⁴ The Fourth Circuit pointed out that the Supreme Court does not focus on whether the exaction is labeled a tax or not. Rather, the nature and character of the exaction is more important.¹⁴⁵ The court also indicated that Congress could have constructed a bar to the AIA, as they have done in the past, if they intended the AIA not to apply.¹⁴⁶

The D.C. Circuit reviewed this issue and decided that the AIA did not bar the suit.¹⁴⁷ The court focused on the definition of tax just

136. *Id.*

137. *Id.* at *14-15.

138. *Id.* at *15.

139. *Id.* at *16-17.

140. *Id.* at *17 (citing *United States v. Butler*, 297 U.S. 1, 61 (1936)).

141. *Id.*

142. *Id.* at *18.

143. *Id.* at *19.

144. *Id.*

145. *Id.* at *24.

146. *Id.* at *45.

147. *Seven-Sky v. Holder*, 661 F.3d 1, 1 (D.C. Cir. 2011).

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as the Fourth Circuit did.¹⁴⁸ D.C. referred to the penalty as a shared responsibility payment.¹⁴⁹ The court viewed the AIA issue as having two key questions: 1) does the term “any tax” in AIA apply to the shared responsibility payment; and 2) if the AIA does not apply, does the ACA invoke the AIA by indicating that the shared responsibility payment is to be assessed and collected in the same manner as penalties subject to the AIA?¹⁵⁰

In its analysis, the court focused on the legislative history of the ACA, revealing that Congress avoided the label of tax for the shared responsibility payment and that the payment is slated to bring in very little revenue (\$4 billion) for the government.¹⁵¹ Perhaps one of the strongest arguments of the D.C. Circuit is that the goal of the coverage requirement is not to assess a penalty, but to encourage voluntary compliance.¹⁵² The penalty will not be assessed regularly and perhaps not at all. The court viewed it as an incentive to get people to behave in a certain way. However, the Fourth Circuit pointed out that the AIA includes the broad notion of a tax being used for regulation only.¹⁵³ The D.C. Circuit also argues against the Fourth Circuit with regard to Congress’ use of tax in the ACA by stating that if Congress wanted tax to be defined broadly they would have done so as they have done for other laws.¹⁵⁴ The court also argued that the government should be given more deference, and because the government does not view the penalty as a tax then it is not a tax.¹⁵⁵ The Fourth Circuit cited Supreme Court precedent to go against this idea. It stated that tax can be evaluated beyond Congress’ definition.¹⁵⁶ The D.C. Circuit stated that the AIA does not define the word “tax,” so there is no clear definition of tax from this law.¹⁵⁷ The Fourth Circuit pointed out that the Supreme Court has interpreted tax, for the purposes of the AIA, as being broad.¹⁵⁸ Further, the court indicated that

148. *See id.* at 10 (“We think that the Anti-Injunction Act does not, by its terms, cover the shared responsibility payment under the term ‘any tax.’”).

149. *Id.*

150. *Id.* at 10-12.

151. *Id.* at 11.

152. *Id.* at 6.

153. *Liberty Univ., Inc. v. Geithner*, No. 10-2347, 2011 U.S. App. LEXIS 18618, at *18 (4th Cir. Sept. 8, 2011).

154. *Seven-Sky*, 661 F.3d at 12.

155. *Id.* at 12.

156. *Geithner*, 2011 U.S. App. LEXIS 18618, at *6.

157. *Seven-Sky*, 661 F.3d at 6.

158. *Geithner*, 2011 U.S. App. LEXIS 18618, at *18.

the terms “tax” and “penalty” are used in the ACA, and Congress intentionally distinguished them.¹⁵⁹

The D.C. Circuit found the focus of the suit a critical aspect of their analysis.¹⁶⁰ The suit is focused on preventing the coverage requirement from being applied to individuals, not the assessment and collection of taxes. However, what the court failed to point out is that the coverage requirement is not a requirement without the penalty. Enforcement is the linchpin of the requirement. If there is no penalty, the requirement is a mere suggestion. In fact, a great deal of the opposition to the coverage requirement is based not on the requirement itself but the penalty. If the penalty was \$1, individuals would be unlikely to file a lawsuit because the injury inflicted upon them would be minimal. The initial penalty of \$95 is not much of an injury for someone who can afford health insurance, but the court did not assess the meaning of injury in this context. The D.C. Circuit viewed this suit as a pre-enforcement challenge to a “discrete regulator requirement that imposes obligations unrelated to tax revenues” simply because Congress chooses to tax some people who violate the law.¹⁶¹

The dissent in this case argued that the ACA states that the penalty should be “assessed and collected in the same manner as an assessable penalty under subchapter B.”¹⁶² As stated earlier, these penalties are considered taxes for the purposes of the Anti-Injunction Act and the dissent thinks the coverage requirement penalty must be the same.¹⁶³ The majority disagreed with this argument based on their interpretation of the phrase “assessed and collected in the same manner.”¹⁶⁴ The majority reasoned that this phrase has a more limited view and does not refer to pre-enforcement review of a federal statute.¹⁶⁵ In their analysis of this more limited meaning, they indicated that assessment and collection do not refer to the timing of challenges against them.¹⁶⁶

159. *Seven-Sky*, 661 F.3d at 6 (“That Congress called numerous other provisions in the Act ‘taxes’ indicates that its decision to use the word ‘penalty’ here was deliberate.”).

160. *See id.* at 19–20. (“[The appellants] seek injunctive and declaratory relief to prevent anyone from being subject to the mandate, irrespective of whether they intend to comply with it, and irrespective of the means Congress chooses to implement it.”).

161. *Id.* at 25.

162. *Id.* at 10, 21–22.

163. *Id.* at 22 (Kavanaugh, J., dissenting) (“Affordable Care Act penalties must be assessed and collected ‘in the same manner as taxes.’”).

164. *See id.* at 25.

165. *Id.*

166. *Id.* at 11 (“‘Assessing and collecting’ a penalty ‘in the same manner’ as a tax, for instance, does not require the same statute of limitations to apply to each.”).

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The majority further indicated that although the ACA refers to penalties that are viewed as taxes in subchapter B of chapter 68, the ACA omits a key phrase found in chapter 68 which reads as follows: “any reference in this title to ‘tax’ imposed by this title shall be deemed also to refer to the penalties and liabilities provided by [subchapter B].”¹⁶⁷ In the court’s eyes, this missing statement made the ACA penalty similar to the penalties mentioned in chapter 68, but not the same in that they are not considered taxes.¹⁶⁸ The court also argued that the government should be given deference in their determination that the penalty is not a tax because they are the sole beneficiaries of the Anti-Injunction Act’s application to the penalty.¹⁶⁹ The court also stated that if the Act is applied to the penalty, then the government can engage in the “uninterrupted collection of taxes” because the IRS is protected from being subject to litigation before they complete the collection of taxes.¹⁷⁰

An issue not discussed by the D.C. Circuit is that the government may have an ulterior motive for not wanting to apply the Anti-Injunction Act to this case. The government may realize that since it has a case that the Supreme Court may hold in its favor, applying the Anti-Injunction Act to the coverage requirement will slow down this case and create a political problem during a presidential election year. Government agencies are assumed by the court to be objective instead of extensions of the Executive branch, which is highly political and biased with the goal of self-preservation. Waiting until 2014 would potentially mean the case could be litigated by an administration that is Republican dominated, if it is litigated at all. Given all the political statements¹⁷¹ by Republican presidential candidates to repeal the ACA, the government is unlikely to litigate these cases if Obama is not in the White House. Hence, the government perhaps should not receive deference because their view is biased. The court ignores these obvious political realities.

The Sixth Circuit also reviewed the applicability of the Anti-Injunction Act because it involved subject matter jurisdiction, despite

167. *Id.* (citing 26 U.S.C. § 6671(a) (2006)).

168. *See id.* at 12, 31.

169. *Id.* at 13.

170. *Id.*

171. *See, e.g., Repeal and Replace ObamaCare with Patient-Centered Healthcare*, RICK SANTORUM, <http://www.ricksantorum.com/repeal-and-replace-obamacare-patient-centered-healthcare> (last visited Mar. 22, 2012).

agreement by both parties that the AIA did not bar the action.¹⁷² The court argued that the use of different terms in the AIA and ACA by Congress suggested that the AIA did not cover the penalty of the ACA.¹⁷³ Similarly to the Eleventh Circuit, the Sixth Circuit stated that the lack of a provision clearly labeling the coverage requirement penalty as a tax made it different from the penalties in chapter 68, which are clearly labeled as taxes.¹⁷⁴ Also, since the ACA penalty is in chapter 48, it was not the penalty being referred to in chapter 68.¹⁷⁵ The court also stated that the ACA penalty has nothing to do with tax enforcement, unlike the penalties in chapter 68.¹⁷⁶ The court also agreed with the Eleventh Circuit that § 5000A(g)(1) of the ACA, which states that the coverage requirement penalty should be assessed and collected in the same manner as the penalties in subchapter B of chapter 68, is not referring to the notion that these penalties are treated as taxes.¹⁷⁷ Instead, the court reasoned that a natural reading of this provision is that it is referring to the mechanisms the IRS uses to enforce the penalty.¹⁷⁸ What the court saw as less pertinent is the argument that the mechanism of enforcement for the penalties in subchapter B of chapter 68 is to label these penalties as taxes. In turn, if the penalties are labeled as taxes, they are treated a certain way including falling under the Anti-Injunction Act.¹⁷⁹ The penalties in subchapter B of chapter 68 have been treated like taxes and have barred suits as a result of the Anti-Injunction Act, so the ACA penalty, which is assessed and collected in the same manner should be treated the same. This argument turns on how a court views the term “same manner.”

C. Commerce Clause

Two of the circuit courts assessed whether the requirement to maintain minimum essential coverage exceeded Congress’ commerce power. In an opinion nearly 200 pages in length, the Eleventh Circuit

172. *Thomas More Law Ctr. v. Obama*, 651 F.3d 529, 539 (6th Cir. 2011) (“The United States and the plaintiffs now agree that the Anti-Injunction Act does not bar this action. Yet because this limitation goes to the subject matter jurisdiction of the federal courts, the parties’ agreement by itself does not permit us to review this challenge.”).

173. *Id.*

174. *Id.*

175. *Id.* at 540.

176. *Id.*

177. *Id.*

178. *Id.*

179. *Id.*

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held that Congress did exceed its commerce power.¹⁸⁰ The Sixth and D.C. Circuits held that the requirement did not exceed Congress' commerce power.¹⁸¹ A number of Commerce Clause issues were analyzed by these courts. Those arguments are analyzed by them in this section.

1. Unprecedented Exercise of Congressional Power

The first argument of the Eleventh Circuit is that the coverage requirement represents an unprecedented exercise of congressional power.¹⁸² The court stated the question as “whether the individual mandate is beyond the constitutional power granted to Congress under the Commerce Clause and Necessary and Proper Clause.”¹⁸³ A number of arguments were made to support the view that the mandate was beyond Congress' constitutional power.

The court stated that the Congressional Budget Office indicated that Congress “has never required people to buy any good or service as a condition of lawful residence in the United States.”¹⁸⁴ However, this statement overstates the coverage requirement's reach given that there are numerous exceptions for citizens. The requirement applies to people not meeting those exceptions, which means that it does not apply to all U.S. citizens. The court also stated that the language of the mandate requires non-market participants to enter into commerce instead of waiting until they enter the market.¹⁸⁵ In addition, the mandate is for people to buy insurance their entire lives.

The court discussed two major limitations on Commerce Clause power for Congress. The first limitation is that any regulation made as a result of the Commerce Clause must “accommodate the Constitution's federalist structure and preserve ‘a distinction between what is truly national and what is truly local.’”¹⁸⁶ The second limitation is that the Commerce Clause cannot be interpreted as a grant of general

180. *Florida v. U.S. Dep't of Health & Human Servs.*, 648 F.3d 1235, 1242, 1307 (11th Cir. 2011).

181. *See Seven-Sky v. Holder*, 661 F.3d 1, 20 (D.C. Cir. 2011) (affirming the district court's dismissal of a challenge to minimum essential coverage provisions); *Thomas More Law Ctr.*, 651 F.3d at 565-66 (finding that Congress does not exceed its Commerce Clause powers in all applications of the individual mandate).

182. *U.S. Dep't of Health & Human Servs.*, 648 F.3d at 1288.

183. *Id.* at 1282.

184. *Id.* at 1288 (citation omitted).

185. *Id.* at 1311 (“Never before has Congress sought to *regulate* commerce by compelling non-market participants to *enter into* commerce so that Congress may regulate them. . . . The individual mandate does not wait for market entry.”).

186. *Id.* at 1284 (quoting *United States v. Lopez*, 514 U.S. 549, 553 (1995)).

police power to Congress.¹⁸⁷ The court also stated that activity is not a precondition for Congress's ability to regulate under the Commerce Clause, which means that whether uninsured people are actively participating in a market or not is a precondition for the constitutionality of the mandate.¹⁸⁸ The court also indicated that those who choose not to purchase health insurance are "hardly involved in the 'production, distribution, and consumption of commodities'"¹⁸⁹ This commodity-based definition offers a limited view of commerce and does not adequately apply to people purchasing insurance, which is a service and not a commodity. Based on this definition, which the court refers to frequently, no one purchasing insurance is participating in commerce, which seems a bit illogical given that the court and both parties recognize that regulating the health insurance industry is a valid use of the Commerce Clause power. Although the court generally viewed the uninsured as not participating in the health insurance market because they lack health insurance,¹⁹⁰ the court did note that the uninsured are active in the health care services market.¹⁹¹ In footnote eighty-five, the court agreed with the government's characterization of the uninsured as active consumers of health care by stating the following: "consume healthcare,"¹⁹² Hence the court contradicts its prior statements that the uninsured are not consuming and thereby not involved in commerce related to health insurance. Consumption of health care services without paying for them impacts the price of health insurance as the government demonstrated and current studies demonstrate. This footnote appears to be the court's admission that it agrees with the government yet the footnote is not reflected in the body of the opinion.

The Eleventh Circuit pointed out that economic mandates such as the coverage requirement are so unprecedented that the government in its brief and oral argument was unable to point the court to Supreme Court precedent that addresses the constitutionality of such a

187. *Id.* ("[T]he Court has repeatedly warned that courts may not interpret the Commerce Clause in a way that would grant to Congress a general police power.").

188. *Id.* at 1286 ("Although the Supreme Court's Commerce Clause cases frequently speak in activity-laden terms, the Court has never expressly held that activity is a precondition for Congress's ability to regulate commerce.").

189. *Id.* (quoting *Gonzales v. Raich*, 545 U.S. 1, 25 (2005)).

190. *See id.* at 1295.

191. *Id.* at 1286-87 ("[T]o the extent the uninsured can be said to be 'active,' their activity consists of the *absence* of . . . behavior . . . with respect to health insurance.").

192. *Id.* at 1287 n.85 (emphasis added).

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mandate.¹⁹³ The court also stated that the fact that Congress “has never before exercised this supposed authority is telling.”¹⁹⁴ Citing the Supreme Court, the Eleventh Circuit noted that the “utter lack of statutes imposing obligations on the States’ executive . . . , suggests an assumed *absence* of such power.”¹⁹⁵ The court spent time noting that compelling purchase of a certain product has not been done even at the height of congressional power under the Commerce Clause during the Great Depression, various recessions, and more.¹⁹⁶ The court also noted that historically Congress has subjected Americans to only a limited number of personal mandates such as registering for the draft or serving on juries.¹⁹⁷ In these situations, the mandates arose from duties “owed to the government attendant to citizenship” and had some constitutional basis.¹⁹⁸

The court went on to compare the coverage requirement to prior Supreme Court Commerce Clause cases. The court stated that *Wickard v. Filburn*,¹⁹⁹ which represents the height of Congress’ powers under the Commerce Clause, is actually less intrusive than the coverage requirement.²⁰⁰ In *Wickard*, a wheat farmer was not allowed to grow wheat for his own family’s consumption because it might impact wheat prices, which Congress was regulating by limiting production of

193. *Id.* at 1288 (“Economic mandates such as the one contained in the Act are so unprecedented . . . that the government has been unable, either in its briefs or at oral argument, to point this Court to Supreme Court precedent that addresses their constitutionality.”).

194. *Id.* at 1289.

195. *Id.* (quoting *Printz v. United States*, 521 U.S. 898, 907-08 (1997)).

196. *Id.* (“Even in the face of a Great Depression, a World War, a Cold War, recessions, oil shocks, inflation, and unemployment, Congress never sought to require the purchase of wheat or war bonds, force a higher savings rate or greater consumption of American goods, or require every American to purchase a more fuel efficient vehicle.”).

197. *Id.* at 1290 (“Americans have, historically, been subject only to a limited set of personal mandates: serving on juries, registering for the draft, filing tax returns, and responding to the census.”).

198. *Id.*

199. *Wickard v. Filburn*, 317 U.S. 111 (1942).

200. *U.S. Dep’t of Health & Human Servs.*, 648 F.3d at 1291 (“Although *Wickard* represents the zenith of Congress’s powers under the Commerce Clause, the wheat regulation therein is remarkably less intrusive than the individual mandate.”).

wheat.²⁰¹ In this instance, the Court pointed out that the farmer was not compelled to buy wheat.²⁰²

While this comparison is informative of the degree to which Congress has used its Commerce Clause power, it is not analogous in that the same farmer may have not eaten wheat for the rest of his life, but he would have received some health care. In addition, his dependents would have received health care. Health care is used by all and in that manner is different from other types of commodities, which the Commerce Clause has typically been used to regulate. People do not choose to get sick, but all get sick at some point. People do not choose birth or illness prior to death, but both often require intervention from health care workers. The court spent time focusing on the notion that people subject to the coverage requirement are not making a voluntary choice but are having a choice imposed upon them by the government.²⁰³ However, these individuals are making a choice—to self-insure themselves instead of purchasing insurance of some type. On the other hand, individuals who are too poor to purchase are not making a choice, they simply cannot afford to purchase insurance. Similarly those with religious objections are choosing not to purchase for religious reason. These and other reasons for not purchasing insurance are exceptions to the coverage requirement as stated earlier.

The coverage requirement focuses on a narrowly defined group of people who can afford to buy some type of insurance, but choose not to, and as a result they impose their choice on other Americans and increase their health care costs. The coverage requirement seeks to prevent such behavior, which intrudes on the economic decisions of other Americans. This is the commerce decision that is being regulated, not forcing people to buy insurance simply to have it, but requiring a select group to purchase insurance in order to prevent inflicting financial harm on other citizens. The court seemed to recog-

201. *Wickard*, 317 U.S. at 127-28. The Supreme Court explained:

The maintenance by government regulation of a price for wheat undoubtedly can be accomplished as effectively by sustaining or increasing the demand as by limiting the supply. The effect of the statute before us is to restrict the amount which may be produced for market and the extent as well to which one may forestall resort to the market by producing to meet his own needs. That appellee's own contribution to the demand for wheat may be trivial by itself is not enough to remove him from the scope of federal regulation where, as here, his contribution, taken together with that of many others similarly situated, is far from trivial.

Id.; see also *U.S. Dep't of Health & Human Servs.*, 648 F.3d at 1291-93.

202. See *Wickard*, 317 U.S. at 129; *U.S. Dep't of Health & Human Servs.*, 648 F.3d at 1291-92.

203. *U.S. Dep't of Health & Human Servs.*, 648 F.3d at 1291-92 (“Individuals subjected to this economic mandate have not made a voluntary choice to enter the stream of commerce, but instead are having that choice imposed upon them by the federal government.”).

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nize this behavior when it indicated that the regulation is not well designed to capture the individuals who are actually shifting costs to other citizens.²⁰⁴ The court seemed to seek legislation that is designed to identify those who shift costs to others and allow other citizens to go without insurance.²⁰⁵ This is exactly what the coverage requirement is designed to do. The court seemed to think that if the coverage requirement did a better job of regulating these individuals, then the requirement would be an acceptable use of Congress' power under the Commerce Clause.²⁰⁶ The court stated that the regulation is over inclusive and even covers those not consuming health care.²⁰⁷ However, this argument ignores the fact that individuals cannot predict when they will consume care and that most people consume care during the year.

While a regulation targeting cost-shifters, perhaps by requiring people to have insurance before they receive health services, seems to be less intrusive, it does not make sense medically. People without insurance would continue to avoid care until they have a problem. These individuals often go to an emergency room or clinic when their problem has reached its worst point, only to find out that they must purchase insurance because they may cause cost shifting. Then, the person who is now quite sick would need to locate an insurer for his or her care, which would likely charge an extremely high rate, perhaps making insurance unaffordable to him or her. In its discussion of cost shifting, the court also said nothing about dealing with people who are exceptions to the rule. Perhaps the court would create an intrusive regulation that forces those with a religious conscience exception to purchase insurance upon coming to seek health care. The coverage requirement in this case would be less intrusive.

2. Aggregation Doctrine: No Refuge for Mandate

Circuit courts also reviewed whether the aggregation doctrine of the Commerce Clause applied to the coverage requirement.²⁰⁸ Ac-

204. *Id.* at 1293 (“[T]he individual mandate’s attempt to reduce the number of the uninsured and correct the cost-shifting problem is woefully overinclusive.”).

205. *See id.* at 1294-95.

206. *See id.* at 1294 (“It is true that Congress may, in some instances, regulate individuals who are consuming health care but not themselves causing the cost-shifting problem.”).

207. *Id.* at 1293 (“[T]he language of the mandate is unlimited, and covers even those who do not enter the health care market at all.”).

208. *See id.* *Seven-Sky v. Holder*, 661 F.3d 1, 19 (D.C. Cir. 2011) (“[A]ppellants’ argument—that Congress’s power to regulate national economic problems, even those resulting from the aggregated effects of intrastate activity, only extends to particular individuals if they have also

ording to the aggregation doctrine, the individual effects of certain types of commerce may not affect interstate commerce but collectively they do.²⁰⁹ The D.C. Circuit argued that if Congress can regulate “purely local conduct that were never intended for . . . an interstate market” then Congress can regulate “ostensible *inactivity* inside a state” if the aggregate of the behavior is just as “injurious to interstate commerce.”²¹⁰ The Eleventh Circuit noted that the Supreme Court stated that the Court has only sustained a federal regulation under the aggregation principle when the regulated activity is of apparent commercial character.²¹¹ The court further stated that the question before it is whether Congress may regulate individuals on the theory that their economic decisions to avoid commerce “themselves substantially affect interstate commerce.”²¹² The court reasoned that if the aggregation doctrine was applied to the decision not to purchase insurance, the substantial effects doctrine would expand to one of unlimited scope.²¹³ The court stated that any decision not to purchase any good when taken in the aggregate could affect commerce.²¹⁴ The court saw no limits to the doctrine when applied to the decisions not to purchase something and did not see how health insurance could be distinguished from other purchases.²¹⁵ The court viewed this expansion of the Commerce Clause as too great.²¹⁶ However, the Eleventh Circuit did not recognize that an individual’s decision not to purchase insurance is making a decision. Individuals’ decisions are being regulated because they harm people; individuals are not being regulated for their lack of a decision.

affirmatively engaged in interstate commerce—has been rejected on that basis.”); *U.S. Dep’t of Health & Human Servs.*, 648 F.3d at 1291-93 (stating that an individual’s decision not to purchase insurance would substantially affect interstate commerce when taken in the aggregate).

209. See *U.S. Dep’t of Health & Human Servs.*, 648 F.3d at 1291 (“Aggregation may suffice to bring otherwise non-regulable, ‘trivial’ instances of intrastate activity within Congress’s reach if the cumulative effect of this class of activity . . . substantially affects interstate commerce.”).

210. *Seven-Sky*, 661 F.3d at 19.

211. See *U.S. Dep’t of Health & Human Servs.*, 648 F.3d at 1292 (citing *United States v. Morrison*, 529 U.S. 598, 611 n.4 (2000)).

212. *Id.*

213. *Id.* (“Applying aggregation principles to an individual’s decision not to purchase a product would expand the substantial effects doctrine to one of unlimited scope.”).

214. *Id.* (“Given the economic reality of our national marketplace, any person’s decision not to purchase a good would, when aggregated, substantially affect interstate commerce in that good.”).

215. *Id.* (“From a doctrinal standpoint, we see no way to cabin the government’s theory only to decisions not to purchase *health insurance*.”).

216. *Id.* at 1295 (“This theory affords no limiting principles in which to confine Congress’s enumerated [Commerce Clause] power.”).

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The Eleventh Circuit also noted that the conduct regulated must have a connection or nexus to commerce as well as the lack of decisions based on Supreme Court statements that reject regulation of noneconomic activity solely on the “conduct’s aggregate effect on interstate commerce.”²¹⁷ The court noted that the nexus is lacking because the regulated conduct is defined by the absence of commerce.²¹⁸ The court again rejected the framing of the regulated conduct as someone making a choice to self-insure.²¹⁹ Instead, the court stated that the regulated conduct is either not buying insurance or a decision to forgo insurance.²²⁰

3. The Enumerated Commerce Clause Power Must Have Judicially Enforceable Limitations

Circuit courts reviewed whether the coverage requirement includes limitations on the Commerce Clause power, which are judicially enforceable. The Eleventh Circuit reasoned that the coverage requirement lacked limits and was overly broad.²²¹ The court stated that the requirement does not focus on the group that is causing the problem—cost-shifters.²²² The court further stated that other than the exemptions, which the court downplays in making its argument, the coverage requirement does not have a language ““which might limit its reach to a discrete set of [activities] that additionally have an explicit connection with or effect on interstate commerce.””²²³ Again the court did not accept the argument that the discrete set of activities is the decision to self-insure instead of purchasing insurance.²²⁴ The coverage requirement clearly provides exceptions for people who are not able to buy insurance and focuses only on people who are able to make this decision, as stated earlier in this Article.²²⁵ The court reasoned that people could be required to get insurance after they generate uncompensated care costs since Congress is seeking to lower these

217. *Id.* at 1293 (quoting *Morrison*, 529 U.S. at 617).

218. *Id.* (“[W]hat matters is the regulated subject matter’s connection to interstate commerce. That nexus is lacking here.”).

219. *Id.* at 1291-92 (“Individuals subjected to this economic mandate have not made a voluntary choice to enter the stream of commerce, but instead are having that choice imposed upon them by the federal government.”).

220. *See id.* at 1293.

221. *See id.* at 1295.

222. *Id.* at 1293 (“The language of the mandate is not tied to those who do not pay for a portion of their health care (i.e., the cost-shifters).”).

223. *Id.* at 1294 (quoting *United States v. Lopez*, 514 U.S. 549, 553 (1995)).

224. *See id.* at 1297-98.

225. *See* discussion *supra* Part II.C.1.

costs.²²⁶ However, this ignores the reality that the health care providers will still lose money in this situation and that insurance does not cover everything. Also, people could lower their costs upfront and lower the costs to insurers and providers if they get health care earlier rather than later. The court also stated that regulation of future activity (buying insurance in the future) is a sign of the lack of limitations of the coverage requirement.²²⁷

Prior Supreme Court Commerce Clause cases deal with “already-existing activity . . . that could implicate interstate commerce.”²²⁸ The Eleventh Circuit reasoned that the government’s position is that at some point in the future, people will consume health care.²²⁹ This “some point in the future” notion is too removed from the “traditional exercises of Congress’s commerce power.”²³⁰ The court and the plaintiffs acknowledged that regulating activity that exists in the future would be an appropriate use of congressional power.²³¹ According to the court, the plaintiffs stated in their oral argument that “when the uninsured actually enter the stream of commerce and consume health care, Congress may regulate their activity at the point of consumption.”²³² Again, this approach ignores the fact that people cannot be prevented from receiving care if they have an emergency. It also ignores the fact that the costs of health care will be lower for the person if he or she has insurance beforehand so that he or she is encouraged to use health care services that can prevent problems from becoming severe. People without insurance are more likely to forego care, not comply with medical prescriptions, and generally engage in behavior which lead to worse health outcomes because they are not getting regular maintenance care as a result of lack of insurance. Also, if people are told they need insurance when they begin to consume health care, insurers are likely to only offer expensive insurance options because the person is now more of a risk for the insurance company. The increased expense will make insurance less of an option for the person and effectively lower the amount of people able to pay for insurance.

226. *U.S. Dep’t of Health & Human Servs.*, 648 F.3d at 1294-95 (“Congress may regulate [uninsured individuals’] activity at the point of consumption.”).

227. *Id.* at 1294 (“[T]he premise of the government’s position—that most people will, *at some point in the future*, consume health care—reveals that the individual mandate is even further removed from traditional exercises of Congress’s commerce power.”).

228. *Id.*

229. *Id.*

230. *Id.* at 1294.

231. *Id.* at 1295.

232. *Id.*

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Thus, the problem of uncompensated care would not be adequately dealt with.

Given the number of exemptions already available and no statement by the court that these should be removed, the suggested approach of the court would simply lessen the chance of Congress actually reducing the amount of uncompensated care. The court also ignores the reality that most Americans seek health care at some point during the year and are more likely to seek care for non-emergency health needs if they have insurance, which can decrease future health care costs by preventing serious problems. The court is also not recognizing the fact that infants and children have different health care needs from adults and must interact with health care providers. The main limiting principle that the government states, according to the Eleventh Circuit, is “uniqueness.”²³³

As the court noted, the government does not think that the coverage requirement can be replicated beyond the health care industry “due to: (1) the inevitability of health care need; (2) the unpredictability of need; (3) the high costs of health care; (4) the federal requirement that hospitals treat, until stabilized, individuals with emergency medical conditions, regardless of their ability to pay; (5) and associated cost-shifting.”²³⁴ However, the court clearly stated that government’s five limiting factors have no constitutional relevance.²³⁵ Instead, the court noted that these are “ad hoc factors that . . . happen to apply to health insurance.”²³⁶ The court further pointed out that other types of insurance have similar characteristics as the factors offered by the government.²³⁷ Thus, the government’s theory could be used to compel the purchase of other types of insurance, which also result in cost-shifting—such as flood insurance.

The second problem the court had with the government’s factors was the factors’ administrability.²³⁸ Given the criteria are fact based, they are difficult to apply to Commerce Clause cases, which need lim-

233. *Id.* at 1295-96.

234. *Id.* at 1295.

235. *Id.* (“The first problem with the government’s proposed limiting factors is their lack of constitutional relevance.”).

236. *Id.* at 1296.

237. *Id.* (“However, virtually all forms of insurance entail decisions about timing and planning for unpredictable events with high associated costs—insurance protecting against loss of life, disability from employment, business interruption, theft, flood, tornado, and other natural disasters, long-term nursing care requirements, and burial costs.”).

238. *Id.* (“[A] second fatal problem with the government’s proposed limits [is] administrability.”).

iting *principles* instead of factual requirements.²³⁹ The court stated that if they adopted these limiting principles, they would have to factually assess each criterion for every Commerce Clause case involving an economic mandate.²⁴⁰ The court further noted that the government's desire for the court to give deference to the government's fact finding regarding the coverage requirement, simply underscores the lack of a judicially enforceable "stopping point" to the unconstitutionally supported uniqueness argument.²⁴¹ The court aptly noted that the government wants to set the terms of the judicial limits and then ask that the courts defer to Congress to see if those terms are met or not.²⁴² The court stated that the Supreme Court "has firmly rejected such calls for judicial abdication in the Commerce Clause realm."²⁴³ These arguments on the limiting principles of the coverage requirement are the strongest arguments made by the court against the constitutionality of the requirement. As the court stated, the government's uniqueness argument is:

[A] convenient sleight of hand to deflect attention from the central issue in the case . . . the nature of conduct being regulated Because an individual's decision to forego purchasing a product is so incongruent with the 'activities' previously reached by Congress's commerce power, the government attempts to limit the individual mandate's far-reaching implications.²⁴⁴

Finally the court stated that "the government's struggle to articulate cognizable, judicially administrable limiting principles only reiterates the conclusion we reach today: there are none."²⁴⁵ The limits of such a requirement are not clear. Although the coverage requirement has multiple exemptions limiting its reach, which the court does not see as significant, the mandate still requires those who are not exempt to purchase something that they may not otherwise buy. One clear limit may be the existence of an option not to purchase. Perhaps with all mandates of this type the government could argue that people are

239. *Id.* ("We are at a loss as to how such fact-based criteria can serve as the sort of 'judicially enforceable' limitations on the commerce power that the Supreme Court has repeatedly emphasized as necessary to that *enumerated* power.").

240. *Id.* at 1297.

241. *Id.* ("[T]he government's insistence that we defer to Congress's fact findings underscores the lack of any judicially enforceable stopping point to the government's 'uniqueness' argument.").

242. *Id.*

243. *Id.* at 1297 ("The Supreme Court has firmly rejected such calls for judicial abdication in the Commerce Clause realm.").

244. *Id.* at 1297.

245. *Id.* at 1298.

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able to opt out by simply paying a fine without any harm—as long as the fine is within reason. However, this argument would again become one of the facts. Specifically, courts would have to compare the fine to the required mandate or requirement, in order to assess whether it limits the mandate appropriately or not. This would be difficult to apply as a rule over time, but at least more straightforward than the government’s five factors.

The D.C. Circuit views this issue differently. The court, similar to the Eleventh Circuit, admits that it is not comfortable with the “[g]overnment’s failure to advance any clear doctrinal principles limiting congressional mandates that any American purchase any product or service in interstate commerce.”²⁴⁶ The court’s discomfort reiterates the strength of the Eleventh Circuit’s reasoning. However, the D.C. Circuit essentially looks beyond this level of discomfort because the court was “interpreting the scope of a long-established constitutional power, not recognizing a new constitutional right.”²⁴⁷ The court did not identify any limiting principle and indicated that the limits are “not apparent” to the court just as they are not apparent to the government.²⁴⁸ The court rested on the uniqueness argument of the government by stating that “the health insurance market is a rather unique one, both because virtually everyone will enter or affect it, and because the uninsured inflict a disproportionate harm on the rest of the market as a result of their later consumption of health care services.”²⁴⁹ The court did not recognize the Eleventh Circuit’s argument that other forms of insurance inflict the same problems on people without insurance, such as flood insurance. The government’s uniqueness claim is clearly lessened by such counter arguments. The D.C. Circuit and government essentially argue against itself by stating that the “[g]overnment concedes the novelty of the mandate and the lack of any doctrinal limiting principles; indeed, at oral argument, the [g]overnment could not identify any mandate to purchase a product or service in interstate commerce that would be unconstitutional, at least under the Commerce Clause.”²⁵⁰

246. *Seven-Sky v. Holder*, 661 F.3d 1, 18 (D.C. Cir. 2011).

247. *Id.*

248. *Id.* (“[T]hose [mandate] limits are not apparent to us, either because the power to require the entry into commerce is symmetrical with the power to prohibit or condition commercial behavior, or because we have not yet perceived a qualitative limitation.”).

249. *Id.*

250. *Id.* at 14-15.

D. Rational Basis Review

The Eleventh Circuit addressed whether rational basis review was the appropriate review standard in *Florida v. United States Health & Human Services*. The Court stated that rational basis review is not triggered by the “mere fact of Congress’s invocation of Article I power.”²⁵¹ The court went on to state that the Supreme Court has applied rational basis review to a more specific question in Commerce Clause cases.²⁵² The question is whether Congress has a rational basis for indicating that “regulated activities when taken in the aggregate, substantially affect interstate commerce.”²⁵³ The Court viewed this as a two-part analysis. A court first asks whether the subject matter being targeted for regulation is suitable for aggregation, then asks whether the link between the “activity and interstate commerce is too attenuated” or not.²⁵⁴

If the connection is too attenuated, then the limit to the use of the commerce power may be essentially limitless, overstepping the bounds of Congress’ enumerated powers. In this case, the cost-shifting theory seems too attenuated. This same theory, according to the Eleventh Circuit, was rejected by the Supreme Court in two prior Supreme Court cases.²⁵⁵ The Eleventh Circuit stated that the cost-shifting theory of Congress as a rationale for developing the coverage requirement required “inferential leaps.”²⁵⁶ In fact, the government did provide some research data to support its case, but this data was not from a peer-reviewed journal, a basic standard for assessing the quality of health services/public health research data.²⁵⁷ The court restated the cost-shifting logic of the government as indicating that the uninsured “*may* at some point, in the *unforeseeable future*, create that cost-shifting consequence.”²⁵⁸ Data demonstrating annual growths in premiums, partially due to uncompensated care provided by health

251. *Florida v. U.S. Dep’t of Health & Human Servs.*, 648 F.3d 1235, 1300 (11th Cir. 2011).

252. *Id.* (“[T]he Supreme Court has applied rational basis review to a more specific question under the Commerce Clause.”).

253. *Id.* (quoting *Gonzales v. Raich*, 545 U.S. 1, 22 (2005)).

254. *Id.*

255. *Id.* at 1301.

256. *Id.* at 1302 (“We see no reason why the inferential leaps in this case are any less attenuated than those in *Lopez* and *Morrison*.”).

257. *See id.* at 1245 n.8 (citing FAMILIES USA, HIDDEN HEALTH TAX: AMERICANS PAY A PREMIUM 7 (2009), available at <http://familiesusa2.org/assets/pdfs/hidden-health-tax.pdf>.) (“Uncompensated care costs translate into ‘a surcharge of \$368 for individual premiums and a surcharge of \$1017 for family premiums in 2008.’”).

258. *Id.* at 1302.

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care institutions, was not discussed by the court as support for a less attenuated relationship between the uninsured and cost-shifting.²⁵⁹

In regards to rational basis review, the Eleventh Circuit stated that the Supreme Court, when analyzing Commerce Clause cases, requires a “tangible link to commerce, not a mere conceivable rational relation.”²⁶⁰ Further, the Supreme Court indicates that “‘simply because Congress may conclude that a particular activity substantially affects interstate commerce does not necessarily make it so.’”²⁶¹ Additionally, the Supreme Court notes “[w]hen the inquiry is whether a federal law has sufficient links to an enumerated power to be within the scope of federal authority, the analysis depends not on the number of links in the congressional-power chain but on the strength of the chain.”²⁶² The Eleventh Circuit’s application of this precedent led the court to reason that the coverage requirement did not pass the rational basis review.²⁶³

E. Areas of State Concern

The Eleventh Circuit also assessed whether the coverage requirement was an area of state concern. As the court noted, the Supreme Court, “in assessing the constitutionality of Congress’s exercise of its commerce authority,” indicates that “a relevant factor is whether a particular federal regulation trenches on an area of traditional state concern.”²⁶⁴ The court also pointed out that the Supreme Court withholds police power from Congress.²⁶⁵ The court also noted that the absence of limiting principles implicates two concerns within the Supreme Court’s jurisprudence: “(1) preserving the federal-state balance and (2) withholding from Congress a general police power.”²⁶⁶ These concerns related to the court’s discussion of the Commerce Clause power as an enumerated power. The power is limited and should not invade areas of traditional state regulation. The court indicated that insurance is one of those areas.²⁶⁷ The court noted that safeguarding the health of citizens is a “quintessential component” of a state’s sov-

259. *Cf.* FAMILIES USA, HIDDEN HEALTH TAX: AMERICANS PAY A PREMIUM 7 (2009), available at <http://familiesusa2.org/assets/pdfs/hidden-health-tax.pdf>.

260. *Florida v. U.S. Dep’t of Health & Human Servs.*, 648 F.3d 1235, 1282 (11th Cir. 2011).

261. *Id.*

262. *Id.*

263. *Id.*

264. *Id.* at 1303.

265. *Id.*

266. *Id.* at 1311-12.

267. *Id.* at 1304.

foreign powers.²⁶⁸ The court further stated that there is no dispute that the coverage requirement “supersedes a multitude of the states’ policy choices” and that this encroachment by Congress favors the plaintiffs by strengthening the “inference that the individual mandate exceeds constitutional boundaries.”²⁶⁹ The court viewed this additional “federalism factor” as increasing the inference that the coverage requirement is not a valid exercise of Congress’ power “to regulate activities that substantially affect interstate commerce.”²⁷⁰

III. TAX POWER

The Eleventh Circuit also analyzed whether the coverage requirement was a valid exercise of Congress’s tax power. The court concluded that the coverage requirement is a civil regulatory penalty and not a tax.²⁷¹ As a result, the court stated that the individual mandate must “find justification in a different enumerated power.”²⁷² In support of this conclusion, the court reasoned that no federal court assessing the constitutionality of the coverage requirement has disagreed with its conclusion.²⁷³ The court also stated that the plain language of the statute indicates that it is a penalty rather than a tax.²⁷⁴

The court used the definition of “tax” and “penalty” from the Supreme Court case *United States v. Reorganized CF & I Fabricators of Utah, Inc.*, 518 U.S. 213.²⁷⁵ According to this case, “tax is an enforced contribution to provide for the support of government” and “penalty . . . is an exaction imposed by statute as punishment for an unlawful act.”²⁷⁶ The court also stated that Congress knew how to enact a tax and did so in the ACA in other sections.²⁷⁷ As the court noted, Congressional findings demonstrate that the goal of the coverage requirement is not to raise revenue, but to reduce the number of uninsured and create effective health insurance markets.²⁷⁸ The court

268. *Id.*

269. *Id.* at 1306.

270. *Id.* at 1307.

271. *Id.* at 1320.

272. *Id.*

273. *Id.* at 1314.

274. *Id.* at 1315.

275. *Id.* (citing *United States v. Reorganized CF & I Fabricators of Utah, Inc.*, 518 U.S. 213, 224 (1996)).

276. *Id.*

277. *Id.* at 1316.

278. *Id.* at 1316-17.

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also noted that in the legislative history of the ACA, Congress initially created a tax for the coverage requirement then removed this term and created a penalty for those who did not meet the requirement.²⁷⁹ After reviewing this change, the court referred to the Supreme Court's statement that "Congress does not intend sub silentio to enact statutory language that it has earlier discarded *in favor of other language*."²⁸⁰

*The court also reasoned that although some money is generated by the coverage requirement penalty, it is not a tax because multiple penalties (such as a speeding ticket) generate some revenue.*²⁸¹ The purpose of the exaction is more important, and the coverage requirement is clearly a "punishment for an unlawful act or omission."²⁸² Finally, the court stated that the penalty is not a tax because some enforcement mechanisms available for taxes are not available for the penalty, such as liens, levies, criminal prosecution, and criminal sanctions.²⁸³

IV. SEVERABILITY

Only the Eleventh Circuit reviewed whether the coverage requirement is severable from the ACA because only this court found the coverage requirement unconstitutional. The court held that the coverage requirement is severable.²⁸⁴ The court stated the test for severability as: "Unless it is evident that the Legislature would not have enacted those provisions which are within its power, independently of that which is not, the invalid part may be dropped if what is left is fully operative as a law."²⁸⁵

As discussed in the court's opinion, the ACA achieves numerous goals having no connection to the coverage requirement.²⁸⁶ The court reasoned that there is a strong presumption of severability "rooted in notions of judicial restraint and respect for the separation of powers in our constitutional system."²⁸⁷ The court stated that the burden to prove that the statute is not severable is high.²⁸⁸

279. *Id.* at 1317.

280. *Id.* (quoting *INS v. Cardoza-Fonseca*, 480 U.S. 421, 442-43 (1987)).

281. *Id.* at 1318.

282. *Id.* at 1319.

283. *Id.* at 1320.

284. *Id.* at 1328.

285. *Id.* at 1321.

286. *Id.* at 1244-62.

287. *Id.* at 1328.

288. *Id.*

The court also stated that the non-existence of a severability clause is not an issue given that the Supreme Court has held that a provision of a statute can be severed in the Commerce Clause context, even though the statute has no severability clause.²⁸⁹ The court indicated that rulings of unconstitutionality can frustrate the “intent of the elected representatives of the people” so courts should act “‘cautiously’ and ‘refrain from invalidating more of the statute than is necessary.’”²⁹⁰ The court referred to the House of Representatives legislative drafting manuals, which indicated that severability clauses are unnecessary “in light of Supreme Court precedent in favor of severability.”²⁹¹ The court’s primary concern is that two provisions of the law are connected to the coverage requirement: guaranteed issue and prohibition on, preexisting condition clauses.²⁹² Congressional findings demonstrated this association and served as the reason for the court to ask whether this provision should also be severed.²⁹³ However, the court reasoned that there was no severability clause attached to these provisions.²⁹⁴ Unlike the entire Act, the House’s drafting manual indicates that “one instance in which a severability clause is important is where ‘it provides in detail which related provisions are to fall, and which are not to fall, if a specified key provision is held invalid.’”²⁹⁵ The court also stated that the sections of the law which discuss these two provisions do not mention their connection to the coverage requirement.²⁹⁶ Essentially, the only place that the connection is made is in the Congressional findings.

V. WRITS OF CERTIORARI ACCEPTED BY SUPREME COURT

The Supreme Court granted writs of certiorari to both parties of the Eleventh Circuit case. The Eleventh Circuit plaintiffs/appellees/respondents include twenty-six states,²⁹⁷ private individuals Mary

289. *Id.* at 1321.

290. *Id.*

291. *Id.* at 1322.

292. *Id.* at 1323.

293. *Id.*

294. *Id.* at 1324.

295. *Id.*

296. *Id.*

297. *Id.* at 1240 n.2 (“The 26 states are Alabama, Alaska, Arizona, Colorado, Florida, Georgia, Idaho, Indiana, Iowa, Kansas, Louisiana, Maine, Michigan, Mississippi, Nebraska, Nevada, North Dakota, Ohio, Pennsylvania, South Carolina, South Dakota, Texas, Utah, Washington, Wisconsin, and Wyoming.”).

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Brown and Kaj Ahlburg, and the National Federation of Independent Business.²⁹⁸ The defendants/appellants/claimants are the Federal Health and Human Services, Treasury, Labor Department, and their Secretaries (“the Government”).²⁹⁹ From March 26, 2012 to March 28, 2012, the Supreme Court heard 4 ½ hours of oral arguments focusing on issues related to the coverage requirement and one hour on the constitutionality of Medicaid expansion as a result of the ACA.³⁰⁰ The questions that the Supreme Court addressed and the dates for review are below in Table 2.

Table 2 – Coverage Requirement Supreme Court Questions³⁰¹

Question for the Court	Date of Oral Argument – Time Allotted
“Whether the suit brought by respondents to challenge the minimum coverage provision of the Patient Protection and Affordable Care Act is barred by the Anti-Injunction Act, 26 U.S.C. §7421(a).”	March 26 – 1 Hour
Whether Congress had the power under Article I of the Constitution to enact the minimum coverage provision.	March 27 – 2 hours
Whether other provisions of the Act could be severed from the Act’s minimum coverage provision, 26 U.S.C.A. 5000A, if that provision were found to be unconstitutional.	March 28 – 1 hour 30 minutes

A ruling is expected by mid-June of 2012.³⁰²

298. *Id.*

299. *Id.*

300. *Patient Protection and Affordable Care Act Cases, March 26 – 28, 2012*, SUPREME CT. U.S., <http://www.supremecourt.gov/docket/PPAACA.aspx> (last visited Mar. 30, 2012).

301. *Certiorari–Summary Dispositions*, SUPREME CT. U.S. (Nov. 14, 2011), <http://www.supremecourt.gov/orders/courtorders/111411zor.pdf>; *October Term 2011: For the Session Beginning March 19, 2012*, SUPREME CT. U.S. (Feb. 21, 2012), http://www.supremecourt.gov/oral_arguments/argument_calendars/MonthlyArgumentCalMAR2012.pdf.

302. James Vicini, *Supreme Court Sets Obama Health Care Arguments*, REUTERS (Dec. 19, 2011), <http://www.reuters.com/article/2011/12/19/us-usa-healthcare-court-idUSTRE7B11FE20111219>.

VI. DECISION OPTIONS FOR THE SUPREME COURT

A number of decisions could arise from the Supreme Court's assessment of the issues raised by the coverage requirement. The decisions options are as follows:

Mandate Challenge Not Allowed Because of Anti-Injunction Act;

Mandate Constitutional;

Mandate Unconstitutional, But Severable; &

Mandate Unconstitutional and Not Severable.

Of these various options, the last is the most unlikely – a ruling of unconstitutional and not severable. This would be extremely unpopular and highly illogical because of the number of provisions in the Act that are completely unrelated to the coverage requirement.

VII. PREDICTING THE SUPREME COURT'S DECISION

Numerous predictions exist regarding how the Supreme Court will rule on the constitutionality of the coverage requirement. There is no way to predict exactly what will happen; however, there are a number of factors which may be indicators of the Court's decision. Some of the key variables likely to affect the Court's view include the ideology of the Justices and past views of the Court. Given the extremely political and controversial nature of the ACA and the perception by numerous Republican pundits that the law is an unnecessary expansion of government, conservative members of the Court will likely be biased against the ACA's provisions. However, as stated, the coverage requirement has its roots in conservative thinking. Thus, an in-depth analysis of the origins of the coverage requirement may persuade conservative Justices to support the coverage requirement.

Other factors, such as respect for lower court judges, may also provide small influences on the Justices' decisions. For example, Judge Sutton, of the Sixth Circuit, is a respected conservative judge who agreed with the Sixth Circuit opinion ruling the coverage requirement constitutional. Multiple Supreme Court experts point to Justice Kennedy as the key swing vote for the Court.³⁰³ If this is true, Ken-

303. Edward Adams, *Kennedy: Swingiest Health Care Justice?*, BLOOMBERG L. (Mar. 11, 2012), <http://go.bloomberg.com/health-care-supreme-court/2012-03-11/kennedy-swingiest-health-care-justice>; Fazal Khan, *Why Justice Kennedy Will Vote to Uphold the Health Care Reform Law*, AM. CONST. & SOC'Y FOR LAW & POL'Y (Nov. 14, 2011), <http://www.acslaw.org/acsblog/why-justice-kennedy-will-vote-to-uphold-the-health-care-reform-law>.

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nedy's past rulings and thoughts on the Commerce Clause are likely to strongly influence the future decision. One factor, which has arisen unexpectedly, is a call for two Justices (Clarence Thomas and Elena Kagan) to recuse themselves because they have potential conflicts of interest related to the coverage requirement and the ACA generally.³⁰⁴ Given these factors, the Supreme Court is likely to hold that the coverage requirement is unconstitutional, but severable from the ACA. It is also likely to rule that the Anti-Injunction Act does not apply because the coverage requirement contains a penalty and not a tax.

VIII. POLICY IMPACT OF THE SUPREME COURT DECISIONS

Whether the Supreme Court decides against the coverage requirement or supports it, health policy will be affected. The requirement is still a couple of years away from being implemented. The public's response to the requirement is still unknown. This section will review the policy impact of a decision in favor of or against the requirement's constitutionality.

A. Unconstitutional Decision

If the Supreme Court determines that the coverage requirement is unconstitutional, other aspects of the ACA will likely lead to coverage for uninsured, which will shift costs to the insured. Individuals who are currently using health care but are uninsured, lack affordable options for health insurance. If no aspect of the law changes beyond severing of the coverage requirement, there will still be multiple ways for uninsured individuals to purchase health insurance that is affordable.

First, low-income uninsured people will be able to enroll in Medicaid, which will be expanded to include people with higher incomes and single adults who are typically not covered in most states, even though they are uninsured people who increase the amount of uncompensated care that must be offered. Tax credits available to working poor people will also help this group. The removal of pre-existing condition clauses also incentivizes people to purchase insurance with the knowledge that they will not be ineligible. Penalties for large and smaller employers, whose workers use tax credits for insurance, incen-

304. Robert Barnes, *Roberts Defends Court's Ethics*, WASH. POST, Jan. 1, 2012, at A03.

tivizes these employers to offer insurance to their workers. The healthy people that Congress wanted to purchase insurance as a result of the coverage requirement are likely working young people. As a result, their employers will be inclined to purchase insurance or, because of the cheaper costs with tax subsidies and appropriate marketing by private insurers, individuals will also be encouraged to purchase insurance on their own. Another incentive for young people, which is already impacting the number of insured people, is coverage of individuals who are twenty-six and under on their parents health plans.

One problem with a decision that the coverage requirement is unconstitutional is that the insurance industry may retaliate against the ACA. To date, America's Health Insurance Plans ("AHIP") has been supportive of the legislation, but they have also stated that without the coverage requirement, their business model is threatened by the ACA.³⁰⁵ AHIP has also pointed out that states that have removed pre-existing conditions from insurance policies without making sure all people are covered have seen increases in premiums and no significant decrease in the number of uninsured people.³⁰⁶ While this may not be completely true, they are clearly exposed to more sick customers and thereby higher costs. Some of these costs can be decreased in other ways such as the ACA provisions that remove co-pay for preventive services, but such policy changes take time. Already, insurance companies have raised their premiums in anticipation of increased costs from the ACA.³⁰⁷ This seems a bit premature, but it is well within the bounds of restrictions placed on their price adjustments.

B. No Decision or Constitutional Decision

If the Supreme Court provides no decision, the coverage requirement will simply be challenged after it is implemented, and someone is penalized for not having insurance. Given all the exemptions, espe-

305. Michael McCord, *Individual Mandate Key Insurance Issue*, SEACOAST ONLINE (Mar. 28, 2012), <http://www.seacoastonline.com/apps/pbcs.dll/article?AID=/20120328/NEWS/203280369/-1/NEWSMAP>; Denis Wilson, *Health Reform Rests Its Case*, HUM. RESOURCE EXECUTIVE ONLINE (Apr. 3, 2012), <http://www.hreonline.com/HRE/story.jsp?storyId=533346666>.

306. See McCord, *supra* note 305 ("Eight states enacted various forms of guaranteed issue and community rating in the 1990s without covering everyone, and these reforms resulted in a rise in insurance premiums, a reduction of individual insurance enrollment and no significant decrease in the number of uninsured.").

307. Reed Abelson, *Health Insurance Costs Rising Sharply This Year, Study Shows*, N.Y. TIMES (Sept. 27, 2011), <http://www.nytimes.com/2011/09/28/business/health-insurance-costs-rise-sharply-this-year-study-shows.html?pagewanted=all>.

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cially ambiguous ones like the hardship exemption, the likelihood of a penalty being assessed may be low. In addition, the size of the penalty may be negligible for people who are not purchasing insurance because they want to use their money for savings, investing, or some other purpose since they are healthy and have no need for insurance. Thus, there is a possibility that challenges to the penalty are unlikely or if they occur, they may occur much later than political opponents of the ACA would like (i.e. post-presidential elections). If the Supreme Court finds that the coverage requirement is a constitutional exercise of Congress' power, the law will still face a number of challenges because of all its exemptions. As stated, the law is not a true mandate because so many people who are the target of the law can find ways to avoid complying with it. In addition, the coverage requirement can be avoided by all citizens for a period of less than three months as long as the period is continuous. In this manner, a person could seek care without insurance during this period, shift costs in a manner that Congress was attempting to prevent, but still be in compliance with the coverage requirement. Indeed, no decision or a constitutional decision will not be the remedy that numerous experts envision.

CONCLUSION

While the constitutionality of the minimum essential coverage requirement is an important question for proponents and opponents of the ACA, the requirement's exemptions leave one to wonder if an unconstitutional ruling actually changes anything for the American people. Regardless of the Supreme Court's decision, America will be faced with the challenge that it began with prior to the ACA, providing care to people who for a variety of reasons are uninsured. EM-TALA creates an open door for these individuals to seek care in America's emergency departments at the expense of hospitals. These hospitals shift the cost to other customers. A solution to this decades old conundrum will remain a challenge for the nation.

The ongoing challenge for federal and state governments moving ahead will be how to encourage people who are healthy and young to purchase insurance early. Governments must work with private insurers to offer more attractive deals for these young people. The deals must fit their budgets. Wellness incentives are another way to attract this group, which generally cares about their outward appearance and its link to health. This group's link to new technology such as smart phones can also be used as a way to offer them unique ways of com-

municating with experts who are focused on keeping them healthy as long as possible—such as nutritionists, personal trainers, etc. Indeed a different philosophy for government—from illness treatment to disease prevention and wellness—is necessary for this group to see insurance as a necessity for them during the healthiest times of their lives. Women are more likely to have insurance because of regular interactions with doctors through pap smears and other routine checkups. But men are particularly difficult to attract, and therefore they are likely to forgo insurance unless some other benefits are offered to them beyond simply preparing for the future. The award for them needs to be more immediate. With a change in the philosophy of what health providers can offer and what health insurance can cover, healthy, young Americans who are forgoing insurance can be brought into the pool of insurers in order to decrease the costs of helping those who suffer from illness and require insurance to survive.

Mixed Messages: The Intersection of Prenatal Genetic Testing and Abortion

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INTRODUCTION

In 2005, advocates and health professionals across the country filed amicus briefs in *Gonzales v. Carhart*, a case before the Supreme

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Court of the United States.¹ The case considered the federal ban of a specific abortion procedure popularly known as “partial birth abortion” and clinically described as intact dilation and evacuation (intact D&E). The procedure is performed in the second or third trimester of pregnancy and received its popular name because the fetus is kept intact as it is extracted through the birth canal. One amicus brief retold the experiences of women who had intact D&Es, banned by the federal law. In almost all of the brief’s examples, women decided to end their pregnancies because prenatal testing revealed severe genetic disorders.

For example, Claudia Crown Ades, following consultation with her obstetrician, a genetic counselor and perinatologist, ended her seven-month pregnancy after learning the baby she carried would be born with a non-functional brain and a malformed heart.² The brief quoted the testimony of Ms. Ades’s husband before a congressional hearing: “I don’t know what I would have done without this medical option . . . I knew, after all the discussions, deliberations and questioning that both Claudia and I did, that [intact D&E] was the safest, most humane procedure available to our family. For that, I am grateful.”³

The Ades’ experience illustrates the difficult decision-making when confronted with information about a serious genetic condition of a potential child. It also highlights a popularly accepted reason for abortion—genetic disorder or fetal malformation.⁴ Indeed, one of the primary rationales for legalizing abortion in the United States was the reason of fetal anomaly.⁵ Since *Roe v. Wade*, women who elect prenatal genetic screening and testing have had the legal option to terminate pregnancies for conditions like the chromosomal deletion at issue for Claudia Crown Ades. Many women will opt to raise children diagnosed with a genetic disorder or will forgo testing because they would not elect abortion in any case. Yet for those who would choose abor-

1. *Gonzales v. Carhart*, 550 U.S. 124, 124 (2007). See discussion *infra* Parts II.D, III (discussing *Gonzalez v. Carhart* case).

2. Brief for the National Women’s Law Center et al. as Amici Curiae Supporting Respondent at 10, *Gonzales v. Carhart*, 550 U.S. 124 (2007) (No. 05-1382).

3. *Id.*

4. Polls in 2007 suggest that seventy percent of Americans believe abortion should be available for reasons of fetal malformation or genetic disorder. Amy Harmon, *Genetic Testing + Abortion = ???*, N.Y. TIMES, May 13, 2007, at 1.

5. Reva B. Siegel, *Roe’s Roots: The Women’s Rights Claims that Engendered Roe*, 90 B.U. L. REV. 1875, 1879 (2011) (citing the 1962 proposals of the American Law Institute that permit abortion, upon the review of two physicians, for reason of rape or incest, mother’s physical or mental health, or fetal anomaly).

tion, the ability to screen and to test prenatally for genetic anomalies is expanding while abortion access, especially near or after viability, is contracting.

In the next two decades, researchers predict that a “simple,” maternal blood test can yield fetal DNA. Coupled with gene sequencing, parents will be able to know much more about a fetus’s genetic make-up much earlier in pregnancy.⁶ Moreover, as testing and sequencing technology evolve, researchers predict that prenatal genetic testing will become more cost-effective, more manageable, more accurate, and, thus, more routine.⁷

At the same time prenatal genetic testing is expanding, women’s ability to gain access to abortion services is contracting. Federal and state laws directly and indirectly restrict abortion in the United States, and states pass new anti-abortion legislation every year. In 2011, state legislatures passed eighty laws, double the number passed only six years earlier, restricting abortion in a variety of ways, such as bans on all terminations after twenty weeks of gestation and onerous regulations of clinic facilities.⁸

The Patient Protection and Affordable Care Act (ACA) and the national debate preceding its passage typify the different treatment of testing and abortion as maternal health care. The question of how the ACA would treat abortion threatened to derail congressional negotiations over the legislation. More specifically, the ACA will practically reduce health care insurance coverage for abortions at the same time that it provides incentives to test and screen as part of routine maternal health care and preventative services. On the one hand, the ACA excludes abortion as an essential benefit and requires the strict segregation of federal funds for new exchange plans offering abortion coverage. On the other hand, the ACA includes prenatal care as an

6. See *infra* Part I.A. This Article does not explore pre-implantation genetic diagnosis (PGD), although similar ethical issues arise. PGD occurs when physicians test embryos created by artificial reproductive technologies. See generally Susannah Baruch, *Preimplantation Genetic Diagnosis and Parental Preferences: Beyond Deadly Disease*, 8 Hous. J. Health L. & Pol’y 245, 260-61 (2008) (describing debates on whether to discard embryos for non-medical characteristics like sex, for late onset disorders, or for the purpose of having a child with a disability like deafness); Joann Bodurtha & Jerome F. Strauss, *Genomics and Perinatal Care*, 366 New Eng. J. Med. 64, 65 (2012) (exploring the implications of whole gene sequencing and noting that pre-implantation diagnosis is highly accurate and relatively unregulated).

7. See, e.g., Henry T. Greely, *Get Ready for the Flood of Fetal Gene Screening*, 469 Nature 289, 290 (2011); Laird Jackson & Reed E. Pyeritz, *Molecular Technologies Open New Clinical Genetic Vistas*, 65 Hum. Genomics 1, 2-3 (2011).

8. *Id.*

essential benefit and will cover a range of prenatal services, including genetic screening and testing.

This Article provides a snapshot of how current law and practice put genetic testing and abortion on a collision course. It considers how the diminishing option of abortion for many pregnant women and increasing options in prenatal genetic testing produce mixed messages for patients and providers alike.⁹ It suggests that termination of pregnancies for reason of fetal anomaly will become a focal point of public policy debates in which questions about the scope of future federal and state regulation will undoubtedly arise.¹⁰ The reduced availability of abortion services nationwide and increasing marginalization of abortion as medical care will influence how providers counsel their patients about post-testing options. Obstetricians recommending testing as a source of valuable information about a woman's pregnancy may be the same physicians unwilling to perform or refer women to termination services. In short, without careful consideration of how prenatal genetic testing and abortion intersect, policy debates may be co-opted by anti-abortion rhetoric, rather than focus on the implications for health care delivery.

The first two parts of this Article briefly describe the state of testing today, future innovations, and the obstacles to and restrictions on abortion services in the United States. The last part considers how similar questions have different answers depending on whether one is discussing testing or abortion—is abortion reproductive health care; what is the nature and scope of informed consent; how should the integrity of health professionals be protected; and what is the value of women's autonomy in making decisions about abortion or testing? Drawing briefly on international experience, the Article concludes with a suggestion about how to reconfigure the current conversation

9. See generally R. Alta Charo & Karen H. Rothenberg, "The Good Mother": *The Limits of Reproductive Accountability and Genetic Choice*, in *WOMEN AND PRENATAL TESTING: FACING THE CHALLENGES OF GENETIC TECHNOLOGY* (Karen H. Rothenberg & Elizabeth J. Thomson eds., 1994) (discussing the social influences and pressures on mothers' choices regarding testing); Karen H. Rothenberg, *The Law's Response to Reproductive Genetic Testing: Questioning Assumptions About Choice, Causation, and Control*, 8 *FETAL DIAGNOSIS & THERAPY* 160 (1993) (discussing the role of informed consent and choice (or lack thereof) in the future of the law governing reproductive testing).

10. Greely, *supra* note 7, at 290. See generally Sonia Suter, *The "Repugnance" Lens of Gonzales v. Carhart & Other Theories of Reproductive Rights: Evaluating Advanced Reproductive Technologies*, 76 *GEO. WASH. L. REV.* 1514, 1518 (2008) (discussing how scientific advances have added complexity to the moral and legal issues surrounding reproductive decision making) [hereinafter Suter, *Carhart*].

in order to understand the interplay of abortion and testing decisions in a more nuanced way.

This Article does not intend to suggest that abortion is the only or always the best option after prenatal testing reveals fetal abnormalities or genetic disorders. To the contrary, skeptics of testing argue that women often feel pressure to choose abortion because of professional and popular bias against disability.¹¹ Indeed, we take seriously the concern that pairing testing and abortion may suggest that disability is an appropriate rationale for termination of a pregnancy, further marginalizing individuals with certain genetic and physical conditions.¹² Our purpose is to highlight that the current stigmatization of abortion as health care leads to an impoverished discourse on why and when to test prenatally. Ultimately, we argue that policy must take account of the increasing gap between law and practice, which could potentially become too wide and the consequences for women and their families become too severe.

I. THE REGULATION OF PRENATAL GENETIC TESTING AND SCREENING

The trend in prenatal genetic screening and testing points toward providing services earlier in pregnancy for broader categories of women. Women will soon have much more information about their pregnancies at lower cost and risk than ever before. In response to advancing technology, professional organizations, scholars, and health professionals have called for better counseling for women before and after screening or testing as well as guidelines about what disorders can be tested for and what results mean.

A. Current Testing and Screening

Most women, after learning they are pregnant, have their first prenatal visit between eight and twelve weeks of gestation.¹³ Historically, an obstetrician would rely only on the pregnant woman's family medical history and maternal age to gauge whether she should test

11. Rothenberg, *supra* note 9, at 162; see discussion *infra* Part III.B (discussing the disability critique of expanded testing options).

12. See generally Mary Crossley & Lois Shepherd, *Genes and Disability: Questions at the Crossroads*, 30 FLA. ST. U. L. REV. xi (2003) (summarizing the discussion of marginalization in a symposium on genes and disability).

13. Ruth M. Farrell et al., *Risk and Uncertainty: Shifting Decision Making for Aneuploidy Screening to the First Trimester of Pregnancy*, 13 GENETICS IN MED. 429, 435 (2011).

cells from the fetus. Modernly, physicians routinely use serum screening (a blood sample from the mother) and ultrasound screening techniques to assess the risk of a fetal genetic disorder.¹⁴ Serum and ultrasound screenings before twenty weeks of gestation are “as commonplace and widely accepted as some of the more routine aspects of prenatal care”¹⁵ for women of all ages and family histories. For example, in 2007, the American Congress of Obstetricians and Gynecologists (ACOG), the leading professional organization for obstetricians and other reproductive health professionals, published a practice bulletin recommending that obstetricians screen all pregnant women before twenty weeks gestation, regardless of maternal age.¹⁶

Although screening has traditionally focused on the detection of aneuploidies, which are abnormalities in the number of chromosomes,¹⁷ patients can screen for over four hundred genetic disorders¹⁸ and normally screen for common mutations and population-based diseases.¹⁹ There are, however, limitations regarding what screening can tell potential parents. For serum screenings, biochemical markers suggestive of certain disorders change dramatically between the first and second trimesters, making an accurate determination of fetal age necessary.²⁰ The usefulness of ultrasound screening depends on the clarity of the sonogram image, which becomes sharper as a fetus develops.²¹ For these reasons, some health professionals suggest that women screen in both the first and second trimesters if indicated.

Ultrasounds or blood tests only provide a probable risk that a fetus carries a genetic disorder, based on the particular screening method and patient-specific factors.²² This risk is normally expressed

14. Deborah A. Driscoll & Susan J. Gross, *ACMG Practice Guidelines: Screening for Fetal Aneuploidy & Neural Tube Defects*, 11 *GENETICS IN MED.* 818, 818-21 (2009).

15. Sonia Suter, *The Routinization of Prenatal Testing*, 28 *AM. J.L. & MED.* 233, 234 (2002) [hereinafter Suter, *Prenatal Testing*].

16. American Cong. of Obstetricians & Gynecologists, *ACOG Practice Bulletin No. 77: Screening for Fetal Chromosomal Abnormalities*, 109 *OBSTETRICS & GYNECOLOGY* 217, 217-220 (2007) [hereinafter *ACOG Practice Bulletin*].

17. The most common aneuploidy, Down syndrome, is caused by having three copies of chromosome 21 (a trisomy) and occurs in 1 in 800 live births. Siobhan M. Dolan, *Prenatal Genetic Testing*, 38 *PEDIATRIC ANNALS* 426, 426 (2009).

18. Samuel R. Bagenstos, *Disability, Life, Death, and Choice*, 29 *HARV. J.L. & GENDER* 425, 438 (2006).

19. Bodurtha & Strauss, *supra* note 6, at 65.

20. Peter Wieacker & Johannes Steinhard, *The Prenatal Diagnosis of Genetic Diseases*, 107 *DEUTSCHES ÄRZTEBLATT INT'L* 857, 859 (2010).

21. *Id.* at 858-59.

22. The “quad screen,” named for the four proteins and hormones it measures in the mother’s blood, can signal the presence of chromosomal abnormalities. N.J. Wald et al., *Prenatal Screening for Down’s Syndrome Using Inhibin-A as a Serum Marker*, 16 *PRENATAL DIAGNOSIS*

as a percentage that represents the likelihood of a genetic condition.²³ If it appears that there is a moderately-high or high-level of risk, based on family history or screening, physicians will recommend testing via amniocentesis or chorionic villus sampling (CVS).²⁴ Amniocentesis and CVS, in which fetal cells are collected and tested for a select panel of disorders, have been the primary means for prenatal genetic testing.²⁵ Each procedure requires extracting cells from the fetus in utero, either through the mother's abdomen or vagina. Both procedures carry around a 1% risk of miscarriage.²⁶

Amniocentesis is performed at fifteen to seventeen weeks of gestation with results in about two weeks.²⁷ CVS can be performed from ten to fourteen weeks of gestation,²⁸ and results can be obtained in one to two weeks.²⁹ Because women receive screenings first, they often receive testing results in the second trimester. Due to the small risk of miscarriage and the late timing, discomfort, and costs of the procedures, only two percent of pregnant women currently undergo invasive testing.³⁰ Moreover, general practice is to test for "no more than a few dozen genes,"³¹ and testing, like screening, has its limits. Knowing the genotype of a fetus does not mean physicians or parents can know with certainty how the disorder or characteristic will be ex-

143, 143-53 (1996); see also Jackson & Pyeritz, *supra* note 7, at 1. Screening normally consists of both ultrasound and biochemical tests of the mother's blood. Ultrasounds can detect physical anomalies, such as increased nuchal translucency (the amount of fluid found at the back of the fetus' neck), which is associated with trisomies like Down syndrome and neural tube defects. Dolan, *supra* note 17, at 428.

23. See Jennifer Czerwinski et al., *Maternal Serum Screening: Results Disclosure, Anxiety, & Risk Perception*, 27 AM. J. PERINATOLOGY 279, 281 (2010). Some screening methods can have high false positives, while other methods are limited by false negatives. Mary E. Norton, *Genetic Screening & Counseling*, 20 CURRENT OPINION IN OBSTETRICS & GYNECOLOGY 157, 160 (2008).

24. Bodurtha & Strauss, *supra* note 6, at 64.

25. A third method, cordocentesis, which targets the fetus's umbilical cord, is rarely employed because it is difficult to administer. Edith Cheng & Vern L. Katz, *Reproductive Genetics: Gene Structure, Mutation, Molecular Tools, Types of Inheritance, Counseling Issues, Oncogenes*, in COMPREHENSIVE GYNECOLOGY 34 (Vern L. Katz et al., 5th ed. 2007).

26. Wieacker & Steinhard, *supra* note 20, at 858.

27. *Id.*

28. *Id.*

29. *Id.*

30. Greely, *supra* note 7, at 289 (noting that the percentage of women who test is small because most women are not considered "at risk" and do not carry pregnancies with genetic complications).

31. Greer Donley et al., *Prenatal Whole Genome Sequencing: Just Because We Can, Should We?*, HASTING CTR. REP. (forthcoming) (on file with authors).

pressed.³² Some genetic conditions may be expressed only partially, ranging from mild to severe symptoms.³³

Early and on-going counseling before and after testing can help patients interpret screening and testing results.³⁴ But often women are not given counseling until after screening and before testing. In theory, patients should receive information about “detection and false-positive rates, advantages, disadvantages, and limitations, as well as the risks and benefits of diagnostic procedures.”³⁵ Included in “advantages, disadvantages” should be counseling about options *after* testing, such as terminating the pregnancy, attempting to treat the condition in utero, managing a pregnancy or delivery, or raising a child with the condition at issue. Yet obstetricians generally receive little training on how to counsel a patient before and after genetic testing.³⁶ Genetic counselors are in demand but are in short supply, and many health care professionals consider themselves to be inadequately prepared to counsel patients about screening generally.³⁷

Two innovations promise to change the scope of prenatal genetic testing: the ability to collect fetal DNA through non-invasive techniques and the use of that DNA to sequence the genome of a fetus. As noted, collecting fetal DNA through amniocentesis or CVS is a costly, potentially painful process that occurs later in pregnancy. New techniques will make it possible to isolate fetal cells or cell-free fetal DNA that cross the placental barrier into the maternal bloodstream.³⁸ The present limitation to the clinical availability of this non-invasive

32. Melissa S. Savage et al., *Evolving Applications of Microarray Analysis in Prenatal Diagnosis*, 23 CURRENT OPINION OBSTETRICS & GYNECOLOGY 103, 104 (2011) (noting that phenotype is unpredictable and “uncertain results can make counseling and parental decisions about pregnancy termination difficult”).

33. *Id.* at 106.

34. *Id.* at 107.

35. ACOG Practice Bulletin, *supra* note 16, at 219.

36. Peter A. Benn & Audrey R. Chapman, *Ethical Challenges in Providing Noninvasive Prenatal Diagnosis*, 22 CURRENT OPINION IN OBSTETRICS & GYNECOLOGY 128, 131 (2010).

37. Farrell et al., *supra* note 13, at 7.

38. Zhouwei Huang et al., *Novel Approaches to Manipulating Foetal Cells in the Maternal Circulation for Non-Invasive Prenatal Diagnosis of the Unborn Child*, 112 J. CELLULAR BIOCHEMISTRY 1475, 1485 (2011). Fetal DNA only constitutes around “3-10% of total amount of plasma DNA in the maternal circulation.” Sinuhe Hahn et al., *Fetal Cells in Maternal Blood: Current & Future Perspectives*, 4 MOLECULAR HUM. REPROD. 515, 516 (1998); W.Y. Tsui et al., *Epigenetic Approaches for the Detection of Fetal DNA in Maternal Plasma*, 1 CHIMERISM 30, 30-35 (2010). A non-invasive test for the identification of Down syndrome has already been introduced. *Sequenom Center for Molecular Medicine Announces Launch of Maternit21 Noninvasive Prenatal Test for Down Syndrome*, PRNEWswire (Oct. 17, 2011), <http://prenewswire.com/news-releases/sequenom-center-for-molecular-medicine-announces-launch-of-maternit21-noninvasive-prenatal-test-for-down-syndrome-131974043.html>.

testing is that there are no reliable markers for sorting fetal cells (or DNA from fetal cells) and DNA of the mother or of prior pregnancies.³⁹ When a reliable fetal cell marker can be used, only ten milliliters of maternal blood, collected at eight to twelve weeks of gestation,⁴⁰ will be needed to analyze fetal DNA.⁴¹ Moreover, new DNA sequencing technologies, and whole genome sequencing, will reveal to parents information beyond diagnoses of severe genetic disorders.⁴² Whole genome sequencing, when part of clinical care, will also “produce variants of unknown significance, non-medical genetic markers, carrier statuses, susceptibility genes, and genes expressing conditions with late onset.”⁴³ Many believe non-invasive testing, paired with advances in sequencing, will soon become the standard: it will become cost-effective⁴⁴ and ultimately accessible to practicing obstetricians, potentially for use in lieu of current screening.⁴⁵

Perhaps as important as these scientific developments, the legal infrastructure exists to support the introduction of non-invasive testing and whole gene sequencing in clinical settings. As the next two sections explain, the regulation of testing can accommodate changes in technology; the tort system penalizes physicians as negligent who do not offer testing; and health care reform portends incentives to pay for screening and testing.

39. Michele G. Curtis et al., *Flow Cytometric Methods for Prenatal & Neonatal Diagnosis*, 363 J. IMMUNIZATION METHODS 198, 198-209 (2011); Ying Li et al., *Detection of Paternally Inherited Fetal Point Mutations for B- Thalassemia Using Size-Fractionated Cell-Free DNA in Maternal Plasma*, 293 J. AM. MED. ASS'N. 843, 844 (2005).

40. Cell-free fetal DNA can be detected in maternal serum at as early as five weeks of gestation. Y.M. Lo et al., *Presence of Fetal DNA in Maternal Plasma & Serum*, 350 LANCET 485, 485-87 (1997).

41. See Carolyn Jacobs Chachkin, *What Potent Blood: Non-Invasive Prenatal Genetic Diagnosis and the Transformation of Modern Prenatal Care*, 33 AM. J.L. & MED. 9, 20 (2007).

42. Donley et al., *supra* note 31, at 1; W. Gregory Feero et al., *Genomic Medicine—An Updated Primer*, 362 NEW ENG. J. MED. 2001, 2001 (2010) (describing the basic innovations in genomic medicine); Geoffrey Carr, *Biology 2.0, A Special Report on Human Genome*, ECONOMIST, June 17, 2010, <http://www.economist.com/node/16349358> (describing the speed of development of and reduced cost of sequencing technology).

43. Donley et al., *supra* note 31, at 2; see *infra* Part III (discussing the relationship of whole genome sequencing to informed consent and decision-making in prenatal genetic testing).

44. As Professor Jaime King explains, the cost of invasive testing is likely to decrease. Technology will evolve to allow testing of multiple regions of DNA, and DNA sequencing is becoming cheaper. Jaime King, *And Genetic Testing for All . . . The Coming Revolution in Non-Invasive Prenatal Genetic Testing*, 42 RUTGERS L.J. (forthcoming 2011).

45. King argues that if testing is used to confirm screening, then some women are likely to have testing if it means faster results at no physical risk. *Id.* at n.96.

B. Federal Regulation and the ACA

Early legislation wrestled with tensions around the voluntariness of testing, the content of information and counseling patients received, and the instances in which amniocentesis should be performed. Congress passed the now-repealed National Genetic Diseases Act in 1976, which provided detailed regulations and separate grants to the states to establish programs for genetic services.⁴⁶ By the 1980s, this funding was folded into the Maternal and Child Health Services Block Grant, forcing genetic services programs to compete for funding with programs for maternal and child health and for children with special needs, among others.⁴⁷ In the 1990s, the Secretary of Health and Human Services (HHS) retained authority to develop genetic research and other programs, but with no clear source of funds for the Secretary to draw upon.⁴⁸

Contemporary federal legislation addresses non-discrimination based on genetic information and support services for families caring for children with genetic conditions. For example, in 2008, Congress passed the Genetic Information Nondiscrimination Act (GINA) and the Prenatally and Postnatally Diagnosed Conditions Awareness Act (PPDCA). At the risk of oversimplification,⁴⁹ GINA forbids certain employers and group health plans or health insurance issuers from discriminating against individuals based on their genetic information.⁵⁰ The PPDCA enables the Secretary of HHS to issue grants to organizations that collect information on genetic disorders and assist

46. Ellen Wright Clayton, *What the Law Says About Reproductive Genetic Testing and What It Doesn't*, in *WOMEN AND PRENATAL TESTING: FACING THE CHALLENGES OF GENETIC TECHNOLOGY* 131, 134 (Karen H. Rothenberg & Elizabeth J. Thomson eds., 1994).

47. *Id.* at 134-35.

48. *Id.* at 135.

49. For further explanation of the provisions of GINA and debates surrounding its enactment and enforcement, see Kathy L. Hudson et al., *Keeping Pace with the Times—The Genetic Information Nondiscrimination Act of 2008*, 358 *NEW ENG. J. MED.* 2661 (2008) (describing the provisions of GINA); Amy L. McGuire & Mary Anderlik Majumder, *Two Cheers for GINA?*, 1 *GENOME MED.* 6.1, 6.1 (2009) (summarizing the debates around GINA); Jessica L. Roberts, *The Genetic Information Nondiscrimination Act as an Antidiscrimination Law*, 86 *NOTRE DAME L. REV.* 597, 601 (2011) (analyzing GINA's approach to discrimination).

50. Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, § 202(a)(2), 122 Stat. 881, 882 (2008). Title I of GINA forbids insurers from using genetic information as the basis for a denial of coverage as a preexisting condition. *Id.* § 102(b)(1)(B). Title II of GINA prohibits employers with fifteen or more employees from requesting, requiring, purchasing or disclosing employee genetic information. Recently, the Equal Employment Opportunity Commission issued final regulations interpreting GINA's requirements of employers. See generally Thomas H. Christopher et al., *EEOC Issues Final Regulations on Genetic Discrimination in the Workplace*, 36 *EMPLOYEE RELATIONS L.J.* 45 (2011) (describing the regulations and guidance by the EEOC).

families raising children with Down syndrome or other prenatally or postnatally diagnosed conditions.⁵¹ The purpose of the PPDCA was to give prospective parents accurate information so that they could make thoughtful decisions about raising children with certain genetic disorders.⁵² Indeed, the PPDCA reflects a bi-partisan effort that brought together pro-life, pro-choice, and disability advocates around the important goal of supporting parents caring for children with genetic conditions.⁵³

In 2001, the Department of HHS Advisory Committee on Genetic Testing recommended FDA oversight over certain genetic tests (prenatal or otherwise) in a report titled, *Enhancing the Oversight of Genetic Tests*.⁵⁴ Federal intervention is decidedly on the side of fostering access to genetic information and reducing what Congress has perceived as harmful consequences of that information, such as discrimination.

There is also federal willingness to fund some testing and screening services. Medicaid programs cover the costs of prenatal genetic screenings in thirty-six states and the District of Columbia⁵⁵ and testing in forty-seven states for particular categories of women. In addition, Medicaid programs in twenty-four states cover the costs of genetic counseling.⁵⁶ Although state Medicaid programs vary, Congress has made clear that testing and abortion are not synonymous.

51. Support services include education programs for health care providers, a hotline for parents, and an information distribution center. The PPDCA also establishes a national registry of families willing to adopt children with genetic conditions. Prenatally & Postnatally Diagnosed Conditions Awareness Act, Pub. L. No. 110-374, § 3, 122 Stat. 4051, 4051-54 (2008) (amending the Public Health Service Act 42, U.S.C. § 254c-8(e) (2006)).

52. See John F. Muller, *Disability, Ambivalence, and the Law*, 37 AM. J.L. & MED. 469, 477 (2011).

53. *Id.* Muller critiques the PPDCA for emphasizing distribution of accurate information but not for giving guidance to parents about how to act upon that information. *Id.* at 478.

54. Secretary's Advisory Committee on Genetic Testing, 65 Fed. Reg. 76,643, 76,643 (Dec. 7, 2000). The report called for test-specific fact sheets that would include the definition and purpose of each test; the condition tested and the test's clinical utility; and the cost of the test and billing/reimbursement information. Secretary's Advisory Committee on Genetic Testing, 65 Fed. Reg. 77,631, 77,632 (Dec. 12, 2000).

55. USHA RANJI ET AL., HENRY J. KAISER FAM. FOUND., STATE MEDICAID COVERAGE OF PERINATAL SERVICES: SUMMARY OF STATE FINDINGS 14 (2009), available at <http://www.kff.org/womenshealth/upload/8014.pdf>.

56. COMM. ON PREVENTIVE SERVS. FOR WOMEN, INST. OF MED., CLINICAL PREVENTIVE SERVICES FOR WOMEN: CLOSING THE GAPS 61 (2011) [hereinafter CLINICAL PREVENTIVE SERVICES FOR WOMEN: CLOSING THE GAPS], available at http://www.nap.edu/catalog.php?record_id=13181.

No Medicaid programs may cover abortion costs unless the mother's life is in danger or the pregnancy arises from rape or incest.⁵⁷

The ACA will expand testing and screening services by increasing Medicaid coverage. The ACA promises to provide new health insurance coverage to approximately thirteen million women of childbearing age through extending Medicaid eligibility⁵⁸ or through state-based exchanges.⁵⁹ The expansion of Medicaid will be of significant value to pregnant women: over forty percent of U.S. women rely on Medicaid for prenatal care.⁶⁰ By introducing higher incomes caps for Medicaid eligibility, even more women will qualify for low-cost or free testing and screening.⁶¹

The ACA also outlines requirements of what "essential benefits" health insurance plans must offer without cost-sharing (co-payments, co-insurance, or deductibles, for example). Maternity and newborn care is an essential health care benefit, although the ACA does not explicitly reference prenatal genetic testing or screening.⁶² In December, the Obama Administration decided that each state, rather than the Secretary of HHS, would determine the definition and scope of essential benefits, leaving the inclusion of testing and screening as prenatal care for states to determine.⁶³

57. *Id.* See *infra* Part II.A (describing the Hyde Amendment).

58. USHA RANJI ET AL., HENRY J. KAISER FAM. FOUND., FOCUS ON HEALTH REFORM 1, 6 n.1 (2010), available at <http://www.kff.org/healthreform/upload/8021.pdf>:

The ACA will expand health care coverage to many of the nation's uninsured by extending Medicaid eligibility to all qualifying individuals with incomes up to 138% of the federal poverty level (FPL).

.....

Legislation extends Medicaid coverage to all individuals with incomes up to 133% of the poverty level (FPL) and includes a provision to disregard first 5% of income, effectively extending Medicaid to all individuals with incomes up to 138% FPL.

Id.

59. *Id.* at 1 ("Uninsured individuals with incomes above 138% FPL will be able to purchase coverage in new state-based insurance exchanges that will act as marketplaces, open to all qualifying, uninsured individuals and small businesses with up to 100 employees.").

60. *Id.* Although federal law requires coverage of pregnant women with family incomes up to 133% of the FPL, states may permit higher-income thresholds. *Id.* States like Texas and South Carolina, with over fifty percent of the state's pregnant women relying on Medicaid, permit women with 185% of the FPL to qualify for Medicaid. *Id.* at 5, 11.

61. Alina Salganicoff & Jane An, *Making the Most of Medicaid: Promoting the Health of Women and Infants with Preconception Care*, 18 WOMEN'S HEALTH ISSUES S41, S41-46 (2008); Chachkin, *supra* note 41, at 44 (citing a survey of forty-six state Medicaid programs that cover amniocentesis or CVS).

62. Patient Protection and Affordable Care Act, Pub. L. No. 111-148, § 1302(b)(1)(D), 124 Stat. 119, 163 (2010).

63. *Id.* § 1302(b)(2)(3); Robert Pear, *Health Care Law Will Let States Tailor Benefits*, N.Y. TIMES, Dec. 16, 2011, at 1.

Prenatal genetic testing and screening might also be part of the preventive services that qualified health plans must cover.⁶⁴ The definitions and scope of preventative services were set out in guidelines issued by the Health Resources and Services Administration (HRSA). In August 2011, the Secretary of HHS approved the guidelines submitted by the HRSA. Among other important features,⁶⁵ the regulations include a well-woman visit, which incorporates prenatal care, in the definition of preventative treatment.⁶⁶ Although neither the guidelines nor the recommendations spell out what prenatal care involves, an Institute of Medicine (IOM) report, on which the HRSA relied, suggests that screening and testing are part of prenatal care.⁶⁷ In describing the routine coverage of private plans and public programs, the IOM report stated: “Pregnant women should receive . . . prenatal screening and testing for neural tube defects (for all women at elevated risk) and chromosomal abnormalities (for all women age 35 years and older), including, but not limited to amniocentesis, chorionic villus sampling, and ultrasound.”⁶⁸

These recommendations represent the present consensus among health care professionals about which women should have testing or screening (women of advanced maternal age) and for what conditions (disorders that traditional technologies can recognize). Because the IOM Committee on Preventative Services for Women is tasked with “regularly updating the preventative screenings and services to be considered,” recommendations on genetic testing and screening can

64. See Patient Protection and Affordable Care Act §1001. Employers will also be able to adjust the premiums of health plans they offer employees based on employee involvement in wellness and preventative care programs. CLINICAL PREVENTIVE SERVICES FOR WOMEN: CLOSING THE GAPS, *supra* note 56, at 15.

65. Preventative services also include contraceptive methods and counseling; screening for gestational diabetes; human papillomavirus testing; counseling for sexually transmitted infections; counseling and screening for human immune-deficiency virus; breastfeeding support, supplies and counseling; and screening and counseling for interpersonal and domestic violence. U.S. Dep’t of Health & Human Servs., *Women’s Preventive Services: Required Health Plan Coverage Guidelines, Affordable Care Act Expands Prevention Coverage for Women’s Health and Well-Being*, HRSA, <http://www.hrsa.gov/womensguidelines> (last visited Mar. 8, 2012).

66. CLINICAL PREVENTIVE SERVICES FOR WOMEN: CLOSING THE GAPS, *supra* note 56, at 12.

67. U.S. Dep’t of Health & Human Servs., *supra* note 65. The IOM formed a committee to analyze preventative services for women and to consult organizations and individuals. The comments refer to genetic screening of parent, as a preventative measure, but not to genetic testing or screening of fetuses.

68. CLINICAL PREVENTIVE SERVICES FOR WOMEN: CLOSING THE GAPS, *supra* note 56, at 56-57.

change over time and may create a forum in which new technology will influence revisions of HHS policy.⁶⁹

C. Examples of State Regulation

Like the federal government, states generally do not regulate the specifics of prenatal genetic testing and screening and do not typically regulate how health care professionals offer screening or explain or treat genetic disorders.⁷⁰ However, the rules governing health care insurance practices, the tort system, and the regulation of genetic counselors reflect current trends in clinical care.

First, some states regulate what screening and testing services must be included in benefit plans.⁷¹ For example, California, Massachusetts, Ohio,⁷² and Washington⁷³ explicitly require health insurance plans to cover prenatal genetic testing and screening, while Louisiana and Illinois require limited insurance coverage for screenings of particular disorders. California requires that all plans covering prenatal care must include a maternal blood screen and genetic testing for particular disorders.⁷⁴ The Massachusetts health insurance program, which provides state insurance for those earning below 200% of the federal poverty line, covers amniocentesis and all pregnancy costs.⁷⁵ Louisiana only requires insurance plans to cover screening for cleft lip/palate,⁷⁶ and Illinois requires insurance plans to cover prenatal

69. *Id.* at 1.

70. California and Iowa are exceptions in this regard: both states require obstetricians to give women an opportunity to screen for genetic and other anomalies. CAL. HEALTH & SAFETY CODE § 124980 (Deering 2012); IOWA CODE § 136A.1 (2011).

71. Whether services are covered by an insurance plan usually depends on whether the service is “medically necessary” or indicative of the standard of care. Chachkin, *supra* note 41, at 39. The norm is for insurance companies, not the state, to define “medically necessary.” State laws, if they speak to the issue, define “medically necessary” broadly. For example, the Illinois Department of Insurance defines medically necessary services as “health care services and supplies provided by a health care provider appropriate to the evaluation and treatment of disease, condition, illness or injury and consistent with the applicable standard of care, including the evaluation of experimental and/or investigational services, procedures, drugs or devices.” ILL. DEP’T OF INS., ILLINOIS INSURANCE FACTS: MEDICAL NECESSITY 1 (2010), available at <http://insurance.illinois.gov/healthinsurance/MedicalNecessity.pdf>.

72. OHIO REV. CODE ANN. § 1751.01 (LexisNexis 2012); OHIO ADMIN. CODE § 5101:3-4-07 (2012). *But see* OHIO REV. CODE ANN. § 4112.01(B) (LexisNexis 2011) (stating that an employer is not required to pay for health insurance benefits for an abortion where the mother’s life is not in danger).

73. WASH. REV. CODE ANN. § 48.21.244 (LexisNexis 2012); WASH. REV. CODE ANN. § 48.44.344 (LexisNexis 2012); WASH. REV. CODE ANN. § 48.46.375 (2012).

74. CAL. INS. CODE §§ 10123.184, .9 (Deering 2012).

75. 130 MASS. CODE REGS § 522.005 (2012).

76. LA. REV. STAT. ANN. § 22:1026 (2012).

HIV screenings.⁷⁷ Alabama, Arkansas, Minnesota, New Hampshire, and Wisconsin appear to require coverage of prenatal genetic testing and screening because they require insurers to cover prenatal care that is medically necessary.⁷⁸ Generally, insurers cover amniocentesis or CVS for women over age thirty-five or with indicative family histories and positive screens, although companies differ in how they define “medically necessary” genetic testing and screening.⁷⁹

Second, the growth of genetic testing and screening has influenced changes to the licensure of genetic counselors across the country. Thirteen states have statutes dealing with licensing genetic counselors, and six more states are debating licensing laws.⁸⁰ The language of state statutes is based, sometimes verbatim, on recommendations by the National Society of Genetic Counselors (NSCG).⁸¹ For example, Delaware’s law establishes a Genetic Counselor Advisory Council to issue regulations and to review license applications.⁸² In 2006, the National Conference of State Legislatures encouraged states to enumerate the services licensed genetic counselors must provide and distributed a policy brief for states to follow.⁸³

Finally, in most states patients may sue physicians in tort for failing to test or screen if a child is born with a physical or genetic disabil-

77. 215 ILL. COMP. STAT. ANN. 5/356z.1 (LexisNexis 2012).

78. See, e.g., N.H. REV. STAT. ANN. § 417-D:2-a (Lexis Nexis 2012) (“Insurers shall not deny payment for services that are within standards of . . . generally accepted medical practice as reflected by scientific and peer medical literature and recognized within the organized medical community in the state of New Hampshire.”). But see WIS. ADMIN. CODE COMM’R OF INS. § 8.72(14)(a) (2012) (mandating companies cover “[p]renatal services normally associated with pregnancy”).

79. Aetna, for example, will cover maternal serum screening in the first trimester, but considers serum screening in the second trimester to be experimental. *Clinical Policy Bulletin: Serum Marker Screening for Down Syndrome*, AETNA (Mar. 8, 2012, 8:55 PM), http://www.aetna.com/cpb/medical/data/400_499/0464.html.

80. Jessica L. Mester et al., *Perceptions of Licensure: A Survey of Michigan Genetic Counselors*, 18 J. GENETIC COUNS. 357, 358-365 (2009) (citing laws of California, Delaware, Hawaii, Illinois, Indiana, Massachusetts, New Jersey, New Mexico, Oklahoma, South Dakota, Tennessee, Utah, and Washington).

81. *State Licensure for Genetic Counselors*, NAT’L SOC’Y OF GENETIC COUNSELORS, <http://www.nsgc.org/Advocacy/StateLicensureforGeneticCounselors/tabid/320/Default.aspx> (last visited Jan. 8, 2012).

82. DEL. CODE ANN. tit. 24, § 1799I (2011). The statute also makes plain that applicants must have ABGC or ABMG certification and sets out grounds for disciplinary action, which include “illegal, competent or negligent conduct” or violation of the NSGC’s code of ethics. *Id.* §§ 1799J, 1799P.

83. The Conference called on states to detail requirements for physician supervision of counselors, set out minimum qualifications for counselors, described penalties for unprofessional conduct, and addressed other issues, such as patients’ confidentiality and continuing education for counselors. Alissa Johnson, *NCSL Genetics Brief: Genetic Counselor Licensing*, NAT’L CONF. OF STATE LEGISLATURES (July 2006), <http://www.ncsl.org/default.aspx?tabid=14276>.

ity. More than half of states permit wrongful birth actions:⁸⁴ suits for damages brought by the parents who claim that their child's birth would have been prevented but for the negligence of the defendant physician, who failed to disclose testing options or failed to provide the correct test results.⁸⁵ By contrast, most state courts will not permit children to bring wrongful life claims.⁸⁶ Wrongful life claims are actions brought by the child for damages associated with his or her birth on the theory that but for the defendant physician's negligence, he or she would have never have been born.⁸⁷

The paucity of regulation at state and federal levels creates space for the introduction of new forms of testing and DNA sequencing as part of routine prenatal care. As the next Part highlights, there is the opposite regulatory response to abortion, where laws closely scrutinize the information given to patients and pregnant women's choices.

II. THE DECLINING AVAILABILITY OF ABORTION SERVICES

As prenatal genetic testing and screening expand, abortion services have become less available, and abortion politics in the United States have never been more contentious. In the last several years, federal and state legislation has restricted abortion care on a number of fronts—reducing funding for services; banning the types or limiting the timing of procedures; imposing liability on providers through the regulation of facilities, licenses, and physician conduct; and requiring patients to submit to counseling, or other “informed consent” requirements, such as ultrasound viewing.⁸⁸ These laws have created a remarkably different picture of abortion accessibility over the last several decades, and legislation currently before statehouses foretell of additional restrictions.

84. See Wendy F. Hensel, *The Disabling Impact of Wrongful Birth and Wrongful Life Actions*, 40 HARV. C.R.-C.L. L. REV. 141, 160 (2005).

85. See Charo & Rothenberg, *supra* note 9, at 112; see also *Wilson v. Kuenzi*, 751 S.W.2d 741, 743 (Mo. 1988).

86. See Jillian T. Stein, *Backdoor Eugenics: The Troubling Implications of Certain Damages Awards in Wrongful Birth and Wrongful Life Claims*, 40 SETON HALL L. REV. 1117, 1132, 1135 (2010); see, e.g., *Curlender v. Bio-Science Labs.*, 165 Cal. Rptr. 477, 481, 489-90 (Cal. Ct. App. 1980); *Procanik v. Cillo*, 478 A.2d 755, 762, 764 (N.J. 1984); *Harbeson v. Parke-Davis, Inc.*, 656 P.2d 483, 496 (Wash. 1983); see also *Kassama v. Magat*, 368 Md. 113, 137, 138 (Md. 2002) (listing California, New Jersey, and Washington as states that recognize wrongful life claims).

87. See *Kuenzi*, 751 S.W.2d at 743.

88. See Erik Eckholm, *Several States Forbid Abortion After 20 Weeks*, N.Y. TIMES, June 27, 2011, at A10; see also Emily Bazelon, *The Reincarnation of Pro-Life*, N.Y. TIMES, May 29, 2011, at MM13.

Our purpose is to note the legal trends that have had real consequences for women's pregnancy choices. Terminating a pregnancy after discovering fetal anomaly has not only been a longstanding option, but also, in some cases, an important health care intervention.⁸⁹ However, the disassociation of abortion as health care has and will shape the choices pregnant women make after prenatal genetic testing.⁹⁰

A. Funding

Who pays for abortion has been at the center of public debate for over thirty years and, as noted, was a sticking point in negotiations of the ACA. Known as the "Hyde Amendment," Congress has passed legislation every year since 1976 to exclude abortion from Medicaid coverage except when the woman's life is at risk or where pregnancy is the result of rape or incest.⁹¹ Some states fund abortions (with state money) on broader grounds. But most states follow Hyde or ban state-based funding for any abortion services or referrals.⁹² Fifteen states have taken the additional step of prohibiting insurance plans that cover public employees from offering abortion benefits.⁹³ Of states limiting public support for abortion, Mississippi and Virginia explicitly permit Medicaid funding for fetal abnormality.⁹⁴

In 2009, a fresh battle over insurance coverage of abortion erupted in negotiations over new benefits plans operating under pro-

89. For example, testing can reveal information about fetal anomaly or other characteristics of the fetus that could threaten the mother's health. King, *supra* note 44, at 6.

90. B. Jessie Hill, *Reproductive Rights as Health Care Rights*, 18 COLUM. J. GENDER & L. 501, 502 (2009).

91. RANJI ET AL., *supra* note 58, at 2. Federal limits on abortion funding have been extended to funding for federal employees, participants in the Indian Health Service, and women in the military. *Id.*

92. NAT'L NETWORK OF ABORTION FUNDS, *ABORTION FUNDING: A MATTER OF JUSTICE* (2005), available at http://www.fundabortionnow.org/sites/default/files/exec_summary_abortion_funding_a_matter_of_justice.pdf (noting thirty-three states in 2005 did not permit use of state Medicaid or other public funds for low-income women's abortion services). Only four of the seventeen states that use public funds for abortion services do so voluntarily; the rest provide state funds because of a court order. See also Am. Civ. Liberties Union, *Public Funding for Abortion*, AM. CIV. LIBERTIES UNION, <http://www.aclu.org/files/FilesPDFs/map.pdf> (last visited Mar. 8, 2012) (map showing which states fund abortion for low-income women through a legislative act or because of a court order).

93. GUTTMACHER INST., *STATE POLICIES IN BRIEF: RESTRICTING INSURANCE COVERAGE OF ABORTION* (2012), available at http://www.guttmacher.org/statecenter/spibs/spib_RICA.pdf (last updated Apr. 1, 2012). Two of these states, Louisiana and Tennessee, permit no abortion coverage, while the rest permit coverage for life endangerment only; for threat to life or health; and in instances of rape or incest. *Id.*

94. See GUTTMACHER INST., *STATE POLICIES IN BRIEF: STATE FUNDING FOR ABORTION UNDER MEDICAID* (2012), available at http://www.guttmacher.org/statecenter/spibs/spib_SFAM.pdf (last updated Apr. 1, 2012).

posed state insurance exchanges.⁹⁵ The purpose of the exchanges is to help individuals and small businesses (those unlikely to avail of employer insurance plans or purchase benefits for employees) buy private health care coverage by creating a federally-subsidized, state-based market. Whether abortion would be offered by plans in new health care exchanges was controversial for all bills introduced in the House and the Senate, as well as the reconciliation bill approved by Congress and signed by President Obama.⁹⁶ The ACA reflects a tense compromise reached by the legislation's drafters, embodied in legislative language known as the Nelson Amendment.

The Nelson Amendment excludes abortion as an essential benefit offered by plans participating in state exchanges, except when a woman's life is threatened and in instances of rape or incest (the Hyde grounds).⁹⁷ Moreover, plans participating in state exchanges may offer abortion coverage but must comply with rules that ensure no federal money subsidizes that care.⁹⁸ First, insurers must offer at least one plan that does not cover abortion. Second, for plans that cover abortion, the insurance company must collect two premiums from plan members—one for abortion benefits and one for everything else.⁹⁹ The cost of the abortion benefit must be at least one dollar per enrollee per month.¹⁰⁰ Finally, the ACA prohibits plans from discriminating against any physician participant that is unwilling to provide abortion care.¹⁰¹ Fifteen states have already passed laws prohibiting insurance companies participating in state exchanges from offering

95. See Susan A. Cohen, *Insurance Coverage of Abortion: The Battle to Date & the Battle to Come*, 13 POL'Y REV. 1, 2 (2010), available at <http://www.guttmacher.org/pubs/gpr/13/4/gpr130402.pdf> (summarizing the debate in Congress over the ACA's treatment of abortion).

96. The Senate Finance bill, for example, prohibited abortion coverage from being required as part of a minimum benefits package and required segregation of public funds in private payments for plans that cover abortion services on non-Hyde grounds. For a summary, see *Health Care Reform Proposals*, KAISER FAMILY FOUND., http://www.kff.org/healthreform/upload/health_reform_tri_full.pdf (last modified Oct. 15, 2009).

97. Patient Protection and Affordable Care Act, Pub. L. No. 111-148, § 1303(a)(1)(A)(i), 124 Stat. 119 (2010).

98. *Id.* § 1303(a)(1)(B)(i).

99. *Id.* § 1303(a)(2)(B). The cost of the abortion benefit must be at least one dollar per enrollee per month. *Id.* § 1303(a)(2)(C)(ii)(II).

100. *Id.* Traditionally, abortion as a health care service offered by health insurance plans was considered a cost saving measure and thus had a negative actuarial value. See generally Roy G. Spece, Jr., *The Purpose Prong of Casey's Undue Burden Test and its Impact on the Constitutionality of Abortion Insurance Restrictions in the Affordable Care Act or Its Progeny*, 33 WHITTIER L. REV. 77, 87-88 (noting earlier legislative attempts to inflate the actuarial figures associated with abortion and to ignore evidence of costs-savings with abortion coverage).

101. See Patient Protection and Affordable Care Act §§ 10104(c), 1303(b)(4). State insurance commissions will oversee the separate accounts into which insurance companies must deposit payments for abortion benefits. *Id.* §§ 10104(c), 1303(b)(2)(E)(i).

any coverage for abortion services; another fifteen debated such laws in 2011.¹⁰²

The combination of disincentives (administrative and financial) for insurance companies to offer abortion coverage¹⁰³ and the expansion of Medicaid with Hyde restrictions means that the number of women paying out-of-pocket will likely increase.¹⁰⁴ The ACA will create additional administrative costs for health insurance companies offering abortion care in state exchange plans, which companies are likely to pass to consumers in the form of higher premiums. Because consumers may not choose a more expensive plan,¹⁰⁵ some policy analysts suggest that insurers will cut abortion benefits in most plans to save costs,¹⁰⁶ thus further marginalizing abortion.¹⁰⁷

B. Conditioning Patient Choice

Unlike most medical procedures, states often require patients to observe waiting periods, for providers to deliver scripted counseling and information, and for women to view ultrasound images before an abortion.¹⁰⁸ Thirty-four states require counseling before a termination, with twenty-six of these states detailing what information women must receive. Twenty-six states require a waiting period between counseling and the abortion procedure. Most waiting periods are

102. Karmah Elmusa, *Map of the Day: States Banning Abortion Coverage*, MOTHER JONES, (June 29, 2011), <http://motherjones.com/mojo/2011/06/map-state-abortion-coverage-ban>. On the federal level, the House of Representatives passed the “No Taxpayer Funding for Abortion Act,” which did not receive a Senate vote. H.R. 3, 112th Cong. (2011). The bill prevents employers from taking a tax deduction for insurance plans that include abortion coverage. It also prevents individuals from paying for plans that cover abortion with pretax dollars and flexible health spending accounts or claiming the federal medical care deduction. *Id.* §§ 101, 201, 202.

103. See Cohen, *supra* note 95, at 4.

104. In 2002, eighty-seven percent of private plans covered medically necessary abortions. The survey did not capture how many of the plans covered elective abortion that was not medically indicated. Adam Sonfield et al., *U.S. Insurance Coverage of Contraceptives and the Impact of Contraceptive Coverage Mandates, 2002*, 36 PERSP. SEXUAL & REPROD. HEALTH 72, 75-76 (2004), available at <http://www.guttmacher.org/pubs/psrh/full/3607204.pdf>.

105. An IOM report shows that even moderate co-pays for some preventative services “deter patients from receiving those services.” CLINICAL PREVENTIVE SERVICES FOR WOMEN: CLOSING THE GAPS, *supra* note 56, at 19.

106. Cohen, *supra* note 95, at 2-4 (discussing ACA segregation rules and disincentives for abortion coverage).

107. For example, abortion was explicitly left out of the IOM’s considerations of what women’s preventative care should include. CLINICAL PREVENTIVE SERVICES FOR WOMEN: CLOSING THE GAPS, *supra* note 56, at 21. Arguably, insurance companies may have an incentive to cover abortion if testing reveals fetal abnormality that is very costly to treat.

108. Professor Maya Manian has shown how different informed consent for abortion is from other medical procedures. Maya Manian, *The Irrational Woman: Informed Consent and Abortion Decision-Making*, 224 DUKE J. GENDER L. & POL’Y 223, 244-45 (2009).

twenty-four hours, but some states either impose longer time periods, or require in-person counseling, necessitating two trips to a provider.¹⁰⁹ South Dakota is the outlier, having imposed a seventy-two hour waiting period that is now the subject of litigation.¹¹⁰

In the abortion context, the trend is also toward more information, but in the form of guidance that might dissuade a woman from abortion by providing her with details about the fetus or the risks of abortion. States commonly mandate information about the physical or psychological consequences of abortion and about the gestational age of the fetus or fetal development.¹¹¹ Eight states require a health professional to describe only negative consequences or risks of abortion. Seven states inaccurately link abortion to the occurrence of breast cancer, and eleven include information about the possibility of fetal pain.¹¹² Described in more detail in Part III, one variant of so-called informed consent laws garnering recent media attention and judicial review are statutes mandating that providers show patients ultrasound images.

C. Regulations of Facilities and Providers

State laws regulating abortion take on a variety of forms: special licensing requirements, such as admitting privileges at hospitals; regulations of clinic or facility space and design; ambulatory surgical center requirements; special ethics trainings for providers; and detailed record-keeping requirements.¹¹³

109. GUTTMACHER INST., STATE POLICIES IN BRIEF: COUNSELING & WAITING PERIODS FOR ABORTION (2012), available at http://www.guttmacher.org/statecenter/spibs/spib_MWPA.pdf (last updated Apr. 1, 2012) (noting that nine states effectively require two trips to an abortion provider); see also Ian Vandewalker, *Abortion & Informed Consent: How Biased Counseling Laws Mandate Violations of Medical Ethics*, 19 MICH. J. GENDER & L. (forthcoming 2012) (citing *Planned Parenthood of Middle Tenn. v. Sunquist*, 38 S.W.3d 1 (Tenn. 2000), which struck down a two-day waiting period).

110. Robin Marty, *South Dakota Mandatory 72 Hour Waiting Period On Hold Until Court Rules on Constitutionality*, RH REALITY CHECK (July 26, 2011, 4:00 PM), <http://www.rhrealitycheck.org/blog/2011/07/26/south-dakota-mandatory-hour-waiting-period-hold-until-court-rules-constitutionality>.

111. See *Planned Parenthood of Se. Pa. v. Casey*, 505 U.S. 833, 882-83 (1992).

112. GUTTMACHER INST., STATE POLICIES IN BRIEF: ABORTION REPORTING REQUIREMENTS (2012), available at http://www.guttmacher.org/statecenter/spibs/spib_ARR.pdf (last updated Apr. 1, 2012) (noting that eleven state laws refer to fetal pain; thirty-three state laws to gestational age; twenty-five state laws to fetal development; eight state laws only negative psychological responses; seven states inaccurately link breast cancer and abortion).

113. Forty-six states require hospitals, facilities, and physicians to submit regular, confidential reports of abortion procedures to the state government; and, twelve states further require certification that counseling and parental involvement standards were met. *Id.* Interestingly,

A law recently passed in Kansas, and now enjoined by a federal district court, is illustrative.¹¹⁴ In April 2011, the Kansas legislature passed an act that created a new licensing category for abortion providers. Regulations issued pursuant to the act require expanded waiting room and janitorial supply spaces, as well as physician admitting privileges to hospitals. The regulations gave providers one month to comply with the new law, which was impossible given the time necessary to establish admitting privileges and redesign clinical space.¹¹⁵

Perhaps the most significant developments in abortion regulation, with acute relevance to screening and testing, are state attempts to ban specific abortion procedures and abortion after twenty weeks of gestation. *Gonzales v. Carhart*¹¹⁶ confirmed that the federal government could ban procedures like intact D&E in order to protect the integrity of the medical profession¹¹⁷ and the emotional health of women (both state interests are examined in the next Part).¹¹⁸ Moreover, the Court held that medical evidence did not conclusively establish that the procedure was necessary to protect a woman's physical health.¹¹⁹

Carhart signaled to state legislatures the willingness of the Supreme Court to permit restrictions in the name of protecting fetal and women's health. Another recent restriction on the availability of abortion services are new state laws that prohibit providers from terminating a pregnancy after twenty weeks, which is, in most cases, three or four weeks before viability and in apparent contradiction with *Planned Parenthood of Southeast Pennsylvania v. Casey*.¹²⁰

fifteen of those forty-six states require reports to list whether the abortion was for reason of fetal abnormality. *Id.*

114. See KAN. ADMIN. REGS. § 28-34-133(b) (2012); see also Brad Cooper, *Federal Judge Blocks New Abortion Licensing Rules*, KAN. CITY STAR, July 1, 2011, http://www.cafemom.com/group/33200/forums/read/14412489/Federal_Judge_blocks_new_abortion_rules_in_Kansas (last visited Mar. 9, 2012).

115. Similar laws have been passed in Virginia and Utah. See Kate Sheppard, *Kansas to Shut Down All but One Abortion Clinic Friday*, MOTHER JONES, June 30, 2011, <http://motherjones.com/mojo/2011/06>.

116. *Gonzales v. Carhart*, 550 U.S. 124, 124 (2007).

117. See *id.* at 157-58, 160; see also Priscilla Smith, *Responsibility for Life: How Abortion Serves Women's Interests in Motherhood*, 17 J.L. & POL'Y 97, 141 (2008).

118. See *Carhart*, 550 U.S. at 159-60.

119. *Id.* at 158, 163-64 ("[T]he State may use its regulatory power to bar certain procedures and substitute others . . .").

120. The Supreme Court gauged viability at about the twenty-third or twenty-fourth week after the last menstrual cycle. See *Planned Parenthood of Se. Pa. v. Casey*, 505 U.S. 833, 860 (1992). These laws are related to the partial birth abortion litigation, because, as Justice Ginsburg noted in dissent, "partial birth abortion laws" do not account for the point of gestation and thus "blur[] the line, firmly drawn in *Casey*, between pre-viability and post-viability abortions."

Thirty-nine states already limit abortion after viability,¹²¹ and the premise of legislation prohibiting abortion at and after twenty weeks is that fetuses can feel pain at that point.¹²² As of June 2011, six states passed twenty week bans with exceptions for the pregnant woman's life or in cases of "serious physical impairment of [the woman's] bodily function."¹²³

D. Refusals or Conscience Clauses

Federal law and the laws of forty-six states permit individual health care providers and institutions to refuse to perform or to offer abortion services. The first federal conscience clause law, the "Church Amendment," was enacted in 1973 as a direct response to *Roe v. Wade*.¹²⁴ The Amendment essentially states that individuals or entities receiving public funds may refuse to perform abortions or sterilization procedures based on moral or religious beliefs.¹²⁵ Within five years of the Amendment, almost every state had conscience clause legislation.¹²⁶ Additional amendments to the Public Health Services Act and Appropriations Act (the Coats¹²⁷ and Weldon¹²⁸ Amendments) broadly prohibit the government and recipients of government

Carhart, 550 U.S. at 171 (Ginsburg, J., dissenting). Professors I. Glenn Cohen & Sadath Sayeed also note that the twenty week bans do not require physicians to resuscitate the premature newborn that is born at or before twenty-three weeks. I. Glenn Cohen & Sadath Sayeed, *Fetal Pain, Abortion, Viability, & the Constitution*, 39 J.L. MED. & ETHICS 235, 237 (2011). The common practice is not to resuscitate given the "poor chance of survival without significant disability." *Id.*

121. GUTTMACHER INST., STATE POLICIES IN BRIEF: STATE POLICIES ON LATER ABORTION (2012), http://www.guttmacher.org/statecenter/spibs/spib_PLTA.pdf (last updated Apr. 1, 2012). Twenty of the thirty-nine states limit abortion after viability; five in the third trimester; and fourteen at a certain number of weeks. *Id.*

122. See, e.g., 2010 Neb. B. 1103, 101st Leg. 2d. Sess. (2010), available at <http://www.nebraska.gov/FloorDocs/101/PDF/Slip/LB1103.pdf>; see also Cohen & Sayeed, *supra* note 120, at 238 (refuting that fetuses can "experience" pain at twenty weeks).

123. Florida and Iowa considered similar bills in 2011. Eckholm, *supra* note 88. For example, the exception for women's health in the Nebraska bill is framed as a "condition that so complicates [the woman's] medical condition as to necessitate the abortion of her pregnancy to avert her death or to avert serious risk of substantial and irreversible physical impairment of a major bodily function." Neb. B. 1103, available at <http://www.nebraskalegislature.gov/FloorDocs/101/PDF/Slip/LB1103.pdf>.

124. Health Programs Extension Act, Pub. L. No. 93-45, 87 Stat. 91, 93 (1973) (codified at 42 U.S.C. § 300 (2006)).

125. 42 U.S.C. § 300a-7(b).

126. Rachel Benson Gold, *Conscience Makes a Comeback in the Age of Managed Care*, 1 GUTTMACHER REP. ON PUB. POL'Y 1, 1-2 (1998), available at <http://www.guttmacher.org/pubs/tgr/01/1/gr010101.pdf>.

127. Omnibus Consolidated Rescissions & Appropriations Act of 1996, Pub. L. No. 104-134, sec. 515, § 245, 110 Stat. 1321, 1321-244-246 (codified as amended at 42 U.S.C. § 238n (2006)).

128. Consolidated Appropriations Act of 2008, Pub. L. No. 110-161, §508(d), 121 Stat. 1844, 2208-09.

funds from discriminating against health care providers who refuse to perform or teach services they find morally objectionable.¹²⁹

More recently, HHS regulations issued in 2008, under the Bush Administration, were criticized for including a medically inaccurate definition of abortion that “conflated most modern contraceptives with abortion.”¹³⁰ In 2011, the HHS rescinded and revised the 2008 regulations.¹³¹ While the HHS still “supports clear and strong conscience protections for health care providers who are opposed to performing abortions,”¹³² it “rescind[ed] those parts of the 2008 Final Rule that were unclear and overbroad in scope.”¹³³

III. IMPLICATIONS AND CONSEQUENCES OF THE MIXED MESSAGE

Prenatal genetic testing and abortion inevitably intersect, producing discordant effects as testing becomes more common and access to abortion becomes less available. This Part highlights common questions or themes in abortion and testing that do share common answers or meanings. In offering a sample of the inconsistencies in this complex area, we identify four issues in which the legal and policy aims of prenatal genetic testing and abortion diverge: what is considered reproductive health care; health care professionals’ autonomy and discretion; the scope and purposes of information given to patients; and attitudes toward women’s pregnancy decisions. In the short term, anti-abortion trends might overly influence policy debates about advances and innovations in prenatal diagnosis.

129. Thaddeus Mason Pope, *Legal Briefing: Conscience Clauses and Conscientious Refusal*, 21 J. CLINICAL ETHICS 163, 163-80 (2010).

130. Adam Sonfield, *For the Record: Obama Administration Rescinds Most of Controversial “Conscience” Regulation*, 14 GUTTMACHER POL’Y REV. 24, 24 (2011), available at <http://www.guttmacher.org/pubs/gpr/14/1/gpr140124.pdf>.

131. Ensuring that the Dep’t of Health & Hum. Serv. Funds Do Not Support Coercive or Discriminatory Policies or Practices in Violation of Fed. Law, 73 Fed. Reg. 78,072 (Dec. 19, 2008) (codified at 45 C.F.R. §§ 88.1-88.6 (2010) (repealed by §§88.2-88.5, amended by §88.6, amended and re-designated as §88.2 (2011)); Reg. for the Enforcement of Fed. Health Care Provider Conscience Protection Laws, 76 Fed. Reg. 9968 (Feb. 23, 2011) (codified as amended at 45 C.F.R. §§ 88.1-.886 (2011)).

132. Reg. for the Enforcement of Fed. Health Care Provider Conscience Protection Laws, 76 Fed. Reg. at 9969.

133. *Id.* The ACA reiterates protection for health professionals’ refusals. See *supra* note 101 and accompanying text (noting the ACA’s inclusion of a refusal right for physicians).

A. Testing and Abortion as Health Care

Testing is increasingly considered an integrated and ordinary part of prenatal care and abortion is decreasingly considered medical care at all. We identify three legal trends in this vein.

First, testing has not traditionally been a site of government regulation *because* it is a health care matter. Whether and when to test, like any other health care choice, is treated as a personal decision made by a patient in consultation with her physician. States for the most part do not mandate screening or testing; do not define what services are “medically necessary”; and do not, by and large, regulate what results patients may learn. For example, state or federal laws do not have consistent definitions of what constitutes a “severe” genetic disorder,¹³⁴ perhaps because of the wide range of clinical opinions and attendant fears of creating over and under inclusive definitions.¹³⁵ Abortion, however, has moved from being a private health care decision, left to the patient-physician relationship as envisioned by *Roe*, to services heavily regulated by the state.¹³⁶

The ACA typifies the view that screening or testing is routine reproductive health care, and abortion is not. The ACA omits abortion as an essential benefit and requires segregation of all funds paid to state exchange plans that cover abortion, potentially reducing insurance coverage over the long term. Certain screening and testing services, however, will be paid for under the ACA while abortion will not. Thus, a woman may receive testing at no or low-cost, but will pay out-of-pocket for an abortion. Indeed, fifty-seven percent of U.S. women already pay out-of-pocket for abortion services, which can be expensive.¹³⁷ A termination at ten weeks of gestation can cost between \$400 to \$600 (whether through surgical or medical methods), with costs increasing to thousands of dollars as the pregnancy progresses in the second trimester.¹³⁸

134. Adrienne Asch, *Disability Equality and Prenatal Testing: Contradictory or Compatible?*, 30 FLA. ST. U. L. REV. 315, 339 (2002).

135. See Elyse Whitney Grant, Note, *Assessing the Constitutionality of Reproductive Technologies Regulation: A Bioethical Approach*, 61 HASTINGS L.J. 997, 1029 (2010) (“Certain genetic characteristics, such as a predisposition to breast cancer, straddle the line between therapeutic and non-therapeutic.”).

136. B. Jessie Hill, *Abortion as Health Care*, 10 AM. J. BIOETHICS 48, 49 (2010).

137. RACHEL K. JONES ET AL., GUTTMACHER INST. CHARACTERISTICS OF U.S. ABORTION PATIENTS, 2008, at 1 (2010), available at <http://www.guttmacher.org/pubs/US-Abortion-Patients.pdf>.

138. For example, one clinic in Houston charges \$420 for surgical and medical abortion before the eleventh week of pregnancy; \$800 for abortion at twelve to thirteen weeks; \$900 at

Second, this underscores the perception that abortion services, unlike testing services, have *no relation* to protecting women's physical or mental health.¹³⁹ *Roe v. Wade* required the state, if restricting abortion in the third trimester, to allow for the preservation of "the life or health of the mother."¹⁴⁰ *Casey*, although abandoning the trimester framework, reiterated that the state must protect women's health throughout pregnancy, including after viability.¹⁴¹ Yet in *Gonzales v. Carhart*, the Supreme Court ignored evidence that intact D&E could be the safest abortion procedure available. In 2000, the Supreme Court struck down a state law banning intact D&Es, which mirrored the federal ban, in *Stenberg v. Carhart* because the Nebraska statute did not have an exception for women's health.¹⁴² Seven years later, the Court upheld the federal analog because evidence of the effects on women's health cut both ways. The Court held that laws like the one in *Carhart* without exceptions to protect pregnant women's health are not unconstitutional per se, but subject to case-by-case analysis.¹⁴³ In the aftermath of *Carhart*, several states have passed or reinstated "partial birth abortion" bans¹⁴⁴ using language that is sometimes unclear as to which procedures or physician actions are illegal, increasing liability fears among providers.¹⁴⁵

Third, and building from the previous two trends, abortion may become less recognizable as medical care after testing reveals serious fetal health problems.¹⁴⁶ We have argued that abortion has traditionally been one option that pregnant women could choose after learning of fetal anomaly. Indeed, a few state abortion laws explicitly recog-

fourteen to fifteen weeks; and does not provide abortion past sixteen weeks. *Fees & Instructions*, HOUS. WOMEN'S CLINIC, <http://www.houstonwomensclinic.com/fees.html> (last visited Mar. 12, 2012).

139. In an early case, a federal district court struck down an Illinois law for vagueness that criminalized experimentation on a fetus unless experimentation was for therapeutic reasons. See *Lifchez v. Hartigan*, 735 F. Supp. 1361, 1363 (N.D. Ill. 1990) (holding that an impermissible consequence of the law was its potential bar to amniocentesis, which the court described as potentially experimental).

140. *Roe v. Wade*, 410 U.S. 113, 164 (1973) (permitting state regulation in the second trimester if "related to maternal health").

141. *Planned Parenthood of Se. Pa. v. Casey*, 505 U.S. 833, 846, 873 (1992).

142. *Stenberg v. Carhart*, 530 U.S. 914, 929-30 (2000).

143. *Gonzales v. Carhart*, 550 U.S. 124, 158 (2007).

144. GUTTMACHER INST., STATE POLICIES IN BRIEF: BANS ON "PARTIAL-BIRTH" ABORTION (2012), available at http://www.guttmacher.org/statecenter/spibs/spib_BPBA.pdf.

145. See LORI FREEDMAN, WILLING & UNABLE: DOCTORS' CONSTRAINTS IN ABORTION CARE 32 (2010).

146. *But see* Asch, *supra* note 134, at 340 (predicting exceptions for fetal anomaly in laws that restrict abortion before viability) (citing Martha Field, *Killing the Handicapped—Before and After Birth*, 16 HARV. WOMEN'S L.J. 79, 110 (1993)).

nize severe fetal conditions as reasons or grounds for terminating a pregnancy after viability. Recently under attack, Texas permits post-viability abortion in the case of “severe and irreversible abnormality identified by reliable diagnostic procedures.”¹⁴⁷ Maryland allows post-viability abortion if “the fetus is affected by genetic defect or serious deformity or abnormality.”¹⁴⁸ Utah allows post-viability abortion of a fetus with a genetic disorder if two physicians agree in writing that the disorder is “uniformly diagnosable and uniformly lethal.”¹⁴⁹

As noted in Part I, by the time a prenatal diagnosis is confirmed, it may well be into the second trimester, at or after seventeen weeks.¹⁵⁰ Less than two percent of abortions occur in the second or third trimesters, and most of those terminations are for reason of fetal condition.¹⁵¹ However, bans on methods like intact D&E and increasingly popular bans on terminations after twenty weeks will significantly affect the population of women who seek abortions after testing in their second and third trimesters.¹⁵² Thus, at the time that most women confirm testing results, states are increasingly curtailing their abortion rights.

Non-invasive methods portend testing, and thus abortion, earlier in pregnancy or at least before twenty weeks of gestation.¹⁵³ However, if most women have their initial prenatal visit between eight and twelve weeks, followed by some combination of counseling, screening, and testing, there may be a short window of time to consider options before the twentieth week of pregnancy.¹⁵⁴ There is also a decreasing number of physicians willing to perform abortions at any point in pregnancy, but especially after the first trimester. Over the last sev-

147. TEX. HEALTH & SAFETY CODE § 170.002(b)(3) (2010). A bill introduced in 2011 sought to delete the fetal abnormality ground as well as remove impairment of mental health as a ground for post-viability abortion. H.R. 2988 § 170.002, 82d Leg., Reg. Sess. (Tex. 2011).

148. MD. CODE ANN., HEALTH-GEN. § 20-209(b)(2)(ii) (LexisNexis 2011). Maryland’s law allowing abortion on the ground of fetal abnormality was passed before *Roe v. Wade*. See MD. CRIM. CODE, Art. 43 §149E (1968) (renumbered by Acts 1970, chap. 736).

149. UTAH CODE ANN. § 76-7-302 (LexisNexis 2011).

150. *ACOG Practice Bulletin*, *supra* note 16, at 221.

151. Lena H. Sun, *From Abortion Provider to Activist*, WASH. POST, July 25, 2011, at A01.

152. Only 1.5% of abortions occur after twenty-weeks, and many are for medical emergencies. Eckholm, *supra* note 88, at MM13. Twelve percent of abortions are in the second trimester, and women who discover fetal abnormality are the majority of that group. Manian, *supra* note 108, at 228. After viability, at twenty-four or more weeks, most states, as noted, prohibit abortion unless the woman’s health or life is at risk. See *supra* Part II.B (discussing post-viability restrictions).

153. Non-invasive testing can occur as early as five to seven weeks of pregnancy, with results by the tenth week of gestation. See *supra* Part I.A (discussing noninvasive methods for prenatal genetic testing).

154. Farrell et al., *supra* note 13, at 6.

eral decades, there has been a significant decrease in the number of abortion providers. Between the years of 1982 and 2005, the number of abortion providers in the United States declined from approximately 2,900 to 1,800.¹⁵⁵ Consequently, the number of counties in the United States with no abortion provider has increased: in 2005, eighty-seven percent of counties had no abortion provider, and ninety-seven percent of all non-metropolitan counties had no physician willing to perform terminations.¹⁵⁶ There are only a handful of physicians in the country that perform late-term abortions; women who seek their services after testing will likely travel hundreds of miles and spend thousands of dollars.¹⁵⁷

As the experience of women like Claudia Crown Ades demonstrates, women pay the consequences of a health care system that refuses to recognize abortion as an important option for women and their families. In the next section, we consider similar trends in the treatment of the health care professionals.

B. The Integrity of the Medical Profession

At the intersection of prenatal genetic testing and abortion are contrasting visions of how much discretion health professionals may or should exercise. On the one hand, professional organizations like ACOG, non-governmental organizations like the NSCG, and policy makers call for better genetic counseling programs and better training for practitioners who counsel patients about genetic screening and testing options. Health care professionals report that they feel ill equipped to help patients fully understand what they may learn through screening and testing.¹⁵⁸ Moreover, pre-screening information is rarely accompanied with a detailed review of the advantages and disadvantages of post-screening options. Concerns about the inaccuracy or inadequacy of counseling, however, have not lead to closer state regulation but to proposals for increased availability of

155. Rachel K. Jones & Kathryn Kooistra, *Abortion Incidence and Access to Services in the United States, 2008*, 43 PERSP. SEXUAL & REPROD. HEALTH 41, 41 (2011).

156. *Id.* at 41, 46. The number of abortion providers appears to have remained the same between 2005 and 2008. *Facts on Induced Abortion in the United States*, GUTTMACHER INST., http://www.guttmacher.org/pubs/fb_induced_abortion.html (last updated Aug. 2011). The decrease in the availability of providers is regional: outside of the Northeast and West, the number of abortions performed decreased from 12% or 9% between 2000 and 2005. Jones & Kooistra, *supra* note 156, at 44 (explaining that the number of abortions decreased 3% in the Northeast; 12% in the Midwest; 9% in the South; 12% in the West).

157. Sun, *supra* note 151.

158. King, *supra* note 44, at 24.

trained genetic counselors and a duty to refer patients to knowledgeable health care professionals.¹⁵⁹ Both suggestions for reform accord health care professionals broad discretion to counsel patients as appropriate to each patient. However, if those same obstetricians perform abortions, their discretion, as well as their motivations, will come under sharp state scrutiny.

Carhart reflects broader skepticism of physicians that provide abortions. Justice Ginsburg, writing in dissent, highlights that the majority opinion repeatedly refers to the obstetricians that perform intact D&Es as “abortion doctors.”¹⁶⁰ Justice Kennedy, writing for the majority, argued that banning the procedure protects the physicians whose medical judgment the law curtails.¹⁶¹ First, the Court suggested that the procedure is so gruesome that its performance cheapens the practice of medicine.¹⁶² Second, the Court concluded that abortion providers cannot be trusted to exercise discretion in employing a health exception.¹⁶³ The Court stated that providers would potentially abuse the exception by claiming that all intact D&Es are performed to protect women’s health.¹⁶⁴ The Court came to these conclusions despite evidence submitted by physicians and organizations like ACOG on the health benefits of intact D&Es versus other procedures for certain pregnancies.¹⁶⁵

Concerns about health professional bias have arisen in the testing context too, but on a much different scale. Skeptics of the present trajectory of prenatal genetic testing question if physicians and genetic counselors overly focus on the medical complications of a child with the genetic condition.¹⁶⁶ In other words, a “powerful professional cul-

159. Amanda van den Heuvel et al., *Will the Introduction of Non-Invasive Prenatal Diagnostic Testing Erode Informed Choices? An Experimental Study of Health Care Professionals*, 78 PATIENT EDUC. COUNS. 24, 24 (2011).

160. *Gonzales v. Carhart*, 550 U.S. 124, 186-87 (2007).

161. Professor Sonia Suter argues that, in effect, *Carhart* “broadens the range of state interests that can justify limiting reproductive decisions,” such as protecting the integrity of physicians, society as a whole, and the mental well being of women. Suter, *Carhart*, *supra* note 10, at 1519; *see also* Grant, *supra* note 135, at 1032 (questioning whether, post-*Carhart*, states could “ban [genetic testing technologies], citing to moral concerns”).

162. *Carhart*, 550 U.S. at 160.

163. *See id.* at 159-60.

164. *Id.*

165. Brief of the American College of Obstetricians and Gynecologists as Amicus Curiae Supporting Respondents, *Gonzales v. Carhart*, 550 U.S. 124 (2007) (No. 05-380); Brief of American Medical Women’s Association et al. as Amici Curiae Supporting Respondents, *Gonzales v. Planned Parenthood Fed’n of America, Inc.*, 549 U.S. 807 (2006) (No. 05-1382).

166. Bagenstos, *supra* note 18, at 334-35, 440.

ture” problematizes and medicalizes all fetal anomalies.¹⁶⁷ As described by Professor Adrienne Asch, the “medical model” of disability envisions disability itself as the problem rather than the discrimination that persons with disabilities face, which misconceives the quality of life or life choices that persons with disabilities have or can make.¹⁶⁸ Wrongful birth and wrongful life claims typify these assumptions, which compensate parents for their “loss” in having a child with a disability.¹⁶⁹

Wrongful birth claims highlight another contradiction in physicians’ roles. The premise of the wrongful birth cause of action is that women would have aborted had they known about or understood the problems with their pregnancies. Liability in tort creates incentives for physicians to offer testing, and indeed obstetricians report increasing pressure to offer testing.¹⁷⁰ However, there is no liability for the same health care professional that does not offer abortion services or explain the advantages or disadvantages of electing abortion after testing. In fact, health professionals express hesitancy to discuss abortion options with their patients. For example, one study found that of physicians interviewed, most offer women testing but tell patients not to have an amniocentesis if they would not have an abortion.¹⁷¹ Moreover, although obstetricians are often the parties that communicate what patients’ options are post-testing,¹⁷² a patient’s primary obstetrician likely will not perform terminations. In 2009, only fourteen percent of obstetricians interviewed would or could provide abortion services.¹⁷³

The hesitancy to discuss abortion may partly reflect states’ heavy regulation of how health professionals communicate the risks of abortion. States have exacting record-keeping requirements for how physicians verify informed consent and states closely manage how physicians communicate information about abortion. For example, a

167. *Id.* at 451.

168. Asch, *supra* note 134, at 316.

169. *Id.* at 337.

170. If non-invasive testing can yield diagnostic results earlier in pregnancy with low risk to the mother, then the justifications that a health care professional might give for failing to offer women testing may seem less and less reasonable. See King, *supra* note 44, at 30.

171. See ROBERT KLITZMAN, *AM I MY GENES? CONFRONTING FATE & FAMILY SECRETS IN THE AGE OF GENETIC TESTING* 232 (2012) (discussing physician approaches to genetic counseling).

172. See Czerwinski et al., *supra* note 23, at 281.

173. Deborah A. Driscoll et al., *Screening for Down Syndrome: Changing Practice of Obstetricians*, 200 AM. J. OBSTETRICS & GYNECOLOGY 459.e1, 459.e5 (2009).

federal district court in Nebraska recently struck down a law imposing heavy penalties on physicians who fail to comply with vague and onerous informed consent standards.¹⁷⁴ Moreover, physicians interviewed believe a clinical practice that focuses mostly or largely on abortion will be “vilified” or seen as “evil” by their communities.¹⁷⁵ There is little reward, in terms of community public relations, in providing abortion services.¹⁷⁶

Researcher Lori Freedman conducted a study of physicians willing and trained to provide abortion services, but who in practice do not.¹⁷⁷ Beginning by noting that only half of the obstetricians who *intend* to provide abortions in the course of their medical careers actually do,¹⁷⁸ Freedman describes how legal restrictions translate to the marginalization of abortion services. Although professional standards recommend training in abortion, federal intervention and the current operation of residency programs means that residents must “opt in” rather than opt out of training.¹⁷⁹ Managed care groups and physician practice groups routinely eliminate abortion from the care they provide. The costs of abortion care for obstetricians with diverse practices are steep because they do not develop the necessary technical skills or familiarity with regulations.¹⁸⁰ Freedman details how standalone abortion clinics can absorb the costs of regulation (waiting periods, licensing, and additional counseling) because they specialize.¹⁸¹

As testing and DNA sequencing evolve, states might seek to regulate genetic counselors and obstetricians as they do abortion providers, with laws, for example, that dictate ethics training, licensing, or facility standards in excess of normal requirements. A few states have already targeted abortion after testing. Tennessee, for example, for-

174. *Planned Parenthood of the Heartland v. Heineman*, 724 F. Supp. 2d 1025, 1043-45 (D. Neb. 2010) (citing the legislative intent of the Nebraska legislature, which the court held was rooted in protecting the fetus and deterring women from abortion).

175. FREEDMAN, *supra* note 146, at 93.

176. *Id.* at 104. Moreover, the murders of abortion providers at the hands of anti-abortion extremists foster a climate of fear. See Emily Bazelon, *The New Abortion Providers*, N.Y. TIMES, July 18, 2010, at MM30.

177. FREEDMAN, *supra* note 146, at 5.

178. *Id.* at 4.

179. *Id.* at 30-31 (describing the Coats amendment).

180. *Id.* at 103, 115.

181. See *id.* at 147. Freedman explains that physicians refer patients to clinics for convenience and, because of managed care rules, to save money. The network of clinics affiliated with Planned Parenthood, for example, can standardize abortion care in ways that minimize operation costs. *Id.* at 147.

bids testing offered in state programs for a condition that cannot be cured.¹⁸² Missouri forbids state-sponsored genetic counseling programs from making a referral for an abortion unless the mother's life is in danger,¹⁸³ and Oklahoma makes it clear that genetic counselors are not required to mention abortion as a possible treatment option.¹⁸⁴

Oklahoma's law illustrates conflicting expectations of health professionals that refuse to provide testing or abortion services. Physicians uncomfortable discussing prenatal genetic testing (either because of a lack of knowledge or because of testing generally) are urged to refer their patients to another physician or genetic counselor, and evidence suggests that they do refer patients to other professionals.¹⁸⁵ In abortion, however, state and federal refusal standards insulate health professionals from the possible repercussions of refusing to provide abortion services. Although ACOG and others also urge refusing physicians to refer patients to willing abortion providers¹⁸⁶ and to perform abortions in cases of medical emergency, obstetricians often do not in practice.¹⁸⁷ Given protections for physicians to refuse care based on moral or religious objection, obstetricians might object to certain aspects of genetic counseling if they believe their patients will choose to end pregnancies as a result.

C. Scope and Purposes of Information for Patients

What women receive in the way of information before testing and before abortion significantly differ, in terms of both the amount of information and the purpose of conveying the information.

There is a dearth of rules and regulations about what women *must* learn about their pregnancies through testing. As with other medical interventions, the expectation is that counseling should be non-directive and physicians' duties should fall on the side of disclosure.¹⁸⁸ Although there are efforts to standardize counseling policies

182. TENN. CODE ANN. § 68-5-504(a)(1) (2011).

183. MO. REV. STAT. § 191.320 (2011).

184. OKLA. STAT. tit. 63, § 1-568 (2011).

185. AMERICAN CONG. OF OBSTETRICIANS & GYNECOLOGISTS COMM. ON ETHICS, COMMITTEE OPINION: INFORMED CONSENT 7 (2009), available at <http://www.acog.org/~media/Committee%20Opinions/Committee%20on%20Ethics/co439.ashx?dmc=1&ts=20111227T1327130008>.

186. *Id.*

187. See Huseina Sulaimanee, *Protecting the Right to Choose: Regulating Conscience Clauses in the Face of Moral Obligation*, 17 CARDOZO J. L. & GENDER 417, 425 (2011).

188. See American Medical Ass'n, *Opinion 8.082: Withholding Information from Patients*, in CODE OF MEDICAL ETHICS: CURRENT OPINIONS WITH ANNOTATIONS 253-54 (2008-09).

across the states, health insurance rules are perhaps the most significant influence on health professionals' behavior.¹⁸⁹ Laws do not require what women must know when deciding whether to screen or test. And pregnant women can learn a great deal about their future children. Whole gene sequencing promises to introduce parents to genetic information that not only predicts conditions like diabetes or mental illness but also reveals non-medical traits, such as eye color.¹⁹⁰

A common complaint is that obstetricians do not communicate enough information about the risks and benefits of knowing testing results or the nature of the disorder at issue. Indeed, patients appear to have limited knowledge about the risks and benefits of prenatal genetic testing and screening.¹⁹¹ There are, of course, limitations on what health professionals can reasonably know about a fetus from testing. Occurrence of a disorder may depend on a series of genetic interactions and environmental factors that determine whether and to what extent a condition manifests. Epigenetic factors, controlled by other genes and environmental influences, determine whether genes turn on or off.¹⁹² It seems unlikely and perhaps unrealistic that obstetricians or genetic counselors could convey all the potential variations and possibilities about a child's future phenotype.¹⁹³ The problem of ambiguous testing results may become more acute as parents are able to learn genetic information that has unknown significance or genetic information that will affect a child later in life, such as carrying a recessive gene or a gene associated with late onset disorders like Huntington's disease.¹⁹⁴ The response to the confusion or anxiety resulting from testing, now and with future advances, is to call for clear and full communication of evidence-based information to patients.¹⁹⁵

189. If testing becomes an everyday occurrence, health professionals may view counseling as a normal practice that does not require special training. Professor Jaime King cites a study of obstetricians' views on informed consent and non-invasive testing, which found that health care professionals are less likely to believe informed consent is as important for non-invasive testing as it is for amniocentesis or CVS. King, *supra* note 44, at 31.

190. Donley et al., *supra* note 31, at 4-5.

191. Studies suggest that patients generally confuse prenatal genetic testing and screening, and that their knowledge related to prenatal genetic testing and screening typically comes from friends or media. Vigdis Stefansdottir et al., *Effects of Knowledge, Education, and Experience on Acceptance of First Trimester Screening for Chromosomal Anomalies*, 89 ACTA OBSTETRICIA ET GYNECOLOGICA 931, 934, 936 (2010).

192. *Id.*

193. Chachkin, *supra* note 41, at 23-24.

194. Donley et al., *supra* note 31, at 4-5 (describing the information that whole genome sequencing can provide).

195. *Id.* at 7; *see also* Asch, *supra* note 134, at 340.

If states and the federal government have been largely absent in regulating information about testing, the opposite is true for abortion. As indicated in Part II, almost all states require communication about fetal development. Some states require that patients see pictures and renderings of fetuses at the various stages of development regardless of the point of gestation.¹⁹⁶ A handful of states mandate that women be told that fetuses might feel pain after a certain point in gestation.¹⁹⁷

Mandatory ultrasound laws illustrate the level to which states control what patients seeking terminations should or must know.¹⁹⁸ Nine states require providers to offer patients the opportunity to view ultrasound images if an ultrasound would have already been conducted, and six states mandate that physicians give all patients opportunities to view ultrasound images regardless of whether the physician would typically conduct an ultrasound.¹⁹⁹ North Carolina, Oklahoma, and Texas have extreme iterations of these ultrasound laws.²⁰⁰ The Oklahoma law, which a court has temporarily enjoined, mandates that physicians provide all women seeking abortion ultrasound images to view regardless of the patient's wishes. Likewise, Texas' and North Carolina's statutes require physicians to display and describe the sonograms of women seeking abortions, as well as play the sound of the fetal heartbeat, even if women ask not to see the images.²⁰¹ The

196. See, e.g., IDAHO CODE ANN. § 18-609(2) (2012). Ian Vandewalker highlights that laws such as the Louisiana informed consent statute require patients undergoing early term abortions to view images of fetuses in the third trimester, without explanation of the difference between third and first trimester images. Vandewalker, *supra* note 109.

197. See, e.g., IND. CODE § 16-34-2-1.1(a)(1)(G) (2011), *enjoined by* Planned Parenthood of Ind. v. Comm'r of Ind. State Dep't of Health, 794 F. Supp. 2d 892 (S.D. Ind. 2011) (holding that disclosing the likelihood of fetal pain offends the First Amendment rights of health professionals who only perform pre-viability abortions, and thus before fetuses can supposedly feel pain); MO. REV. STAT. 188.027(1)(5) (2011).

198. See Carol Sanger, *Seeing Is Believing: Mandatory Ultrasound & the Path to Protected Choice*, 56 UCLA L. REV. 351, 376 (2008).

199. GUTTMACHER INST., STATE POLICIES IN BRIEF: REQUIREMENTS FOR ULTRASOUND (2012), available at http://www.guttmacher.org/statecenter/spibs/spib_RFU.pdf (last visited Jan. 2012).

200. OKLA. STAT. tit. 63, § 1-738.3d(B) (2012) (stating that, at least one hour prior to abortion, a qualified medical professional shall describe the ultrasound image of the fetus, including a description of visible body parts and organs); H.R. 854, 2011 Leg., 405th Sess. (N.C. 2011) (providing that twenty-four hours prior to abortion, a qualified medical professional must personally or by telephone offer the patient an opportunity to view an ultrasound image of the fetus and listen to the heartbeat); H.R. 15, 82d Leg., 1st Spec. Sess. (Tex. 2011) (requiring, prior to an abortion, that a medical professional perform a sonogram, allow the patient to hear the heartbeat, and describe the sonogram to the patient).

201. Press Release, Ctr. for Reprod. Rts., Federal Judge Rejects Key Provisions of Texas Anti-Abortion Law (Aug. 30, 2011), <http://reproductiverights.org/en/press-room/federal-judge-rejects-key-provisions-of-texas-anti-abortion-law>:

North Carolina ultrasound law, for example, makes no exception for women who are victims of rape or incest.²⁰² Interestingly, in these three states, a woman could refuse an ultrasound for screening purposes, but not in the abortion context.

As noted, much of the informed consent standards for abortion communicate information about abortion's harmful effects on pregnant women. For example, most states mandate that patients receive information about the health risks of abortion, and a handful of states require communication of dubious long-term effects like breast cancer²⁰³ or suicidal tendencies²⁰⁴ or infertility.²⁰⁵ Many of these laws require health professionals to inform women of the mental health or psychological problems they may suffer, such as depression, anxiety, and eating disorders, following abortion.²⁰⁶ West Virginia, for example, requires practitioners to advise women that they may suffer from post-traumatic stress syndrome.²⁰⁷

In *Casey*,²⁰⁸ the Supreme Court opened the door to these types of laws—laws that the Court in some instances held were biased or con-

[In August 2011,] U.S. District Judge Sam Sparks granted a preliminary injunction, ruling that doctors cannot be penalized if they violate the law's requirement that doctors show women seeking abortions their sonogram images, describe the images in detail, and play the sound of the fetal heartbeat if the women decline this information.

Id. However, the Fifth Circuit Court of Appeals recently lifted the injunction, holding that the district court erred in ruling that the physician-plaintiffs were likely to succeed in challenging the law's constitutionality. NPR, *Appeals Court Rules Texas May Enforce Abortion Law*, BOISE STATE PUB. RADIO (Jan. 10, 2011), <http://www.boisestatepublicradio.org/2012/01/10/appeals-court-rules-texas-may-enforce-abortion-law/>.

202. The Center for Reproductive Rights also won a temporary injunction against the North Carolina law. See Press Release, Ctr. for Reprod. Rts, *Federal Court Blocks Demeaning North Carolina Ultrasound Law* (Oct. 25, 2011), <http://reproductiverights.org/en/press-room/federal-court-blocks-demeaning-north-carolina-ultrasound-law>.

203. See, e.g., ALASKA DEP'T OF HEALTH & SOC. SERVS., *MAKING A DECISION ABOUT YOUR PREGNANCY: REFERENCES, STATE OF ALASKA HEALTH & SOCIAL SERVICES 6-7* (June 2010), <http://www.hss.state.ak.us/dph/wcfh/informedconsent/assets/References.pdf> (citing studies that support and negate the link between breast cancer and abortion).

204. However, the Eighth Circuit recently struck down a South Dakota law on First Amendment grounds for compelling physicians to discuss misleading risks of suicide. *Planned Parenthood Minn., v. Rounds*, 530 F.3d 724, 726, 733-37 (8th Cir. 2008).

205. See, e.g., WIS. STAT. ANN. § 253.10(3)(c)(1)(f) (West 2011).

206. See, e.g., Vandewalker, *supra* note 109, at 15 (citing laws in Michigan and West Virginia).

207. W. VA. DEP'T OF HEALTH & HUM. RES., *INFORMATION ON FETAL DEVELOPMENT, ABORTION & ADOPTION 15* (2003), available at <http://www.wvdhhr.org/wrtk/wrtkbooklet.pdf>.

208. *Planned Parenthood of Se. Pa. v. Casey*, 505 U.S. 833, 846 (1992). The Court held that states may limit abortion access so long as the state does not create an undue burden on the woman's choice to have an abortion, which, as applied, gives states much more discretion to restrict access to abortion and to extend protections for fetal life. See Linda J. Wharton et al., *Preserving the Core of Roe: Reflections on Planned Parenthood v. Casey*, 18 YALE J. L. & FEMINISM 317, 319-21 (2006).

veyed “irrelevant or inappropriate” information.²⁰⁹ In previous cases, the Court expressed skepticism of informed consent laws that were plainly anti-abortion.²¹⁰ In *Thornburgh v. ACOG*, the Court held that states may not try to dissuade women from abortion or substitute the legislator’s view of medically necessary information for the physician’s.²¹¹ Likewise, in *City of Akron v. Akron Center for Reproductive Health*, the Court struck down an informed consent law that related only negative side effects to patients.²¹² However, in *Casey*, the Court upheld an informed consent law that imposed a waiting period, described the risks to the procedure and the alternatives to abortion and conveyed the gestational age of the fetus.²¹³ The Supreme Court held that laws may express a preference for childbirth over abortion so long as the counseling requirement does not impose an undue burden on women’s decisions.²¹⁴ The Court reasoned that informed consent for abortion need not be treated similarly to other medical procedures.²¹⁵

Although *Casey* maintained that information must be “truthful, nonmisleading” and “calculated to inform the women’s free choice, not hinder,”²¹⁶ states have passed numerous laws that are arguably misleading and designed to hinder women’s free choice. Decisions on the constitutionality of such laws have varied in the lower courts. Laws communicating information about the development of the fetus appear to be consistent with *Casey*.²¹⁷ For example, in *Planned Parenthood of Minnesota v. Rounds*, the Eighth Circuit upheld a

209. Manian, *supra* note 108, at 254.

210. *Id.* at 253.

211. *Thornburgh v. Amer. Coll. of Obstetricians & Gynecologists*, 476 U.S. 747, 771-72 (1986) (striking down requirements for informed consent, record-keeping, and techniques designed to protect post-viability fetuses).

212. *City of Akron v. Akron Ctr. for Reprod. Health*, 462 U.S. 416, 452 (1983) (striking state hospitalization requirement for second trimester abortions).

213. 18 PA. CONS. STAT. § 3205 (2011).

214. Professor David Meyer has argued that *Casey* enacts a type of reasonableness requirement because, absent banning abortion altogether, the Court did not strike down state provisions that make abortion access logistically or financially difficult. David D. Meyer, *The Paradox of Family Privacy*, 53 VAND. L. REV. 527, 537-38 (2000).

215. *Planned Parenthood of Se. Pa. v. Casey*, 505 U.S. 833, 882-83 (1992); *see also* Manian, *supra* note 108, at 253; Pamela Laufer-Ukeles, *Reproductive Choices and Informed Consent: Fetal Interests, Women’s Identity and Relational Autonomy*, 37 AM. J.L. & MED. 567, 610-11 (2011) (indicating that abortion counseling departs from the liberal model of individual decision-making and is paternalistic as compared to other informed consent processes).

216. *Casey*, 505 U.S. at 882, 934. Courts have disagreed about the meaning of truthfulness in abortion informed consent laws. *See* Laufer-Ukeles, *supra* note 216, at 614 (contrasting cases in which courts found counseling information biased or not biased).

217. *See Casey*, 505 U.S. at 882.

South Dakota law that required providers to inform patients that they were about to terminate “the life of a whole separate, unique, living human being . . . , [and] that the pregnant woman has an existing relationship with that unborn human being.”²¹⁸

As in regulating the physician’s role, legislatures seek to reduce the information that a woman can learn through testing *only if* the results might lead to abortion. Oklahoma permits health care professionals to withhold information learned from sonogram about fetal conditions. The statute also prohibits parents from suing physicians in wrongful birth actions if the physician withheld information that may have encouraged the parents to terminate pregnancies.²¹⁹

This legislative example illustrates the different purposes of giving patients information in testing versus abortion. For testing, and as dictated by most informed consent standards, physicians generally must provide patients with enough information to weigh the risks and benefits of testing.²²⁰ However, in abortion, information may attempt to dissuade the woman from the termination or to express the state’s animus toward abortion.

In theory, testing for genetic disorders should be accompanied with information that is tailored to the patient and her particular needs. In practice, there is wide variation in how communication between the patient and health professional takes place. However, if a woman elects abortion after testing, she will encounter a system with different goals and a different approach: counseling of and information to women is not contextual or individualized. Informed consent rules for abortion treat all patients the same.²²¹ Scott Woodcock, in advocating a more nuanced, contextualized approach to abortion counseling, notes that “there is no single, uniform ‘pregnant woman’ perspective to which we can appeal in order to set a fixed policy that

218. *Planned Parenthood Minn. v. Rounds*, 530 F.3d 724, 726 (8th Cir. 2008). *But see Doe v. Planned Parenthood Chicago Area*, 956 N.E.2d 564, 572 (Ill. App. Ct. 2011) (holding that physicians have no common law duty to inform patients that abortion “kills” a human being); *Acuna v. Turkish*, 930 A.2d 416, 428 (N.J. 2007) (holding that a physician is not liable for failing to disclose that a fetus is a “complete, separate, unique and irreplaceable human being”).

219. OKLA. STAT. ANN. tit. 63, § 1-738.2 (West 2011); OKLA. STAT. ANN. tit. 63, § 1-741.12 (West 2011). The Arizona Senate has recently passed a similar bill. Assoc. Press, *Senate Approves Bill on ‘Wrongful Births’*, AZ. CAP. TIMES, Mar. 6, 2012, available at <http://azcapitoltimes.com/news/2012/03/06/senate-approves-bill-on-wrongful-births/>.

220. King, *supra* note 44, at 30-31.

221. Scott Woodcock, *Abortion Counseling & the Informed Consent Dilemma*, 25 *BIOETHICS* 495, 502-03 (2010) (“The best strategy is instead to provide the education, time and background training necessary to connect meaningfully with each patient and to help her to make an appropriately informed decision.”).

will facilitate the autonomous decision-making of patients considering abortion.”²²² The next section explores what the current approach suggests about pregnant women’s judgment and ability to make decisions.

D. Pregnant Women and Decision-Making

At the heart of testing and abortion are deeply engrained perceptions about women’s roles as decision-makers and women’s attitudes toward their pregnancy options. The responsible pregnant woman wants information about her pregnancy. Yet, the law expects women as patients to make independent decisions about testing, but not abortion. As the last section demonstrated, in abortion, laws detail what women should know and how their decisions should be made. In testing, there is very little regulation of what decisions women can make before and after testing, although women may feel intense social pressure to test and to uncover potential problems with their pregnancies.

Several studies document the anxiety pregnant women can feel after learning test results. And, indeed, many women express uncertainty about whether or not to screen (and then to test) in the first place. For example, research shows that a positive screen causes some women to decline screening in subsequent pregnancies, and women express varying levels of anxiety between learning results and genetic counseling appointments.²²³ Another study showed that women are uncertain about the risks and benefits of screening, which are “layered on to more general baseline concerns” about their pregnancies.²²⁴ Some women do not elect screening or testing if they would not terminate the pregnancy.²²⁵ This suggests that women begin conversations about screening by discussing “downstream options:” the choice of potentially ending a pregnancy is “an ethical part of the whole decision about whether or not to take any of these tests.”²²⁶ Increased screening or testing may not necessarily correspond with higher abortion rates.²²⁷

222. *Id.* at 499 (noting the powerful social influences on women to bear and care for children).

223. Czerwinski et al., *supra* note 23, at 280.

224. Farrell et al., *supra* note 13, at 4.

225. *See* Norton, *supra* note 23, at 158.

226. Farrell et al., *supra* note 13, at 5 (citing the statement of a study participant).

227. Driscoll et al., *supra* note 174, at 459.e4. *But see* Benn & Chapman, *supra* note 36, at 131 (describing the role of non-invasive testing as potentially resulting in increased abortion).

Thus, proposals in the testing context seek to manage anxiety in ways that will differ for each woman. But anxiety in abortion decisions invites states to regulate decision-making more closely—to “protect” women from the psychological consequences of abortion. For example, in *Carhart*, the Court held that there was a legitimate state interest in protecting the emotional health of women who may come to regret their decision.²²⁸ In making this assumption, the Court opined that some women inevitably regret their decisions: “[w]hile we find no reliable data to measure the phenomenon, it seems unexceptionable to conclude that some women come to regret their choice to abort the infant life they once created and sustained.”²²⁹

Policy following the introduction of non-invasive prenatal genetic testing could reflect the concern that women receiving genetic test results are in difficult decisional spaces and need more information about their pregnancies. Professor Samuel Bagenstos has written about how the jurisprudence on informed consent for abortion could be the place where states seek to limit any social pressures women may feel to abort after learning test results.²³⁰ States could also try to limit women’s access to particular genetic information until after viability. For example, states might restrict a woman’s reasons for abortion, particularly for terminations based on non-medically relevant fetal traits.²³¹ Pennsylvania and Illinois already forbid sex selective abortion, and Arizona and Oklahoma recently passed laws restricting abortion because of the sex (and, in Arizona, race) of the fetus.²³²

228. Suter, *Carhart*, *supra* note 10, at 1576-77.

229. *Gonzalez v. Carhart*, 550 U.S. 124, 159 (2007); *cf. id.* at 183 n.7 (Ginsburg, J., dissenting) (stating that while abortion may be a “painfully difficult decision,” having an abortion is no more harmful in the long run than having a child). In a recent Nebraska case, a federal district court found that a law creating substantial penalties for physicians who did not comply with onerous, “impossible to meet” rules *presumes* women will experience regret. *Planned Parenthood of the Heartland v. Heineman*, 724 F. Supp. 2d 1025, 1045 (D. Neb. 2010) (“[The law] provides the remorseful woman and her lawyer with a very substantial financial incentive to initiate such litigation, whether or not she truly does regret her decision to obtain an abortion—her regret is *presumed*.”). *But see* *Planned Parenthood of Middle Tenn. v. Sundquist*, 38 S.W.3d 1, 23 (Tenn. 2000) (noting that expert opinion suggests women that “seriously contemplated their [abortion] decision before making their appointment”).

230. Bagenstos, *supra* note 18, at 452.

231. Suter, *Carhart*, *supra* note 10, at 1516-17.

232. 720 ILL. COMP. STAT. ANN. 510/6-(8) (West 2011); OKLA. STAT. tit. 63, § 1-731.2(b) (2011); H.B. 2443, 50th Leg., 1st Reg. Sess. (Ariz. 2011); 18 PA. CONS. STAT. ANN. § 3204(c) (West 2000) (“No abortion which is sought solely because of the sex of the unborn child shall be deemed a necessary abortion.”); *see also* Sunita Puri, “I Know It’s a Girl and I Need Your Help to Get It Out of Me,” SLATE (Aug. 2, 2011, 2:39 PM), http://www.slate.com/articles/double_x/doublex/2011/08/i_know_its_a_girl_and_i_need_your_help_to_get_it_out_of_me.html (discussing providers’ conflicts with patients over sex selection).

Laws banning sex selective abortion raise questions as to what are permissible restrictions on a woman's reasons for abortion, especially before viability. Could a state forbid abortion based on genetic information that is medically relevant, but does not put the mother's physical health or life at risk?²³³ Or, could states prohibit terminations based on genetic information about late onset disorders, such as Alzheimer's disease?²³⁴

These questions would be difficult for anyone to answer without baseline principles to help navigate the ethical complexities of abortion and testing. And the United States is not alone in mulling out these debates.²³⁵ For example, the Council of Europe issued a Recommendation on Prenatal Genetic Screening, Prenatal Genetic Diagnosis, and Associated Genetic Counseling that sets out standards for non-directive counseling for all options prior and after testing, including abortion; the central role of the physician in carrying out screening and testing "adapted to the person's circumstances"; and testing focused on the detection of serious risk. Likewise, the International Federation of Gynecology and Obstetrics (FIGO) frames abortion as a health care choice after testing, urging that terminations "must be offered" if a woman submits to testing which uncovers "a severe untreatable fetal disease or malformation."²³⁶

More recently, the European Court of Human Rights (ECtHR) highlighted the approach of the Recommendation and FIGO in the 2011 case, *R.R. v. Poland*.²³⁷ In *R.R. v. Poland*, the ECtHR held that Poland was in violation of the European Convention on Human Rights for denying a woman prenatal genetic testing, which would

233. See Suter, *Prenatal Testing*, *supra* note 15, at 255-56.

234. *Id.* at 266.

235. Greely, *supra* note 7, at 291 (noting consortiums organized by the European Union and foundations in the United Kingdom have been studying the medical and ethical issues of non-invasive testing for years). There also appears to be growing international consensus on serious fetal anomaly as a ground for abortion. See Christina Zampas & Jamie M. Gher, *Abortion as a Human Right—International and Regional Standards*, 8 HUM. RTS. L. REV. 249, 284-86 (2008). For example, the African Protocol on the Rights of Women to African Charter explicitly supports women's right to abortion if "the continued pregnancy endangers the . . . life of . . . the foetus." *Id.* at 250, 286 (citing Article 14.2(c) of the Protocol).

236. FED'N OF GYNECOLOGY & OBSTETRICS COMM. FOR THE STUDY OF ETHICAL ASPECTS ON HUMAN REPROD., RECOMMENDATIONS ON ETHICAL ISSUES IN OBSTETRICS AND GYNECOLOGY 76 (2009), available at <http://www.figo.org/files/figo-corp/Ethical%20Issues%20-%20English.pdf>. FIGO is currently composed of 124 professional societies of obstetricians and gynecologists worldwide, including ACOG. FIGO recognizes that many countries do not allow abortion on request but recognize a legal ground for fetal malformation or disorder. *About FIGO*, FIGO, <http://www.figo.org/about> (last visited Mar. 20, 2012).

237. *R.R. v. Poland*, 27617/04 Eur. Ct. H.R. at 12-13, 20 (2011), available at <http://cmiskp.echr.coe.int/tkp197/search.asp?skin=hudoc-en>.

have allowed her to decide whether or not to seek a legal abortion.²³⁸ The ECtHR noted that non-directive genetic counseling should leave the woman free to make her own decision.²³⁹ Moreover, the ECtHR held that testing should be “made as widely available as possible,” and abortion decisions should be “discouraged only if the disorder is treatable and will not necessarily affect the future quality of life.”²⁴⁰ *RR v. Poland* illustrates an approach concerned with the effects of having the child on the woman and her family, as well as the ethical questions of the conditions under which to terminate a pregnancy.²⁴¹ The decision is not necessarily pro-abortion or pro-testing; rather, it attempts to facilitate decision-making suited to the individual’s needs, guided by respect for women, parents, and potential life.

By contrast, there has been no concerted effort in the United States to wrestle with these questions, despite calls for guidance from federal agencies and professional organizations.²⁴² Almost forty years after *Roe* was decided, there are few guideposts or standards in this country to weigh these competing and mixed messages.

CONCLUSION

This Article began by noting that a catalyst for change in U.S. abortion law was the health needs of women who discovered problems with their pregnancies. It is critical to women’s health and well-being that abortion is part of a continuum of health care. Increased prenatal testing should be accompanied by policies that recognize abortion as a medical option for some women. Without a robust dialogue about the mixed messages at the intersection of abortion and testing, the current stigma and opposition to abortion may dominate

238. See *id.* at 5, 33. Polish law provided, “[t]he State and local administration shall ensure unimpeded access to prenatal information and testing, in particular in cases of increased risk or suspicion of a genetic disorder or development problem or of an incurable life-threatening ailment.” 1993 Family Planning (Protection of the Human Foetus & Conditions Permitting Pregnancy Termination) Act, Official Journal of the Republic of Poland no. 17, item 78, § 2(a) (1993). A physician working in a hospital may perform an abortion pre-viability where “[p]renatal tests or other medical findings indicate a high risk that the fetus will be severely and irreversibly damaged or suffering [sic] from an incurable life-threatening ailment.” *Id.* § 4(a).

239. Comm. of Ministers of the Council of Europe, *Recommendation No. R (90) 13 on Prenatal Genetic Screening, Prenatal Genetic Diagnosis & Associated Genetic Counseling*, 41 INT’L DIG. OF HEALTH LEGIS. 615 (1990).

240. Int’l Fed’n of Gynecology & Obstetrics Ethics Comm., *Ethical Aspects of Termination of Pregnancy Following Prenatal Diagnosis*, 39 INT’L J. GYNECOLOGY & OBSTETRICS 1, 1-2 (1992).

241. *Id.*

242. Benn & Chapman, *supra* note 36, at 130.

the national conversation. Indeed, former presidential candidate, Rick Santorum, recently promoted his anti-abortion beliefs by arguing that the ACA, in providing funding for prenatal genetic screening and testing, “ends up in more abortions.”²⁴³ But the conversation cannot and should not be that conclusive. Law and practice need to conceptualize testing and abortion as interconnected health care choices that implicate complex and contextual considerations for pregnant women.

243. Rebecca Kaplan, *Santorum Attacks Obama on Prenatal Screening*, CBSNEWS (Feb. 18, 2012), http://www.cbsnews.com/8301-503544_162-57380887-503544/santorum-attacks-obama-on-prenatal-screening/?tag=contentMain;contentBody.

NOTE

Defending Access to Community-Based Services for Individuals with Developmental Disabilities in the Wake of the “Great Recession”

SHARAYA L. CABANSAG*

INTRODUCTION

Mr. N. works four days a week at Rubios Mexican Seafood Restaurant where he has worked for over fifteen years. After work, he eats lunch and spends time with his friends at the mall. One day out of the week, he travels to the beach, mall, coffee shops, or parks all over the community using the San Diego trolley and bus system. He often spends his days off volunteering with friends, organizing items at a non-profit thrift store. Mr. N. is also an individual with intellectual and developmental disabilities. As a result, he experiences hallucinations and does not communicate verbally. Through a community-based employment program, he manages these disabilities and participates in his community.

In *Olmstead v. L.C.*, the Supreme Court held that “institutional isolation is discriminatory and illegal” under the Americans with Disabilities Act (“ADA”).¹ The Court specifically held that states are re-

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1. KAISER COMM’N ON MEDICAID AND THE UNINSURED, *OLMSTEAD v. L.C.: THE INTERACTION OF THE AMERICANS WITH DISABILITIES ACT AND MEDICAID 5* (2004) [hereinafter *MEDICAID*], available at <http://www.kff.org/medicaid/7096a.cfm>.

quired to place qualified² persons with disabilities “in community settings rather than in institutions.”³ This placement depends on the resources available to the state, including not only the costs of community-based treatment,⁴ “but also the range of services the State provides others with mental disabilities.”⁵ The Court relied on Title II of the ADA stating, “no qualified individual with a disability, shall, ‘by reason of such disability,’ be excluded from participation in, or be denied the benefits of, a public entity’s services, programs, or activities.”⁶ The Court also reiterated that “isolation and segregation of individuals with disabilities” is a “serious and pervasive form of discrimination.”⁷

As of 2009, over a decade after the *Olmstead* decision, there are almost a quarter of a million eligible individuals with developmental and intellectual disabilities on waitlists for home and community-based services.⁸ These individuals are openly denied their right to community- and employment-based services by states in violation of the ADA Title II Integration Clause.⁹ Many of these individuals “could live in the community, with the proper long-term services and supports, but are segregated in an institution as their only option.”¹⁰

This Note proposes that addressing the fiscal vulnerability of community-based services and exposing discrimination within mental

2. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 597 (1999).

3. *Id.* at 587.

4. Home and Community-Based Services include (but are not limited to): “personal care assistance, home health care, skilled nursing care, homemaker service, home-delivered meals, behavioral supports, habilitation, transportation, case management, rehabilitation, supported employment, and congregate housing.” Sara Galantowicz, *Medicaid Home and Community-Based Services Measure Scan: Project Methodology*, AGENCY FOR HEALTHCARE RES. AND QUALITY (May 2007), <http://www.ahrq.gov/research/ltc/hcbsmethods.htm#background>.

5. *Olmstead*, 527 U.S. at 597.

6. 42 U.S.C. § 12132 (2006).

7. *Olmstead*, 527 U.S. at 581, 602 (“‘Qualified individuals,’ the ADA further explains, are persons with disabilities who ‘with or without reasonable modifications to rules, policies, or practices, . . . mee[t] the essential eligibility requirements for the receipt of services or the participation in programs or activities provided by a public entity.’”).

8. DAVID BRADDOCK ET AL., *THE STATE OF THE STATES IN DEVELOPMENTAL DISABILITIES 2011*, at 64 (2011) (“In 2009, 35 states reported that 99,870 persons with I/DD [intellectual and developmental disabilities] were on formal state waiting lists for residential services . . . [and an estimated] 122,870 persons with I/DD nationally.”); KAISER COMM’N ON MEDICAID AND THE UNINSURED, *MEDICAID HOME AND COMMUNITY-BASED SERVICE PROGRAMS: DATA UPDATE 2-3 (2011)* [hereinafter HCBS PROGRAMS], available at <http://www.kff.org/medicaid/upload/7720-04.pdf> (“In 2009, 39 states reported waiver wait lists totaling 365,553 individuals.”).

9. See generally Department of Justice, *Participation by the United States in Olmstead Cases*, ADA (Jan. 26, 2012), http://www.ada.gov/olmstead/olmstead_cases_list2.htm#usparty (showing that current Department of Justice *Olmstead* litigation and findings letters reveal a proliferation of state violations).

10. MEDICAID, *supra* note 1, at 5.

Defending Access to Community-Based Services for Individuals

health jurisprudence is necessary to address the barriers preventing qualified individuals with disabilities from receiving services. There is a wide range of scholarship analyzing the right to and costs of community-based care.¹¹ However, there is a lack of discussion addressing the systemic barriers to receiving community-based services in the context of the current budgetary crisis.

Part I discusses the history behind the legal treatment of persons with developmental and intellectual disabilities, including a discussion incorporating the evolution of institutional segregation, Section 504 of the Rehabilitation Act of 1973, the ADA, and *Olmstead v. L.C.* Part II summarizes the costs and rights-based scholarship on community services for individuals with disabilities. Part III analyzes the barriers preventing individuals with disabilities from receiving community-based services including: political and fiscal barriers to integration; an institutional bias inherent in the Medicaid system; legal barriers to *Olmstead* enforcement; and discriminatory attitudes towards individuals with disabilities. Part IV proposes a multifaceted approach to addressing these difficulties, including measures addressing budget cuts to community services and a judicial overhaul exposing discrimination within mental health jurisprudence.

I. HISTORY

A. Institutional Segregation of Individuals with Developmental Disabilities

Institutional segregation is deeply rooted in the history of discrimination toward persons with developmental and intellectual disabilities.¹² Individuals with disabilities were historically confined to

11. See Lucille D. Wood, Note, *Costs and the Right to Community-Based Treatment*, 16 YALE L. & POL'Y REV. 501, 502 (1998) (describing the role of cost analyses in judicial opinions). See generally Stacy E. Seicshnaydre, Comment, *Community Mental Health Treatment for the Mentally Ill—When Does Less Restrictive Treatment Become a Right?*, 66 TUL. L. REV. 1971 (1992) (describing the substantive due process right to treatment in the community); Jefferson D.E. Smith & Steve P. Calandrillo, *Forward to Fundamental Alteration: Addressing ADA Title II Integration Lawsuits After Olmstead v. L.C.*, 24 HARV. J.L. & PUB. POL'Y 695 (2001) (surveying judicial interpretations of the *Olmstead* language “unreasonable modifications” and “fundamental alterations” in the context of the right to community care); Mark C. Weber, *Home and Community-Based Services, Olmstead, and Positive Rights: A Preliminary Discussion*, 39 WAKE FOREST L. REV. 269 (2004) (discussing the positive right to community-based services in light of the ADA’s “statutory equality mandate”).

12. See 42 U.S.C. § 12101(a)(2) (2006) (“[H]istorically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem.”).

almshouses, asylums, and hospitals.¹³ In the 1845 case, *Matter of Josiah Oakes*, an individual committed to a Massachusetts institution for the “insane” challenged the legality of his commitment.¹⁴ The court considered the issue of whether the safety of the patient, or others, justified “restraint . . . necessary for his restoration.”¹⁵ The court reasoned that “the right to restrain an insane person of his liberty is found in that great law of humanity, which makes it necessary to confine those whose going at large would be dangerous to themselves or others.”¹⁶ On this basis, the court determined that “[t]he restraint can continue as long as the necessity continues . . . [t]his is the limitation, and the proper limitation.”¹⁷ This American approach toward individuals with disabilities often led to a “total, and perhaps permanent, loss of liberty.”¹⁸

The Eugenics and Social Darwinist movements resulted in the practice of mass sterilization of persons with disabilities, a practice upheld by the Supreme Court in *Buck v. Bell*.¹⁹ In *Buck*, the superintendent of the “State Colony for Epileptics and Feeble Minded” was ordered to sterilize Carrie Buck, an eighteen-year-old developmentally disabled woman, whose mother and child were also disabled.²⁰ The court upheld the forced sterilization, reasoning that individuals with disabilities were a “menace” to society and if these individuals were sterilized, they “might be discharged with safety and become self-supporting”²¹ In the words of the Supreme Court:

It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind. The principle that sustains compulsory

13. Weber, *supra* note 11, at 273.

14. *Lessard v. Schmidt*, 349 F. Supp. 1078, 1085 (E.D. Wis. 1972) (citing *Matter of Josiah Oakes*, 8 Law Rep. 123 (Mass. 1845)).

15. *Id.*

16. *Id.*

17. *Id.*

18. *Id.* By contrast, in the English approach, actions were taken solely “for the benefit and protection of the incompetent.” *Id.* In relevant part:

A person found to be a lunatic was committed to the care of a friend who received an allowance with which to care for the unfortunate person. During “lucid moments” the incompetent was permitted to manage his own property, and to generally exercise his civil rights. He was also entitled to an accounting from the King.

Id.

19. See generally *Buck v. Bell*, 274 U.S. 200 (1927) (affirming the order to perform the operation of salpingectomy upon the plaintiff).

20. *Id.*

21. *Id.* at 205-06.

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vaccination is broad enough to cover cutting the Fallopian tubes.

Three generations of imbeciles are enough.²²

In *Buck*, the Supreme Court articulated sanist²³ attitudes towards the disabled: beliefs fed by fear, misinformation, and ignorance that actively perpetuate discrimination and segregation of individuals with disabilities today.²⁴

The mass institutionalization of individuals with developmental disabilities resulted in severe harms including lack of safety,²⁵ loss of freedom,²⁶ lack of legal protections,²⁷ and inadequate options for home-based care.²⁸ By 1961, only thirty-seven jurisdictions provided any judicial procedures to govern involuntary hospitalization.²⁹ The National Institute of Mental Health's Draft Act Governing Hospitalization of the Mentally Ill attempted to standardize the language of civil commitment statutes to two main grounds on which civil commitment might be ordered: "(1) the likelihood that the individual will injure himself or others if he is not confined, and (2) the need of

22. *Id.* at 207.

23. See Michael L. Perlin, "Their Promises of Paradise": *Will Olmstead v. L.C. Resuscitate the Constitutional "Least Restrictive Alternative" Principle in Mental Disability Law?*, 37 *Hous. L. Rev.* 999, 1046 (2000) ("[Defining 'sanism' as] an irrational prejudice of the same quality and character of other irrational prejudices that cause, and are reflected in, prevailing social attitudes of racism, sexism, homophobia and ethnic bigotry.").

24. These attitudes also pervade mental disability jurisprudence. As Perlin explains:

The entire legal system makes assumptions about persons with mental disabilities—who they are, how they got that way, what makes them different, what there is about them that lets us treat them differently, and whether their conditions are immutable.

MICHAEL L. PERLIN, *THE HIDDEN PREJUDICE: MENTAL DISABILITY ON TRIAL* 23 (2000) [hereinafter *PREJUDICE*]; see also discussion *infra* Part III.D.

25. See Weber, *supra* note 11, at 275.

26. See *id.* at 276. This includes a "[l]ack of privacy, autonomy, and opportunity for individual development . . ." *Id.* Further, persons confined to state facilities "sleep in large, overcrowded wards, spend their waking hours together in large day rooms and eat in a large group setting. They must conform to the schedule of the institution which allows for no individual flexibility." *Id.* at 277 (internal quotes omitted); see also Perlin, *supra* note 23, at 1007 ("[C]ommitment could be effected with 'the greatest of ease,' and there were no specific legislative safeguards to protect the personal liberty of the supposedly mentally ill person . . .").

27. See Weber, *supra* note 11, at 277 ("Many courts continue to deny any constitutional right to safety and habilitation when an individual is voluntarily rather than civilly committed."); see also *Fialkowski v. Greenwich Home for Children, Inc.*, 921 F.2d 459, 465 (3d Cir. 1990) (holding that there was no due process violation by reasoning that the mentally-retarded man that choked to death on a peanut butter sandwich had been voluntarily committed); Perlin, *supra* note 23, at 1005-06. Perlin discusses the mode of commitment at a Pennsylvania facility as:

[S]o easy and free from formality that a few words hastily scribbled upon a chance scrap of paper were sufficient to place a supposed insane person in the Hospital Once in his cells, or quarters for the insane, the patient had no appeal from the opinion of the attending physician.

Id.

28. Weber, *supra* note 11, at 278.

29. Perlin, *supra* note 23, at 1009.

hospitalization and lack of sufficient insight or capacity to make responsible decisions with respect to the question of hospitalization.”³⁰ This Act sparked revisions in commitment statutes throughout the “late 1950s and 1960s reflecting ‘a trend toward restricting involuntary civil commitment to the dangerous mentally ill and toward limiting the type and increasing the severity of harm necessary to support a finding of dangerousness.’”³¹

B. Section 504 of the Rehabilitation Act of 1973

Section 504 of the Rehabilitation Act of 1973 was the first federal statute addressing discrimination towards individuals with disabilities.³² The Act was hailed as the “civil rights bill of the disabled.”³³ The relevant language provides: “No otherwise qualified individual with a disability in the United States . . . shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance”³⁴ Despite these high hopes, judicial interpretations of the Act quickly revealed shortcomings and deficiencies.³⁵

The judicial interpretation of Section 504 that “federal courts cannot enforce section 504 . . . against a state agency” led to the appalling endorsement of discriminatory practices by the states.³⁶ In *Southeastern Community College v. Davis*, the Court held that Section 504 imposed no requirement for Southeastern’s Nursing Program to accommodate a hearing-impaired applicant because her admission would lower or substantially modify the standards of the program.³⁷ In *Alexander v. Choate*, the Court held that a Tennessee state action,

30. *Id.* at 1010.

31. *Id.*

32. Rehabilitation Act of 1973, 29 U.S.C. § 794(a) (2006); *Helen L. v. DiDario*, 46 F.3d 325, 330 (3d Cir. 1995).

33. *Id.*

34. 29 U.S.C. § 794 (2006).

35. See Robert L. Burgdorf, Jr., *The Americans with Disabilities Act: Analysis and Implications of A Second-Generation Civil Rights Statute*, 26 HARV. C.R.-C.L. L. REV. 413, 430-31 (1991) (“Experience with the application of . . . section 504 of the Rehabilitation Act of 1973, uncovered or highlighted weaknesses of such laws arising from their statutory language, the limited extent of their coverage, inadequate enforcement mechanisms, and erratic judicial interpretations.”); Timothy M. Cook, *The Americans with Disabilities Act: The Move to Integration*, 64 TEMP. L. REV. 393, 394 (1991) (“As a remedy for segregated public services, the Rehabilitation Act and its regulations have been practically a dead letter.”).

36. Cook, *supra* note 35, at 395.

37. *Se. Cmty. Coll. v. Davis*, 442 U.S. 397, 413 (1979).

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reducing Medicaid coverage of inpatient hospital days from twenty to fourteen days, was not discriminatory under Section 504.³⁸ In *Society for Good Will to Retarded Children, Inc. v. Cuomo*, the court denied the petitioner community placement³⁹ despite findings of “conditions of filth . . . flea and cockroach infestations . . . rodent infestation . . . and . . . diseases such as shigella and hepatitis.”⁴⁰

The Developmentally Disabled Assistance and Bill of Rights Act of 1975 was another futile effort to provide individuals with developmental disabilities “the right to receive appropriate treatment, services, and habilitation in a setting that is least restrictive of [their] personal liberty.”⁴¹ Despite high hopes for the “Bill of Rights,” the Supreme Court eviscerated the Act in *Pennhurst State School & Hospital v. Halderman* when it held that “nothing in the Act or its legislative history . . . suggest[s] that Congress intended to require the States to assume the high cost of providing ‘appropriate treatment’ in the ‘least restrictive environment’ to their mentally retarded citizens.”⁴² In combination, Section 504 and the Developmentally Disabled Assistance and Bill of Rights Act laid the groundwork for disability civil rights; nevertheless, often due to judicial interpretation of the statutes,⁴³ this legislation failed as enforcement mechanisms against discrimination and segregation.⁴⁴

38. *Alexander v. Choate*, 469 U.S. 287, 302 (1985). In relevant part, the Court stated: [I]t cannot be argued that “meaningful access” to state Medicaid services will be denied by the 14-day limitation on inpatient coverage; nothing in the record suggests that the handicapped in Tennessee will be unable to benefit meaningfully from the coverage they will receive under the 14-day rule. The reduction in inpatient coverage will leave both handicapped and nonhandicapped Medicaid users with identical and effective hospital services fully available for their use, with both classes of users subject to the same durational limitation.

Id.

39. *Soc’y for Good Will to Retarded Children, Inc. v. Cuomo*, 737 F.2d 1239, 1249 (2d Cir. 1984).

40. *Id.* at 1244.

41. Cook, *supra* note 35, at 395 (quoting the Developmentally Disabled Assistance and Bill of Rights Act).

42. *Pennhurst State Sch. & Hosp. v. Halderman*, 451 U.S. 1, 18 (1981).

43. See Cook, *supra* note 35, at 396-97. As Cook describes:

Many of our section 504 and constitutional desegregation claims have been denied by judges who are simply uninformed about what it is like to be a person with a disability; how important it is to our dignity and self-worth to be educated, and to work in community settings; how easily our disabilities can be accommodated; or the services we need provided in nonsegregated, regular settings.

44. See *id.* at 394. Cook argues:

[W]hat effect did these wondrous new regulations, published fourteen years ago as our salvation, have on the forty-three million persons with disabilities in this country? The answer is—very little. As a remedy for segregated public services, the Rehabilitation Act and its contemporaneously enacted regulation have been practically a dead letter.

Id.

C. The Americans with Disabilities Act

The Americans with Disabilities Act of 1990 was enacted in order “to strike at the whole range of problems that result from discrimination against individuals with disabilities, including unnecessary segregation.”⁴⁵ The ADA was enacted based on Congress’ findings that society has historically discriminated against individuals with disabilities “in such critical areas as employment, housing, public accommodations, education, transportation, communication, recreation, institutionalization, health services, voting, and access to public services.”⁴⁶ The Act “was intended to accord to individuals with disabilities the same protection against discrimination that the law provides to racial minorities.”⁴⁷ The ADA focused on integration as the key to combating prejudice against persons with developmental disabilities.⁴⁸ Finally, with respect to those with developmental disabilities, the ADA set the nation’s goals: “to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals.”⁴⁹

Central to the enforcement of the ADA is the Title II provision that prohibits discrimination on the basis of disability.⁵⁰ In order to enforce this anti-discrimination mandate, Title II provides that: “A public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.”⁵¹ Title II also incorporated Section 504, and case law developed under the Rehabilitation Act⁵² and also extended the scope of Section 504 to state and local governments.⁵³ As a whole, the

45. John Stark, Case Note, *A New Mandate for the Expansion of the Rights of the Mentally Ill: Olmstead v. Zimring and its Further Exposition of the Americans with Disabilities Act*, 4 T.M. COOLEY J. PRAC. & CLINICAL L. 83, 89 (2000).

46. 42 U.S.C. § 12101(a)(3) (2006).

47. Seicshnaydre, *supra* note 11, at 1992 (quoting 136 CONG. REC. 2421-02 (1990) (statement of Rep. Brooks)). Congress also recognized the key difference between discrimination on the basis of race, color, sex, national origin, religion, or age, and discrimination on the basis of disability, namely that “individuals with disabilities often had no legal recourse to redress such discrimination.” *See* 42 U.S.C. § 12101(a)(4) (2006).

48. *See* Seicshnaydre, *supra* note 11, at 1992.

49. 42 U.S.C. § 12101(a)(7).

50. 28 C.F.R. § 35.130(a) (2011). The provision mandates that: “No qualified individual with a disability shall, on the basis of disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any public entity.” *Id.*

51. *Id.* at § 35.130(d).

52. *See* Helen L. v. DiDario, 46 F.3d 325, 331 (3d Cir. 1995).

53. *See* 28 C.F.R. § 35.102 pmb1. (extending section 504’s coverage of federally assisted programs to all “services, programs, and activities” of state and local governments).

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ADA brought about decisive civil rights protections for individuals with disabilities who would otherwise face isolation and segregation.⁵⁴ Despite these gains, confusion about whether institutionalized individuals with disabilities have a right to community-based services paved the way for a decisive interpretation of the provision.⁵⁵

D. *Olmstead v. L.C.*

The Supreme Court first articulated a limited right to community-based treatment in *Olmstead v. L.C.*⁵⁶ In *Olmstead*, L.C. and E.W., two women with intellectual and developmental disabilities whose needs could be met appropriately in a community-based setting, challenged their continued confinement in a segregated, institutional environment as a violation of the ADA.⁵⁷ The Commissioner of the Georgia Department of Human Resources and others contended that L.C. and E.W. did not show discrimination on the basis of their disabilities and that providing community services in this case “would ‘fundamentally alter’ the State’s activity.”⁵⁸ The United States District Court for the Northern District of Georgia held that the failure of the State to place L.C. and E.W. in a community-based treatment program violated Title II of the ADA.⁵⁹ The court rejected the “fundamental alteration” defense reasoning that state programs existed that

54. MEDICAID, *supra* note 1, add. at 6. In relevant part, it states:

Civil rights laws help to ensure that individuals with disabilities are able to participate fully in all aspects of life in the community, whether it is voting, receiving a public education in a non-restrictive environment, accessing communications . . . or accessing transportation systems . . . Civil rights laws have also made the physical environment more accessible to people with disabilities.

Id.

55. See Perlin, *supra* note 23, at 1033-34 (“In *Olmstead*, the Court qualifiedly affirmed a decision by the Eleventh Circuit that had provided the first coherent answer to the question of the right of institutionalized persons with mental disabilities to community services under the ADA.”).

56. See *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 587 (1999). In relevant part: [W]e confront the question whether the proscription of discrimination may require placement of persons with mental disabilities in community settings rather than in institutions. The answer, we hold, is a qualified yes. Such action is in order when the State’s treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.

Id.; see also Stark, *supra* note 45, at 83 (“The Supreme Court expressed that the right to community-based treatment for qualified institutionalized mentally ill persons was a right subject to a certain degree of limitation regardless of the extent which those people qualified for community mental health treatment.”).

57. *Olmstead*, 527 U.S. at 593-94.

58. *Id.* at 594.

59. *Id.* at 593-94.

were appropriate for L.C. and E.W. and “that the State could ‘provide services to plaintiffs in the community at considerably *less* cost than is required to maintain them in an institution.’”⁶⁰

The Eleventh Circuit Court of Appeals affirmed the District Court’s judgment but remanded to the lower court to consider the State’s cost-based defense.⁶¹ The Eleventh Circuit held that the Title II mandate that required the states to provide integrated services came within the realm of “reasonable modifications,” but not “fundamental alterations” to the state programs.⁶² The Eleventh Circuit remanded the case for the District Court to consider whether the additional cost “to treat L.C. and E.W. in community-based care would be unreasonable given the demands of the State’s mental health budget.”⁶³

The Supreme Court granted certiorari and held that “the ‘unjustified institutional isolation’ of the disabled, including persons with developmental disabilities, constituted a form of discrimination.”⁶⁴ The court reasoned that: 1) “institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life” and 2) “confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.”⁶⁵ In response to the remand instructions of the Eleventh Circuit, the Court also articulated a more expansive cost-based analysis by saying specifically, “the District Court must consider, in view of the resources available to the State, not only the cost of providing community-based care to the litigants, but also the range of services the State provides others with mental disabilities, and the State’s obligation to mete out those services equitably.”⁶⁶ The Court’s incorporation of costs into the analysis reflected an awareness of the complexity of the cost analysis.⁶⁷ The holding thus carved out more leeway for states to have a

60. *Id.* at 594-95.

61. *Id.* at 595.

62. *Id.*

63. *Id.*

64. Stark, *supra* note 45, at 96.

65. *Olmstead*, 527 U.S. at 600-01.

66. *Id.* at 597.

67. *See id.* at 604. As the Court explains:

[T]he District Court compared the cost of caring for the plaintiffs in a community-based setting with the cost of caring for them in an institution. That simple comparison

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reasonable “working plan for placing qualified persons with mental disabilities in less restrictive settings, and a waiting list that moved at a reasonable pace”⁶⁸

Hailed as the “*Brown v. Board of Education* for individuals with disabilities,”⁶⁹ this ruling was significant because “[f]or the first time, a majority of the Supreme Court acknowledged the corrosive and debilitating effects of improper institutionalization . . . that such institutionalization ‘severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.’”⁷⁰ The Supreme Court’s recognition of a limited right to community-based treatment for persons with developmental disabilities was an important milestone for disability advocates because it provided a “legal rationale—and a moral authority for federal and state Medicaid policy making to support the full integration of people with disabilities into American society.”⁷¹

Many of the difficulties of implementing the Supreme Court’s ruling in *Olmstead* mirror the difficulties with school desegregation following *Brown v. Board of Education*.⁷² The deeply-rooted racism that fueled school segregation can be compared to historic stereotypes about individuals with disabilities.⁷³ The mechanics of school desegregation, including building new schools that required funding, com-

showed that community placements cost less than institutional confinements. As the United States recognizes, however, a comparison so simple overlooks costs the State cannot avoid; most notably, a “State . . . may experience increased overall expenses by funding community placements without being able to take advantage of the savings associated with the closure of institutions.”

68. *Id.* at 605-06.

69. Smith & Calandrillo, *supra* note 11, at 698; see Charles R. Bliss & C. Talley Wells, *Applying Lessons from the Evolution of Brown v. Board of Education to Olmstead: Moving from Gradualism to Immediate, Effective, and Comprehensive Integration*, 26 GA. ST. U. L. REV. 705, 706-09 (2010), for a comparison and contrast of *Brown v. Board of Education* and *Olmstead v. L.C.* including an analysis of costs. *But see* John F. Muller, Comment, *Olmstead v. L.C. and the Voluntary Cessation Doctrine: Toward A More Holistic Analysis of the “Effectively Working Plan,”* 118 YALE L.J. 1013, 1013 (2009) (“Ten years after the Court’s decision, comparisons with *Brown* have proved apt if inauspicious.”).

70. Perlin, *supra* note 23, at 1052.

71. MEDICAID, *supra* note 1, at 5.

72. See Bliss & Wells, *supra* note 69, at 705-06.

73. See *id.* at 706-07. As the authors discuss:

In the case of school desegregation, the attitudes to be overcome included straightforward racism. There was an expressed belief that African-American children would not be able to compete with white children and thus needed to be in different schools. Prejudices also face people in institutions. Some people feel uncomfortable with or apprehensive of them. Others believe that people with disabilities can better or more safely be served in institutions. Where people did not want African-American children in their schools, similarly people sometimes do not want people with disabilities living in their neighborhoods. While it may seem hard to equate current attitudes allowing

pare to the funding necessary to create community placements.⁷⁴ In both cases “the courts faced complex, sometimes intractable, interests opposing significant change.”⁷⁵ In *Brown v. Board of Education*, the Supreme Court recognized these opposing interests, as well as the logistics of school desegregation, in their order for desegregation to occur with “all deliberate speed.”⁷⁶ Eventually, it was a “succession of intermediate remedial measures” on the part of the courts that set in motion the process of school desegregation.⁷⁷ In contrast, over ten years after *Olmstead*, the lack of remedial measures by courts and social service agencies to reduce waiting lists and require immediate integration have stripped thousands of individuals of their right to community-based services.⁷⁸

II. COSTS AND THE RIGHT TO COMMUNITY-BASED SERVICES

A. Due Process Right to Community Services and the “Least Restrictive Alternative” Doctrine

A due process right to community-based services was first articulated by the political and legal activism of the disability rights movement.⁷⁹ Beginning in the mid-1950s through the 1960s and 1970s, there was a mass effort to replace large institutions with community services.⁸⁰ As part of the movement, in 1960, Morton Birnbaum first argued that adequate mental health treatment for those committed to institutions is grounded in due process constitutional rights.⁸¹ This

segregation of people with disabilities to long rejected attitudes supporting racial segregation, it is important to remember that those attitudes were once widely held.

Id.; see also discussion *infra* Part III.C.

74. Bliss & Wells, *supra* note 69, at 707. In relevant part:

States have built large institutions to segregate individuals with mental health and developmental disabilities. There often is no plausible use for these buildings when the residents are shifted to community placements. The community placements must often be developed as well. Personnel must be shifted from providing institutional care to providing care in community settings. Jobs are lost and different jobs are created to serve people in more integrated settings.

Id.

75. *Id.*

76. *Brown v. Bd. of Educ.*, 349 U.S. 294, 301 (1955).

77. Bliss & Wells, *supra* note 69, at 707.

78. See *id.* at 718-19.

79. See Smith & Calandrillo, *supra* note 11, at 707.

80. *Id.*

81. Seicshnaydre, *supra* note 11, at 1975-76. As Seicshnaydre describes:

Dr. Morton Birnbaum . . . argued that individuals should receive adequate treatment in return for their commitment to institutions and proposed that courts under their traditional powers to protect . . . constitutional rights . . . begin to consider the problem of whether or not a person who has been institutionalized . . . actually does receive ade-

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scholarship and activism led to the “deinstitutionalization of large numbers of the mentally ill.”⁸² The mass deinstitutionalization was also credited to “[a]dvances in psychotropic medications, the development of the community health-center movement, and litigation brought by mental health advocates and civil rights lawyers.”⁸³ Since then, almost 1.5 million people have transitioned into community settings.⁸⁴

The least restrictive alternative (“LRA”) doctrine has permeated mental disability law more than any other principle.⁸⁵ Simply put, the Supreme Court’s doctrine “requires the government ‘to pursue its ends by means narrowly tailored so as to not encroach unnecessarily on important competing interests.’”⁸⁶ The Supreme Court has held that “even though the governmental purpose be legitimate and substantial, that purpose cannot be pursued by means that broadly stifle fundamental personal liberties when the end can be more narrowly achieved.”⁸⁷

This doctrine was first applied in a mental health context in *Lessard v. Schmidt*.⁸⁸ In *Lessard*, the plaintiff brought suit on behalf of herself and others held involuntarily, challenging Wisconsin’s involuntary commitment statutes as violating her due process rights.⁸⁹ The United States District Court for the Eastern District of Wisconsin held that the statute was unconstitutional, reasoning that “the Wisconsin statutory scheme for involuntary civil commitment fails to afford persons alleged to be mentally ill with adequate procedural safeguards.”⁹⁰ The court applied the LRA doctrine in their reasoning, stating “persons suffering from the condition of being mentally ill, but who are not alleged to have committed any crime, cannot be totally deprived of their liberty if there are less drastic means for achieving the same

quate medical treatment so that he may regain his health, and therefore his liberty, as soon as possible; that the courts do this by means of recognizing and enforcing the right to treatment . . . as a necessary and overdue development of our present concept of due process of law.

Id.

82. Smith & Calandrillo, *supra* note 11, at 707.

83. *Id.*

84. Dana M. Bessette, *Reinterpreting the ADA: Finding a Freedom from Unnecessary Segregation*, 24 NEW ENG. J. CRIM. & CIV. CONFINEMENT 131, 163 (1998).

85. Perlin, *supra* note 23, at 1010.

86. *Id.* at 1011.

87. *Id.* at 1012.

88. *Id.* at 1013.

89. *Lessard v. Schmidt*, 349 F. Supp. 1078, 1082 (E.D. Wis. 1972).

90. *Id.* at 1093.

basic goal.”⁹¹ The court required the person recommending full-time involuntary hospitalization to prove:

(1) what alternatives are available; (2) what alternatives were investigated; and (3) why the investigated alternatives were not deemed suitable. These alternatives include voluntary or court-ordered outpatient treatment, day treatment in a hospital, night treatment in a hospital, placement in the custody of a friend or relative, placement in a nursing home, referral to a community mental health clinic, and home health aide services.⁹²

In *Romeo v. Youngberg*, the court relied on the LRA doctrine to hold that “involuntarily institutionalized persons with mental disabilities had a right to habitation in the least restrictive alternative.”⁹³ The Court expanded this holding by declaring a right to training and to “reasonably nonrestrictive confinement conditions.”⁹⁴ Despite the landmark holding in *Youngberg*, establishing the right to LRA treatment, many post-*Youngberg* courts have refused to recognize this right.⁹⁵ It was not until *Olmstead* that the Supreme Court first articulated a due process right to community-based services.⁹⁶

In the wake of the ADA and *Olmstead*, the number of individuals with developmental and intellectual disabilities served in institutions has steadily declined by roughly four percent each year from 1968 to the present.⁹⁷ In 2009, forty-one states still owned and operated institutional facilities for individuals with disabilities, and eleven states no

91. *Id.* at 1096.

92. *Id.*

93. Perlin, *supra* note 23, at 1018 (citing *Romeo v. Youngberg*, 644 F.2d 147, 164-70 (3d Cir. 1980), *vacated*, 457 U.S. 307 (1982)).

94. *Youngberg*, 457 U.S. at 324.

95. See *Soc’y for Good Will to Retarded Children, Inc. v. Cuomo*, 737 F.2d 1239, 1249 (2d Cir. 1984) (holding that “there is no constitutional right to community placement”); *Rennie v. Klein*, 720 F.2d 266, 269 (3d Cir. 1983) (showing that the court refused to recognize a “least intrusive means” analysis in a case involving a plaintiff asserting his right to refuse antipsychotic medications); *Johnson v. Brelje*, 701 F.2d 1201, 1210 (7th Cir. 1983) (“Due process, however, does not guarantee the plaintiffs the right to be treated in the least restrictive environment that money can buy.”); *Ass’n for Retarded Citizens of N.D. v. Olson*, 561 F. Supp. 473, 486 (D.N.D. 1982) (“While the *Youngberg* decision does not directly address this specific right [to treatment alternatives to institutionalization], the Court’s analysis indicates that it would reject an absolute right to the least restrictive alternatives.”); *cf.* *State v. Sanchez*, 80 N.M. 438, 441 (1969) (holding that appellant’s constitutional rights were not violated by involuntary and indefinite commitment).

96. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 587 (1999) (“Specifically, we confront the question whether the proscription of discrimination may require placement of persons with mental disabilities in community settings rather than in institutions. The answer, we hold, is a qualified yes.”).

97. BRADDOCK ET AL., *supra* note 8, at 50.

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longer operated institutions.⁹⁸ A majority of states have closed institutions in response to the dwindling numbers of individuals served by institutions and increasing operating costs.⁹⁹ However, as of 2009, twelve states have not closed any institutions, including: Arkansas, Delaware, Idaho, Mississippi, Missouri, Nebraska, Nevada, North Carolina, Utah, Virginia, and Wyoming.¹⁰⁰

It is well established that some individuals with disabilities are better served medically in an institutional setting.¹⁰¹ Broad deinstitutionalization without alternate community services in place for individuals with disabilities has horrific effects including “wide ranging homelessness and the creation of ghettos inhabited by the mentally disabled.”¹⁰² Today, under the guise of deinstitutionalization, recent state budget cuts are leaving many individuals without any services at all.¹⁰³ However, for the thousands of individuals eligible for community-services, but forced to live out their lives in institutions, the illegality of unnecessary segregation, as defined by *Olmstead*, is crystal-clear.¹⁰⁴

There is also evidence that less access to community-based services also has an effect on the judgment of mental health professionals.¹⁰⁵ Under *Olmstead*, courts have determined that eligibility for community services is dependant on the individualized determination

98. *Id.* at 50-51. Eleven states “no longer run state-operated I/DD institutional facilities: Alaska, the District of Columbia, Hawaii, Michigan, Maine, New Hampshire, New Mexico, Oregon, Rhode Island, Vermont, and West Virginia.” *Id.*

99. *See id.* at 52. On a revealing note, institutions that have been closed are often used as correctional facilities. *Id.* at 53.

100. *Id.*

101. Smith & Calandrillo, *supra* note 11, at 765; *see also Olmstead*, 527 U.S. at 601-02 (“[N]othing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings. Title II provides only that ‘qualified individual[s] with a disability’ may not ‘be subjected to discrimination.’”).

102. Smith & Calandrillo, *supra* note 11, at 765; *see also* RON HONBERG ET AL., NAT’L ALLIANCE ON MENTAL ILLNESS, STATE MENTAL HEALTH CUTS: THE CONTINUING CRISIS 3 (2011), available at <http://www.nami.org/ContentManagement/ContentDisplay.cfm?ContentFileID=147763> (“The situation has gotten so bad that Cook County Sheriff Tom Dart announced in May 2011 that he was considering filing a lawsuit against the state, ‘accusing it of allowing the jail to essentially become a dumping ground for people with serious mental health problems.’”).

103. *See* HONBERG ET AL., *supra* note 102, at 5 (“Large numbers of individuals, including some with the most severe illnesses and among those most vulnerable, are being left out in the cold.”).

104. *Olmstead*, 527 U.S. at 607 (“Unjustified disparate treatment, in this case, ‘unjustified institutional isolation,’ constitutes discrimination under the Americans with Disabilities Act of 1990.”).

105. Seicshnaydre, *supra* note 11, at 1984 (“Mental health professionals who continually recommend services that do not exist become frustrated and tend to conform their recommendations . . . to the constraints imposed by the state’s inadequate service delivery system, rather than . . . exercise true professional judgment.”).

by a mental health professional that such treatment is needed.¹⁰⁶ Unfortunately, there are instances of tainted professional judgment on the part of some mental health professionals and departure from the accepted practice when community services are not available.¹⁰⁷ The following costs analysis reflects the interrelationship between access to community-based services and budget cuts.

B. The Costs of Discrimination

It is well-established that “disability discrimination and segregation ‘impose staggering economic and social costs’ on the nation.”¹⁰⁸ In drafting the ADA, Congress weighed the moral and economic factors underlying the continued segregation of persons with disabilities and “determined that the costs of continued segregation of persons with disabilities were outweighed by the benefits of integration.”¹⁰⁹ Congress also cited the billions of dollars in costs resulting from dependency and non-productivity.¹¹⁰ At the time of the passage of the ADA, Congress estimated that \$200 billion were lost each year as a result of factors of disability discrimination including: “tax revenues, lost expenditures by persons with disabilities on consumer goods, and in the expenditures of nonprofit organizations and family members of persons with disabilities due to the nation’s failure to integrate individuals with disabilities into regular community settings.”¹¹¹ The estimated federal cost savings wrought by the passage of the ADA was \$60 billion.¹¹² Congress accepted the likelihood of short-term financial and administrative burdens in the name of full integration of individuals with disabilities, reasoning that “those costs were thought to be exaggerated, and, in any event, the long-range effects of integration would benefit society as a whole.”¹¹³

106. *Id.* at 2000.

107. *Id.* As Seicshnaydre explains:

Courts have recognized a substantive due process right to treatment in the community where a professional has made an individualized determination that such treatment is needed, but the treatment has not been implemented; where the professional’s judgment has been tainted by lack of available resources in the community; and where the professional’s judgment substantially departs from accepted practice.

Id.

108. Cook, *supra* note 35, at 458.

109. *Id.*

110. 42 U.S.C. § 12101(a)(8) (2006).

111. Cook, *supra* note 35, at 458.

112. *Id.*

113. *Id.* at 465.

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Despite Congress' clear intent to effect the full integration of individuals with disabilities, judicial interpretations of the ADA have incorporated a cost-based analysis to decide the extent to which the ADA will be enforced.¹¹⁴ As one advocate pointed out, "the different ways in which courts handle costs lead to very different outcomes for people with disabilities."¹¹⁵ Courts have applied three "pure approaches" regarding the costs of community-based services.¹¹⁶ First, the no-costs approach states that integration should be pursued regardless of cost.¹¹⁷ Second is the efficiency approach, which requires the pursuit of only those integrative steps that are more cost-efficient than their segregative counterparts.¹¹⁸ Finally, the strict separation of powers approach is based on the concept "that the court must reject any claim requiring re-allocation of a state's funds, whether more or less efficient."¹¹⁹

Community-based treatment is far less expensive than institutional care.¹²⁰ In 2009, the average cost ranged from \$26,086 per person for supported living to \$191,118 per person for institutional care.¹²¹ State Medicaid programs are the main sources of funding for home and community-based services.¹²² These programs include the home health benefit, state plan services, and home and community-based services ("HCBS") waivers.¹²³ The HCBS waiver provides additional optional Medicaid services for those with disabilities.¹²⁴ In 2009, 572,493 individuals with disabilities received community services through an HCBS waiver.¹²⁵ As of February 2011, HCBS waivers "ac-

114. 42 U.S.C. § 12101 (2006) ("It is the purpose of this chapter . . . to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities."); Wood, *supra* note 11, at 533 ("Advocates must remind courts—through briefs and through argument—that the ADA was meant to achieve integration. Many courts have lost sight altogether of the premium placed on integration and have focused exclusively on costs.").

115. Wood, *supra* note 11, at 502.

116. *Id.* at 508-09.

117. *Id.*

118. *Id.*

119. *Id.*

120. See L.C. *ex rel.* Zimring v. Olmstead, No. 95-CV-1210-MHS, 1997 WL 148674, at *4 n.4 (N.D. Ga. Mar. 26, 1997) ("The record establishes that, on an annual basis, institutional care for the mentally retarded costs more than twice as much as community care, and that the same is true for the mentally ill.").

121. BRADDOCK ET AL., *supra* note 8, at 18.

122. Mirjana Jovic, *Will Budget Cuts Threaten Mental Health in Your State?*, ABC NEWS (Nov. 10, 2011, 7:00 AM), <http://abcnews.go.com/blogs/health/2011/11/10/will-budget-cuts-threaten-mental-health-in-your-state/>.

123. MEDICAID, *supra* note 1, at 3.

124. Interview with Erin Leveton, Senior Attorney, Quality Trust for Individuals with Disabilities, in Washington, D.C. (Oct. 27, 2011).

125. BRADDOCK ET AL., *supra* note 8, at 24.

count[ed] for two-thirds of spending on care in the community.”¹²⁶ The HCBS waiver requires states “to show that it is cost neutral to serve people in the community, even with these added services, versus through an institutional setting.”¹²⁷

After the *Olmstead* decision, many advocates anticipated a “rapid expansion of Medicaid community-based long-term services.”¹²⁸ This predicted expansion was negatively impacted by state fiscal crises that created a “barrier to states implementing their own *Olmstead* compliance plans.”¹²⁹ Although states have prioritized the creation of home and community-based services over the past three decades, “the worst recession in decades has taken a heavy toll on state budgets.”¹³⁰ Specifically, “many states have struggled to balance cost-control policies on HCBS services with the broader objective of serving more people in the community rather [sic] institutions.”¹³¹ The result is that states are using more restrictive cost limits in their HCBS waivers, leaving many individuals with disabilities without community-based services.¹³²

State budget cuts to mental health services in light of the “Great Recession” “are turning out to be more expensive than simply providing people with mental health services.”¹³³ For example, as states close institutions in response to budget cuts, without providing community-based services, individuals in crisis end up boarding in emergency rooms, “police have become first-line responders to mental health crises they aren’t trained to deal with, and prisons, already overcrowded, are the new psychiatric hospitals.”¹³⁴ This bleak picture results from federal and state cuts to mental health budgets without regard for the catastrophic individual consequences. The reasons behind this failure to invest in cost effective community-based services are explored below.

126. HCBS PROGRAMS, *supra* note 8, at 3.

127. Interview with Erin Leveton, *supra* note 124.

128. MEDICAID, *supra* note 1, at 3.

129. *Id.*

130. HCBS PROGRAMS, *supra* note 8, at 4.

131. *Id.* at 3.

132. *See id.*

133. Jojic, *supra* note 122.

134. *Id.*

III. BARRIERS TO RECEIVING COMMUNITY-BASED SERVICES

As discussed below, continuing segregation of individuals with disabilities is a multifaceted problem containing legal and political elements on the backdrop of the economic recession and deeply rooted discrimination against persons with disabilities. For example, community-based services are threatened by a systemic Medicaid bias towards funding institutional care and the lack of state and federal funding for community-based services.¹³⁵ State administration of Medicaid funding for community-based services is often skewed toward the least disabled individuals and is often on the fiscal chopping block.¹³⁶ This leaves individuals attempting to transition into the community without proper medical insurance, equipment, and treatment.¹³⁷ Misinformation about individuals with disabilities and overly narrow judicial interpretations of *Olmstead* and the ADA further threaten the distribution of community-based services.¹³⁸ Finally, the less obvious influence of discrimination against individuals with disabilities is a systemic problem inherent in judicial and political actions.¹³⁹

A. Fiscal and Political Barriers to Integration

Community-based services are critically threatened by massive state budget cuts¹⁴⁰ resulting from the “ongoing impacts of the worst recession in decades.”¹⁴¹ From 2011 to 2012, many states cut millions of dollars from their mental health budgets.¹⁴² For example, California cut \$177.4 million, New York cut \$204.9 million, and Illinois cut \$187 million from their mental health budgets.¹⁴³ In the period from 2009 to 2012, South Carolina, Alabama, Alaska, Illinois, and Nevada cut up to forty percent of their mental health budgets.¹⁴⁴ The nation-

135. See MEDICAID, *supra* note 1, at 3.

136. See discussion *infra* Part III.A.

137. See Interview with Mat McCollough and Jessica Hunt, Exec. Dir., D.C. Developmental Disabilities Council, in Washington, D.C. (Nov. 22, 2011).

138. See discussion *infra* Part III.C.

139. See discussion *infra* Part III.D.

140. See HONBERG ET AL., *supra* note 102, at 2.

141. HCBS PROGRAMS, *supra* note 8, at 1.

142. See HONBERG ET AL., *supra* note 102, at 2.

143. *Id.*

144. Jojic, *supra* note 122.

wide total during this period was a staggering \$1.6 billion cut from state funds for mental health services.¹⁴⁵

Services for individuals with disabilities are in jeopardy across the nation.¹⁴⁶ In Illinois, “[u]p to 5,000 children and adults with serious mental illness could be cut off from needed [medical] services.”¹⁴⁷ In Michigan, the Detroit-Wayne County Community Mental Health Agency, a large provider of funding for community-based services experienced \$30 million in budget cuts since 2008.¹⁴⁸ In California, “the governor suspended the mandate on counties to provide mental health services for special education students” and slashed its state mental health staff, in effect “divest[ing] itself of accountability for its residents living with serious mental illness.”¹⁴⁹ In New Jersey, the state is scheduled to close Hagedorn Psychiatric Hospital, a specialty hospital that serves elderly individuals with dementia, without a clear plan for providing community-based services to the hospital residents.¹⁵⁰

Budget cuts to state Medicaid programs are a frightening result of the “Great Recession.” As the major source of funding for long-term services for persons with disabilities,¹⁵¹ in 2002, “Medicaid provided coverage to more than 8 million non-elderly people with disabilities.”¹⁵² On June 30, 2011, state Medicaid programs suffered a “projected loss of 14 billion dollars” in federal stimulus funds.¹⁵³ In order to “tap into federal matching funds” states are shifting their resources to Medicaid services.¹⁵⁴ However, this practice has “led to the near abandonment of individuals who are not Medicaid recipients[,] . . . including some with the most severe illnesses.”¹⁵⁵ Regrettably, cuts to Medicaid are projected to increase, with current proposals to cut

145. HONBERG ET AL., *supra* note 102, at 2.

146. *See id.* at 1 (“Today, with demand for public mental health services extremely high, especially at a time of severe economic distress, the crisis in mental health care continues.”).

147. *Id.* at 3.

148. *Id.*

149. *Id.*

150. *Id.* at 4.

151. *See* BRADDOCK ET AL., *supra* note 8, at 26 (“The Medicaid program is the single most important public sector program in the United States for people with I/DD [Intellectual and/or Developmental Disabilities]. Federal-State Medicaid spending in 2009 constituted 75.5% of the \$53.21 billion in I/DD long-term care spending.”).

152. MEDICAID, *supra* note 1, at 2.

153. HONBERG ET AL., *supra* note 102, at 4.

154. *Id.* at 5.

155. *Id.*

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Medicaid ranging from “\$75 billion to almost \$200 billion over ten years.”¹⁵⁶

Recent federal health care initiatives to expand community-based care under Medicaid have been crippled by the recession.¹⁵⁷ For example, under the Patient Protection and Affordable Care Act (“PPACA”), signed into law on March 23, 2010, the Community Living Assistance Services and Supports Program (“CLASS Act”) established a “voluntary insurance program for purchasing community living services and supports.”¹⁵⁸ The CLASS Act had the potential to reduce reliance on Medicaid and “supplement this coverage by providing a mechanism to pay for the non-medical expenses that allow a person with a disability to remain independent.”¹⁵⁹ In effect, the program gave working adults with disabilities a cash benefit to offset the costs of community services in exchange for meeting particular work requirements.¹⁶⁰ The CLASS Act was projected to “reduce the federal deficit by 70.2 billion and Medicaid spending over the course of a ten year period.”¹⁶¹ However, in response to cost concerns, the program was cancelled on October 14, 2011 by the Obama administration.¹⁶² The cancellation of the CLASS Act left unresolved the problem of hundreds of thousands¹⁶³ of eligible individuals with disabilities waiting for access to community-based services.¹⁶⁴

In 2009, President Obama launched the “Year of the Community Living” as an effort to assist Americans with disabilities.¹⁶⁵ The effort

156. *Id.*

157. See generally Scott Spoerry, *Obama Drops Long Term Health Program*, CNN POL. (Oct. 14, 2011), http://articles.cnn.com/2011-10-14/politics/politics_health-care-program_1_long-term-care-sebelius-community-living-assistance-services?_s=PM:POLITICS (discussing the Obama administration’s decision to halt a long term insurance program due to cost concerns).

158. THE HENRY J. KAISER FAMILY FOUND., FOCUS ON HEALTH REFORM: HEALTH CARE REFORM AND THE CLASS ACT 1 (2010) [hereinafter CLASS ACT], available at <http://www.kff.org/healthreform/upload/8069.pdf>.

159. *Id.* at 3.

160. *Id.* at 1; BRADDOCK ET AL., *supra* note 8, at 29 (“The CLASS Act provides those who participate with cash to help pay for needed assistance, if they become functionally limited, in a place they call home—from independent living to a nursing facility, if they so choose.”).

161. CLASS ACT, *supra* note 158, at 3.

162. Spoerry, *supra* note 157.

163. MEDICAID, *supra* note 1, at 3.

164. See BRADDOCK ET AL., *supra* note 8, at 64 (“In 2009, 35 states reported that 99,870 persons with I/DD [intellectual and developmental disabilities] were on formal state waiting lists for residential services. Based on this figure . . . [it is] estimated that 122,870 persons with I/DD nationally were awaiting residential services.”).

165. Press Release, The White House Office of the Press Sec’y, On Anniversary of *Olmstead*, Obama Administration Recommits to Assist Americans with Disabilities (June 22, 2011), <http://www.whitehouse.gov/the-press-office/2011/06/22/anniversary-olmstead-obama-administration-recommits-assist-americans-dis>.

was backed by the Department of Housing and Urban Development's and the Department of Health and Human Services' ("DHHS") release of \$40 million dollars in housing vouchers for 5,300 people over 12 months.¹⁶⁶ Facilitating the push to community living, "[a]s part of the 'Year of Community Living,' [DHHS] created [a] 'Community Living Initiative' to coordinate the efforts of Federal agencies and The Money Follows the Person Rebalancing Demonstration Program, through funding awards to States, [which] has also helped almost 12,000 individuals transition from institutions to the community."¹⁶⁷ However, the program has had a marginal impact on the 365,553 individuals forced to wait up to two years for HCBS waivers in 2009.¹⁶⁸ State and federal budget cuts to community-based services Medicaid waivers are a worsening problem resulting from the budgetary crisis of 2008-2009.¹⁶⁹ The budget for state- and federally-funded long-term care services for individuals with disabilities must compete with other state budget priorities including "regular and special education, higher education, prisons, health care, welfare, roads and bridges, and other priorities."¹⁷⁰

Another sinister state trend is the practice of distributing community-based services exclusively to persons with less severe disabilities, leaving individuals with more severe disabilities unaddressed.¹⁷¹ Equally sinister is the continuance of institutional segregation based on "[p]olitical goals to save money, bureaucratic pressures to allocate mental health funds primarily to state institutions, and neighborhood resistance to the establishment of alternative community facilities."¹⁷² Too often, individuals with disabilities are deprived of the right to vote and therefore removed from political discourse.¹⁷³ Too often, the needs of the developmentally disabled are "invisible, both to the general public and to the academy."¹⁷⁴

166. *Id.*

167. *Id.*

168. HCBS PROGRAMS, *supra* note 8, at 2.

169. See BRADDOCK ET AL., *supra* note 8, at 76-77 ("[T]he impact of the *Great Recession* on state general fund budget gaps was unprecedented.").

170. *Id.* at 77.

171. See HONBERG ET AL., *supra* note 102, at 5 ("States are also shifting resources to Medicaid mental health services in order to tap into federal matching funds. This helps stabilize care for children and adults with serious mental illness who are Medicaid-eligible, but has led to the near abandonment of individuals who are not Medicaid recipients.").

172. Smith & Calandrillo, *supra* note 11, at 716 (alteration in original); see also MEDICAID, *supra* note 1, at 5.

173. PREJUDICE, *supra* note 24, at 42.

174. Perlin, *supra* note 23, at 1020. As Perlin describes:

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B. Institutional Bias Inherent in the Medicaid System

Despite the cost-effectiveness of community-based services, Medicaid's institutional bias is reflected in the fact that as of 2008, fifty-seven percent of Medicaid spending is still institutionally based while forty-three percent of funding goes to community services.¹⁷⁵ This bias is also inherent in the Medicaid law that "requires state Medicaid programs to provide institutional services to all eligible individuals as a mandatory benefit, and permits (but does not require) states to make services available in the community as an optional benefit."¹⁷⁶

Medicaid's institutional bias is also deeply rooted in fears about a lack of funding for community-based services, shortage of health-care workers and housing, and political unpopularity.¹⁷⁷ The bias is sustained by fears that an entitlement to community-based services could open the floodgates to large numbers of persons with disabilities seeking Medicaid funded community-based services.¹⁷⁸ Another reason for Medicaid's institutional bias is the "shortage of direct care workers who are trained and willing to provide community-based personal assistance"¹⁷⁹ and other services resulting from low wages, poor benefits, and limited promotion opportunities.¹⁸⁰ Because "Medicaid funds generally cannot be used for housing," opponents of community services project that persons with disabilities that would require affordable housing would tax government housing assistance programs like Section 8.¹⁸¹ Finally, closing large institutions in small towns is often politically unpopular.¹⁸² There is political pressure to keep insti-

Mental disability law is a topic dealt with on a daily basis by trial courts across the country in a series of unknown cases involving unknown litigants, where justice is often administered in assembly-line fashion. Sophisticated legal arguments are rarely made, expert witnesses are infrequently called to testify, and lawyers all too often provide barely-perfunctory representation.

Id.

175. BRIAN BURWELL, KATE SREDL & STEVE EIKEN, *MEDICAID LONG-TERM CARE EXPENDITURES IN FY 2008*, at 2 (2009), available at <http://www.nasuad.org/documentation/aca/Reference%20Manual/1-Overview%20Section/6-MedicaidLongTermCareExpFY2008.pdf>.

176. *MEDICAID*, *supra* note 1, at 3.

177. *See id.* at 4-5.

178. *Id.* at 4.

179. *Id.* at 5.

180. *See* Samantha A. DiPolito, Comment, *Olmstead v. L.C.—Deinstitutionalization and Community Integration: An Awakening of the Nation's Conscience?*, 58 *MERCER L. REV.* 1381, 1401 (2007) (discussing the inadequacies and disincentives for qualified community-care workers and their effect on the continuity of care for individuals with disabilities). *See generally* BRADDOCK ET AL., *supra* note 8, at 65-66.

181. *See, e.g.*, *MEDICAID*, *supra* note 1, at 4.

182. *See id.* at 5.

tutions open in places where institutions are large employers and “shifting resources from institutions to the community could lead to lost jobs.”¹⁸³ In general, the labor and nursing home industries have powerful lobbyists that work against de-institutionalization.¹⁸⁴

C. Legal Barriers to *Olmstead* Enforcement

Litigation under *Olmstead* and the ADA “remains a force in the states in shaping the provision of services to persons with I/DD [intellectual and/or developmental disabilities].”¹⁸⁵ Class action litigation has sought to address waiting lists for community-based services, integrate individuals with disabilities into the community, and expand Medicaid services for eligible individuals.¹⁸⁶ In 2010, “[s]ix waiting list lawsuits, 12 *Olmstead* lawsuits, and four Medicaid-access lawsuits remained active in 17 states.”¹⁸⁷ For example, a Tennessee waiting list lawsuit, originally filed in 2000, resulted in over 3,000 people being enrolled in a Medicaid waiver program, an increase in providers of waiver services, people on the Tennessee waiting list receiving more than \$15 million in support funds, and eligible individuals receiving information about the Medicaid waivers.¹⁸⁸

Despite these strides, formalist adherence to overly narrow interpretations of the ADA and “vague deference to state plans”¹⁸⁹ for integration has deprived many individuals of their right to community-based services.¹⁹⁰ Cases of failed enforcement of the ADA and *Olmstead* show these overly narrow interpretations.¹⁹¹ In *United States v. Arkansas*, the Attorney General alleged ADA violations based on the defendant Conway Human Development Center’s (“CHDC”) failure to provide safe conditions, habilitation and training, professional use of restraints, professional care, public education and assessment of individuals to ascertain whether these individuals are receiving adequate treatment, supports, and services “in the most integrated setting

183. *Id.*

184. *Id.*

185. BRADDOCK ET AL., *supra* note 8, at 80.

186. *Id.*

187. *Id.*

188. *Id.* at 69-70.

189. Muller, *supra* note 69, at 1014 (“This vague deference to state plans has occasioned a struggle for enforcement comparable to the struggle that followed *Brown*.”).

190. *See id.* (“[F]ederal courts have embarked on a path of judicial interpretation that threatens to render the ‘working plan’ provision in *Olmstead* a ‘get out of jail free’ card for states otherwise in violation of the decision’s integration mandate.”).

191. *See, e.g., United States v. Arkansas*, 794 F. Supp. 2d 935, 984 (E.D. Ark. 2011).

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appropriate for their individual needs.”¹⁹² The Attorney General detailed a system of lifelong institutionalization and segregation at CHDC beginning when residents were first admitted as children and continuing throughout their lives isolated from their families and communities.¹⁹³ The United States District Court for the Eastern District of Arkansas dismissed the suit with prejudice, holding that there was no violation of Fourteenth Amendment Rights and no violation of the ADA.¹⁹⁴ The court reasoned that “the United States is in the odd position of asserting that certain persons’ rights . . . are being violated while those persons—through their parents and guardians—disagree.”¹⁹⁵ Overly narrow judicial interpretations of the ADA, like the interpretation in *United States v. Arkansas*, leave the residents of CHDC trapped in a system of lifelong segregation and institutionalization.¹⁹⁶

Many Department of Justice *Olmstead* cases end in settlement agreements with the states that set in place plans for immediate relief for individuals unnecessarily institutionalized. As an example, the settlement agreement for *United States v. Delaware* resulted in: (1) a crisis system with a full range of crisis services, with the goal of reducing hospitalization by fifty percent; (2) intensive case supports and community supports; (3) integrated supported housing; and (4) a rebalancing of “Delaware’s mental health system from one reliant on state-funded institutional care to one focused on Medicaid-reimbursable community-based services.”¹⁹⁷ Similarly, in *U.S. v. Georgia*, the settlement agreement generally provided that the state will: (1) cease all admissions of individuals with developmental disabilities to their state hospitals by July 1, 2011; (2) transition individuals with developmental

192. See Complaint at 5-7, *Arkansas*, 794 F. Supp. 2d 935 (No. 4:09CV00033 JLH), available at http://www.ada.gov/olmstead/documents/arkansas_ada_complaint.pdf.

193. United States’ Post Trial Brief at 310, *Arkansas*, 794 F. Supp. 2d 935 (No. 4:09CV00033 JLH), available at http://www.ada.gov/olmstead/documents/arkansas_post_trial.pdf. As the Attorney General summarized:

Defendants’ system for delivering care and services to CHDC residents illegally condemns individuals . . . to lifelong institutionalization. The vast majority of people currently living at CHDC were first admitted as children, many of them not even ten years old. Once admitted, most CHDC residents spend the rest of their lives within the confines of the institution, never re-joining the communities and families from which they came, nor given a meaningful opportunity to maximize their capacity for independent, self-directed living.

Id.

194. *Arkansas*, 794 F. Supp. 2d at 984-85.

195. *Id.* at 937.

196. See United States’ Post Trial Brief, *supra* note 193.

197. DEP’T OF JUSTICE, DELAWARE ADA SETTLEMENT [sic] FACT SHEET 1-2 (2011), available at http://www.ada.gov/delaware_fact_sheet.htm.

disabilities to the most appropriate, integrated setting by July 1, 2015; (3) create 1,150 home and community based waivers by July 1, 2015; and (4) create family supports and support coordination to assist them in “gaining access to medical, social, education, transportation, housing, nutritional, and other needed services”;¹⁹⁸ (5) create crisis teams, community support teams, and case management teams; and 6) provide supported housing to 2000 individuals and supported employment to 550 individuals by July 1, 2015.¹⁹⁹

Findings letters following Department of Justice investigations also shed light on the types of violations states continue to perpetuate. An investigation of the North Carolina mental health system showed the state’s failure to comply with the ADA.²⁰⁰ Specifically, the investigation revealed that North Carolina’s mental health system delivers services to thousands of people with mental illness in segregated adult care homes that were essentially “institutional settings that segregate residents from the community and impede residents’ interactions with people who do not have disabilities.”²⁰¹ The institution-like settings of the care homes were described by residents as regimented and controlling and as offering little in the way of training or activities.²⁰² The report found that the majority of adults living in the care homes could be served in more integrated settings and were at risk of unnecessary institutionalization in the adult care homes.²⁰³

Despite the lofty goals of state settlement agreements, these agreements are too often procedural scapegoats that allow a state to continue segregating individuals with disabilities.²⁰⁴ For example, federal circuit rulings on *Olmstead* reflect two main approaches to analyzing whether a state has an effective working plan to desegregate as required by *Olmstead*.²⁰⁵ The retrospective approach, used by the Ninth Circuit, examines a state’s past commitment to desegregation to determine whether the state has a working plan for desegregation.²⁰⁶

198. DEP’T OF JUSTICE, UNITED STATES V. GEORGIA SETTLEMENT AGREEMENT FACT SHEET (2010), available at http://www.ada.gov/olmstead/documents/georgia_fact_sheet.pdf.

199. *Id.*

200. See Letter from Thomas E. Perez, Assistant Att’y Gen., to Hon. Roy Cooper, Att’y Gen. for the State of N.C., at 1 (July 28, 2011), available at http://www.ada.gov/olmstead/documents/nc_findings_letter.pdf.

201. *Id.*

202. See *id.* at 7-8.

203. *Id.* at 1-2.

204. See Muller, *supra* note 69, at 1014.

205. *Id.* at 1015.

206. *Id.* at 1016.

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Using the retrospective approach, courts almost always find for the state defendants.²⁰⁷ The prospective approach, used by the Third Circuit, examines a state's future commitment to desegregation, and requires an existing general plan.²⁰⁸ This approach also leads courts to find for the state defendants, because all that is necessary is a "reasonably specific and measurable" plan that is communicated.²⁰⁹

Neither of these analytical approaches to evaluating state plans brings about compliance with the *Olmstead* integration mandate because the fact "[t]hat a state has acted appropriately in the past or promises to do so in the future may demonstrate that it has a comprehensive plan, but it does not suffice to demonstrate that it has an effectively working plan."²¹⁰ One advocate suggests that courts adopt a "voluntary cessation" approach to analyzing state plans.²¹¹ This approach requires the court to assess whether a state plan for integration "can be considered a cessation of the discriminatory policies" and then assess whether the state can feasibly follow its plan.²¹² Regardless of the approach, the complex analytical interpretations used by courts have ultimately deprived individuals of community-based services.²¹³ Along with these legal barriers to *Olmstead* enforcement, discrimination against the disabled is another barrier to integration that feeds stereotypes and pervades mental health jurisprudence as discussed below.

D. Discrimination Against the Developmentally and Intellectually Disabled

The ideology underlying the institutional segregation of the disabled is built upon ignorance and fear of persons with developmental and intellectual disabilities.²¹⁴ The previous discussion on the legal treatment of individuals with disabilities barely skims the surface of

207. *Id.*

208. *Id.* at 1016-17.

209. *Id.* at 1017.

210. *Id.*

211. *Id.* at 1018.

212. *Id.* at 1020.

213. *Id.* at 1017 ("Neither of these approaches provides adequate assurance of future compliance with *Olmstead*'s integration mandate.")

214. See Perlin, *supra* note 23, at 1032-33. As Perlin explains:

Persons with mental disabilities have faced the brunt of discrimination for years. Surveys show that mental disabilities are the most negatively perceived of all disabilities. Mentally disabled individuals have been denied jobs, refused access to apartments in public housing or entry to places in public accommodation, and turned down for participation in publicly-funded programs because they appear "strange" or "different." A series of behavioral myths has emerged suggesting that mentally disabled per-

the “regime of state-mandated segregation and degradation . . . that in its violence and bigotry rivaled, and indeed paralleled, the worst excesses of Jim Crow.”²¹⁵ This legal treatment is driven by deeply rooted stereotypes about individuals with disabilities.²¹⁶

Stereotypes are the primary justification behind the marginalization of individuals with disabilities.²¹⁷ These stereotypes run the gamut from beliefs that individuals with disabilities are “less than human,”²¹⁸ to the belief that individuals with disabilities are “erratic, deviant, morally weak, unattractive, sexually uncontrollable, emotionally unstable, lazy, superstitious, ignorant, and demonstrate a primitive morality.”²¹⁹ One pervasive public attitude is that “[m]entally ill individuals should be segregated in large, distant institutions; their presence threatens the economic and social stability of residential communities.”²²⁰ Another bias-driven view is “that homelessness is

sons are deviant, worth less than “normal” individuals, disproportionately dangerous, and presumptively incompetent.

Id. Studies of the stereotypes hindering persons with disabilities in mental health jurisprudence are encapsulated by author Michael Perlin’s descriptions of sanism, pretextuality, and therapeutic jurisprudence. *Id.* Perlin defines sanism as “an irrational prejudice . . . based predominantly upon stereotype, myth, superstition and de-individualization . . .” *Id.* at 1046 (footnotes omitted). Perlin explains that “[p]retextuality” means that courts accept (either implicitly or explicitly) testimonial dishonesty and engage similarly in dishonest (frequently meretricious) decisionmaking [sic], specifically where witnesses, especially expert witnesses, show a ‘high propensity to purposely distort their testimony in order to achieve desired ends.’” *Id.* at 1047. Finally, Perlin describes therapeutic jurisprudence as a study of:

[T]he role of the law as a therapeutic agent, recognizing that substantive rules, legal procedures and lawyers’ roles may have either therapeutic or antitherapeutic consequences, and questioning whether such rules, procedures and roles can or should be reshaped so as to enhance their therapeutic potential, while not subordinating due process principles.

Id. at 1047-48.

215. PREJUDICE, *supra* note 24, at 39 (citing *City of Cleburne v. Cleburne Living Ctr.*, 473 U.S. 432, 462 (1985); *see also* Cook, *supra* note 35, at 404 (discussing how the Jim Crow system of racial segregation and the segregation of individuals with disabilities stemmed from the same “separate but equal” mentality legitimized in *Plessy v. Ferguson*, 163 U.S. 537 (1896), *overruled* by *Brown v. Bd. of Educ.*, 347 U.S. 483 (1954)).

216. *See* PREJUDICE, *supra* note 24, at 27. As Perlin explains:

Eventually stereotypes—often brought together in a “web”—come to serve as the basis of a legitimating ideology that perpetuates the mythology and rationalizes racial, sexual, or religious oppression. These stereotypes lead to yet others: The separated and stigmatized others are seen as “different, deviant and morally weak” or as individuals “without hope or dignity.”

Id. (citations omitted).

217. *See id.*

218. PREJUDICE, *supra* note 24, at 43.

219. *Id.*

220. *Id.* at 46 (citing *N.Y. State Ass’n for Retarded Children, Inc. v. Carey*, 551 F. Supp. 1165, 1185 (E.D.N.Y. 1982)).

[T]he larger the facility the less likely it is that residents will become part of the community and will be accepted by their neighbors. Larger community facilities exacerbate community opposition to and fear of the retarded. This is because neighbors have more

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largely a problem of mental illness, and that, if mental patients had never been granted their modest amount of civil rights, homelessness would largely disappear as a social phenomenon.”²²¹ Media depictions of individuals with disabilities are most often negative and distorted.²²²

These stereotypes are also deeply rooted in mental disability law jurisprudence,²²³ from the trial court to the Supreme Court.²²⁴ For example, some of Chief Justice Rehnquist’s judicial opinions ignore underlying psychological issues in favor of superficial issues such as whether an individual has a “normal appearance.”²²⁵ Trial judges also frequently rely on the appearance of an individual saying, “‘he [the defendant] doesn’t look sick to me,’ or even more revealingly, ‘he is as healthy as you or me.’”²²⁶

Among other dangers, stereotypes often lead to “dispositional consistency”—the “tendency for people to seek information which confirms rather than disconfirms their beliefs.”²²⁷ Stereotypes, which accentuate the differences between “us” and “them,” also preclude empathy because we are more likely to empathize with those like ourselves.²²⁸ Ultimately, stereotypes are at the heart of “social and judicial helplessness” the idea that social problems are beyond remediation.²²⁹

difficulty adjusting to a large group of individuals who happen to be different, and have more difficulty in breaking down stereotypes in order to see these residents as individuals who happen to be retarded.

Id.

221. *Id.* at 39-40.

222. *Id.* at 42.

223. See PREJUDICE, *supra* note 24, at 47 (“[S]anist attitudes pervade statutes, court decisions, and lawyering practices and thus infect all aspects of mental disability law.”).

224. See *id.* at 16-17.

225. *Id.* at 16. Perlin explains that:

Chief Justice Rehnquist’s opinions reflect the . . . ‘fear of feigning’—see *Ake v. Oklahoma*, 470 U.S. 68, 87, 91 (1985) (Rehnquist, J. dissenting); *Ford v. Wainwright*, 477 U.S. 399, 435 (1986) (Rehnquist, J. dissenting); of stereotypical visions of mental disability informed primarily by surface views of defendant’s external appearance, see *Wainwright v. Greenfield*, 474 U.S. 284, 297-98 (1986) (Rehnquist, J., concurring); and of mental illness as an improperly exculpatory excuse, see *Colorado v. Connelly*, 479 U.S. 157, 163-69 (1987).

Id. at 16 n.104.

226. *Id.* at 17; see also *id.* at 47. Perlin states:

Judges “are embedded in the cultural presuppositions that engulf us all.” Their discomfort with social science (or any other system that may appear to challenge law’s hegemony over society) makes them skeptical of new thinking and allows them to take deeper refuge in . . . the myths and stereotypes of sanism.

Id.

227. *Id.* at 8.

228. See *id.* at 28.

229. *Id.*

CONCLUSION

This Note surveys some of the systemic barriers to full community integration for individuals with disabilities. Identifying these barriers is an important first step in the initiative to end the unnecessary segregation of persons with disabilities. Next steps should focus on restoring spending cuts to mental health services, legislative intervention addressing the massive gap in access to community-based services left by budget cuts and an effort on the part of the judiciary to purge their decision making of stereotypes about individuals with disabilities.

Federal intervention is a critical component to end unnecessary institutional segregation. The American Recovery and Reinvestment Act of 2009 (“ARRA”) “provided a temporary increase in the Federal Medical Assistance Percentage,” helping states maintain their Medicaid programs, including home and community-based services.²³⁰ However, the ARRA funding ended on June 30, 2011.²³¹ The cancellation of the CLASS Act removed the major component of the PPACA that addressed community integration.²³² The elimination of these major federal acts safeguarding home and community-based services, leaves hundreds of thousands of individuals waiting for their constitutionally guaranteed right to community services.²³³

Critical spending cuts to mental health services must be restored. The practice of state cuts to mental health budgets, under the guise of “deinstitutionalization efforts” must be exposed as a violation of the ADA. It is equally important that those eligible for community-based services be provided these services according to a reasonable “working plan for placing qualified persons with mental disabilities in less restrictive settings, and a waiting list that move[s] at a reasonable pace.”²³⁴

Judicial overhaul is another overarching component of the effort to integrate individuals with disabilities into the community.²³⁵ Al-

230. HCBS PROGRAMS, *supra* note 8, at 4.

231. *Id.*

232. CLASS ACT, *supra* note 158, at 1 (The program would have “establishe[d] a national, voluntary insurance program for purchasing community living services . . .”).

233. HCBS PROGRAMS, *supra* note 8, at 2.

234. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 605-06 (1999).

235. See PREJUDICE, *supra* note 24, at 307. As Perlin describes:

Participants in the mental disability law system must acknowledge these concepts and must use the bully pulpits of the courtroom, the legislative chamber, the public forum, the bar association, the psychology or psychiatry conference, and the academic journals

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though mental health researchers have pioneered a body of research from the perspective of the disabled individual, the results of these studies are rarely used by judges or legislators.²³⁶ Judges, lawyers, and advocates must recognize and seek to eliminate stereotypical sanist attitudes from their decision making.²³⁷

Disability advocates envision a system with wide-ranging early intervention services.²³⁸ Investment in rehabilitation programs for individuals with disabilities, as early as possible, such as in preschool and Head Start programs, would minimize the disability over time.²³⁹ Support systems to encourage children with disabilities to graduate with a diploma, instead of a certificate of completion,²⁴⁰ will equip them with the educational background necessary to secure employment.²⁴¹ With the opportunity to work in their communities, individuals with disabilities will therefore rely less on government services, and thus participate in and enrich their communities.²⁴²

Segregation of individuals with disabilities strips our very “social fabric or consciousness”²⁴³ of the experiences of these individuals segregated in “large, remote institutions.”²⁴⁴ As a “fragmented and disenfranchised minority,”²⁴⁵ individuals with disabilities represent a virtually invisible segment of society to the general public and often to the very people who treat them.²⁴⁶ It is precisely because of this history of marginalization that desegregation efforts must “incorporate

to identify and deconstruct sanist and pretextual behaviors whenever and wherever they occur.

Id.

236. *Id.* at 42.

237. *Id.* at 307.

238. See Interview with Mat McCollough and Jessica Hunt, Exec. Dir., D.C. Developmental Disabilities Council, in Wash., D.C. (Nov. 22, 2011).

239. *Id.*

240. *Id.*

241. *Id.*

242. *Id.*; see also DiPolito, *supra* note 180, at 1408. As Dipolito explains:

When individuals with disabilities are valued by society and are met with compassionate, caring, and competent service providers who treat them as collaborative partners, they become empowered individuals with increased self-esteem. As respected and empowered individuals, they can develop their abilities and skills to become fulfilled and productive members of society.

Id.

243. PREJUDICE, *supra* note 24, at 41.

244. *Id.* at 40.

245. *Id.* at 42.

246. See *id.* at 41 (“Few mentally ill patients are ever consulted about their treatment program or informed of their rights. The potential of a consumer voice is often ‘neglect[ed] or even discouraged.’”).

the viewpoints and perspective of the eventual consumers of mental health services.”²⁴⁷

In the wake of the “Great Recession,” it is essential that cost-effective community-based services are made available to eligible individuals. The quality of Mr. N.’s life was greatly improved by a community-based employment program. As his support specialist, my life was also transformed. Segregation of individuals with disabilities creates a boundless economic and cultural loss. However, when individuals with disabilities are fully integrated, the positive transformation to society is equally boundless.

247. *Id.* at 263.

NOTE

A Fighting Chance: Inequities in Charter School Funding and Strategies for Achieving Equal Access to Public School Funds

JEANETTE M. CURTIS*

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INTRODUCTION

In 1991, state legislators tried something new. They began enacting charter school laws to create a new generation of schools,¹ with the hope of improving the future of public education.² However, the dawn of the public charter school era has sparked a hotly debated issue—inequities in funding for public charter schools, *i.e.* public charter schools do not receive the same amount of public funds as traditional public schools.³ Inequities in funding for public charter schools often result in missed educational opportunities for many students like Anthony—a fifth grade student documented in the movie *Waiting for “Superman.”*⁴

1. See *Origins of Chartering Timeline*, EDUC. EVOLVING, <http://www.educationevolving.org/system/chartering/history-and-origins-of-chartering> (last visited Mar. 4, 2012) (providing a timeline for the evolution of charter schools). Charter schools are typically focused on improving education for “underserved children.” See Robert Cane, *Robert Cane: Equal Funding for Charter Schools Is Next Reform Frontier in D.C.*, WASH. EXAMINER (Oct. 22, 2010), <http://washingtonexaminer.com/op-eds/2010/10/robert-cane-equal-funding-charter-schools-next-reform-frontier-dc/37081>.

2. When referring to public education and public schools (both traditional and charter), this Note focuses solely on those underperforming schools located mostly in communities and districts that serve underprivileged students and low-income families.

3. See THOMAS B. FORDHAM INST., CHARTER SCHOOL FUNDING: INEQUITY’S NEXT FRONTIER 1 (2005).

4. See WAITING FOR “SUPERMAN” (Participant Media 2010); see also TakePart LLC, *About the Children—Anthony*, WAITING FOR “SUPERMAN,” <http://www.waitingforsuperman.com/action/page/about-children-anthony> (last visited Feb. 24, 2012) (explaining that the film fol-

Meet Anthony. Anthony attends “one of the worst performing” public schools in Washington, D.C., and lives in a drug and crime ridden neighborhood.⁵ By default, Anthony is set to matriculate to a deficient middle school unless he can beat the odds and attend SEED Charter School.⁶ SEED Charter School is the first public boarding charter school in the country and would give a student like Anthony the opportunity to attend school in a healthier environment where nine out of ten children go to college.⁷ However, due to its limited capacity, SEED can only admit twenty-four students out of over sixty applicants.⁸ As a result, Anthony has less than a 50% chance of gaining acceptance to SEED through the school’s lottery admissions system.⁹ This limited capacity, which is common at successful charter schools, is often attributed to a lack of public funding equal to that provided to traditional public schools.¹⁰

lows the lives of several students burdened with situations similar to Anthony). Daisy, a L.A. fifth-grader never gives up on big plans for her future, no matter what. See TakePart LLC, *About the Children—Daisy*, WAITING FOR “SUPERMAN,” <http://www.waitingforsuperman.com/action/page/about-children-daisy> (last visited Feb. 23, 2012). Francisco, a Bronx first-grader has a mom who will do anything to give him a shot at a better life. See TakePart LLC, *About the Children—Francisco*, WAITING FOR “SUPERMAN,” <http://www.waitingforsuperman.com/action/page/about-children-francisco> (last visited Feb. 23, 2012). Emily is an eighth-grader in Silicon Valley who fears being permanently stamped as unfit for college. See TakePart LLC, *About the Children—Emily*, WAITING FOR “SUPERMAN,” <http://www.waitingforsuperman.com/action/page/about-children-emily> (last visited Feb. 23, 2012).

5. See TakePart LLC, *About the Children—Anthony*, *supra* note 4.

6. See *id.*; see also *About SEED*, SEED FOUND., <http://www.seedfoundation.com/index.php/about-seed> (last visited Feb. 24, 2012) (discussing that SEED is a college preparatory charter school, which boards students 24 hours a day to provide a “nurturing, . . . safe, and secure environment” for learning.). “[Ninety one] percent of SEED students who enter the ninth grade graduate from high school.” *About SEED: Results*, SEED FOUND., <http://www.seedfoundation.com/index.php/about-seed/results> (last visited Feb. 18, 2012).

7. See TakePart LLC, *About the Children—Anthony*, *supra* note 4.

8. See *id.*

9. See *id.*

10. Recently, a number of studies, including documentary films like *The Lottery* and *Waiting for “Superman”* have noticed the unfortunate results that occur when some charter schools reach their limited capacity for serving students. The results of these studies and documentaries are staggering and emotionally provocative. See *THE LOTTERY* (Great Curve Films 2010) (documenting challenges experienced by four families that seek admission to Harlem Success—one of the nation’s best performing public charter schools that has very limited space for new students, making the chance for admission slim); WAITING FOR “SUPERMAN,” *supra* note 4 (documenting the current state of education in America and exploring the lives of five children who sought to escape the public school system by applying for a very limited number of slots at successful public charter schools); see also *Our History*, SUCCESS ACADEMY CHARTER SCH., <http://www.successacademies.org/page.cfm?p=602> (last visited Mar. 4, 2012) (The first Success Academy Charter School—Harlem Success Academy Charter School—opened in 2006 in New York.). Success Academy Charter School students “are among the brightest, highest-achieving students” in New York. *Our Results*, SUCCESS ACADEMY CHARTER SCH., <http://www.successacademies.org/page.cfm?p=11> (last visited Mar. 4, 2012) (“Ninety-five percent of Success Academy (SA) scholars passed the state math exam.”).

Anthony's scenario gives rise to several questions that provide for a stimulating debate. First, are charter schools creatures of the state, such that they should be privy to public funds? If so, do charter schools work so well that all states with charter school laws should abandon disparate funding in order to supplement funding for charter schools? What are the sound legal arguments in favor of and against unequal funding? Finally, *if* the solution to disparate funding is to equalize or improve funding for charter schools, then how do we accomplish that goal?

First, charter schools are creatures of state law.¹¹ Each state has the power to govern its own system for education.¹² As a part of that power, the state may decide to enact charter school laws or not.¹³ State charter school laws allow individuals or organizations to apply for a charter with the state in order to open and operate a charter school.¹⁴

Further, charter schools are public schools. They are accessible to all students, and free to attend—they are not allowed to charge tuition.¹⁵ As such, charter schools—like traditional public schools—receive public funds based on enrollment, *i.e.* the number of pupils that attend that particular school.¹⁶ However, an issue arises with the

11. See *Frequently Asked Questions: What Is an Authorizer?*, NAT'L CHARTER SCH. RESOURCE CTR., <http://www.charterschoolcenter.org/page/frequently-asked-questions#What%20is%20an%20authorizer> (last visited Mar. 4, 2012) (explaining that there are various types of governing bodies that authorize charter schools based on the *State law* – “school districts, institutions of higher education, municipalities, state education agencies, and other designated organizations”).

12. See *Frequently Asked Questions: What Role Do State Governments Play in the Development of Charter Schools?*, NAT'L CHARTER SCH. RESOURCE CTR., <http://www.charterschoolcenter.org/page/frequently-asked-questions#What%20is%20an%20authorizer> (last visited Mar. 4, 2012).

13. See CTR. FOR EDUC. REFORM, UNDERSTANDING CONSTITUTIONS & CHARTER SCHOOLS 1 (2007) (on file with author). Education is not governed by the Constitution; as a result, education is traditionally acknowledged as a matter of state governance. See STUART BIEGEL, EDUCATION AND THE LAW 2 (2d ed. 2009); see also U.S. CONST. amend. X (“The powers not delegated to the United States by the Constitution, nor prohibited by it to the States, are reserved to the States respectively, or to the people.”); *San Antonio Indep. Sch. Dist. v. Rodriguez*, 411 U.S. 1, 35 (1973) (“Education, of course, is not among the rights afforded explicit protection under our Federal Constitution. Nor do we find any basis for saying it is implicitly so protected.”).

14. See *Charter School FAQ: Who Can Start a Charter School?*, PBS, <http://www.pbs.org/closingtheachievementgap/faq.html#q4> (last visited Mar. 4, 2012) (“Parents, community leaders, businesses, teachers, school districts, educational entrepreneurs, and municipalities can submit a charter school proposal to their state’s charter authorizing entity.”).

15. *Charter School FAQ: Do Charter Schools Have Admission Policies?*, PBS, <http://www.pbs.org/closingtheachievementgap/faq.html#q4> (last visited Mar. 4, 2012); see also CTR. FOR EDUC. REFORM, *supra* note 13, at 1.

16. See *Charter School FAQ: How Are Charter Schools Funded?*, PBS, <http://www.pbs.org/closingtheachievementgap/faq.html#q4> (last visited Mar. 4, 2012).

fact that in most states, charter schools receive “less than 100% of the per-pupil funding” allocated to their traditional counterparts.¹⁷ Further, some states do not provide funds for charter schools to procure or build facilities, or cover capital costs.¹⁸

Nevertheless, charter schools are considered public creatures of the state.¹⁹ They serve the same students that traditional public schools serve, yet they are faced with more hurdles to jump over—rigorous accountability standards, less financial support, and other challenges.²⁰ These obstacles may detract from charter schools’ achievement of their objective—to educate children so that they meet or surpass academic standards and develop the necessary skills to become successful in and contribute to society.²¹ Arguably, many of the challenges charter schools face are due to a lack of adequate funding.²² Therefore, the issue at hand concerns the states’ authority to

17. *Id.*

18. *See id.*; *see also Elementary & Secondary Education: Summaries of State Charter School Facility Laws*, U.S. DEP’T. EDUC., <http://www2.ed.gov/policy/elsec/leg/statecharter/index.html> (last visited Feb. 24, 2012) (noting that California, Minnesota, Utah, and the District of Columbia are the only states that received special facility incentive grants for providing funding to public charter schools).

19. Charter School opponents argue that since charter schools are not public entities, they should not be privy to the same public funds. Although charter schools serve all students, and do not charge tuition, opponents continue to argue that charter schools are similar to private institutions because they are typically not bound by districting guidelines, and are not required to adopt state methods for administering education. For a discussion of the private versus public status of charter schools, see Greg Rubio, *Surviving Rodriguez: The Viability of Federal Equal Protection Claims by Underfunded Charter Schools*, 2008 U. ILL. L. REV. 1643, 1664-65. *See also* Jessica P. Driscoll, *Focus: What’s Wrong with Education in America? Student Research: Hot Topics in Education*, 8 GEO. J. ON POVERTY L. & POL’Y 505, 505 (2001) (“[C]harter schools’ ambiguous status as neither public nor private has fueled legal discourse, state and federal litigation, and political rhetoric.”); James Forman, Jr., *Do Charter Schools Threaten Public Education? Emerging Evidence from Fifteen Years of a Quasi-Market for Schooling*, 2007 U. ILL. L. REV. 839, 843 (noting that even though charter schools appear to have greater flexibility and more autonomy, in actuality, they “act in a highly regulated marketplace”).

20. *See Charter School FAQ: How Do Charter Schools Differ From Traditional District Public Schools?*, PBS, <http://www.pbs.org/closingtheachievementgap/faq.html#q3> (last visited Mar. 4, 2012) (identifying that charter schools differ from traditional public schools with respect to three categories: accountability, school choice, and autonomy). *See generally* Robert J. Martin, *Rigid Rules for Charter Schools: New Jersey as a Case Study*, 36 RUTGERS L.J. 439, 523-24 (2005) (describing the barriers that New Jersey charter schools have faced through rigid legislation as a result of some failed charter schools, and suggesting that the greater flexibility to operate comes at a cost to charter schools – having to cope with greater rigidity with fewer financial resources).

21. *See Charter School FAQ: What Is a Charter School?*, PBS, <http://www.pbs.org/closingtheachievementgap/faq.html#q3> (last visited Mar. 4, 2012); *see also* MARIAN WRIGHT EDELMAN, *THE SEA IS SO WIDE AND MY BOAT IS SO SMALL: CHARTING A COURSE FOR THE NEXT GENERATION* 89 (2008) (“[E]ducation is a key determinant of future success.”).

22. *See Charter School FAQ: What If a Charter School Fails?*, PBS, <http://www.pbs.org/closingtheachievementgap/faq.html#q3> (last visited Mar. 4, 2012) (identifying that financial issues can be a factor in charter school closings).

stymie support to public charter schools by providing them with less money than traditional public schools. The questions presented earlier concerning the merits of both sides of the equal funding debate and proposed solutions are addressed in the following discussion.

This Note addresses whether public charter schools should receive funding equal to their traditional counterparts and reveals compelling arguments from both sides of the dispute. This Note argues that states should endorse equal funding changes to charter school laws because these improvements will place all public schools (regardless of traditional or charter status) on the same financial footing, thus providing students with equal educational opportunities under the law. Arguably, an effort to equalize funding to charter schools will shift the spotlight from the finance disparity debate, to a more important issue—how to provide the best educational programs (*regardless of traditional or charter status*) to students that so often slip through the cracks.

This Note presents the following two proposals. First, equal funding litigation efforts should be modeled after successful disparate funding cases like *Sugar Creek Charter School, Inc. v. Charlotte-Mecklenburg Board of Education*,²³ which sought the transfer of the local current education expense for each child who transferred from a traditional public school to a charter school. Second, state legislatures should amend their charter school laws to include provisions for equal funding to charter schools. In the alternative, state legislatures should implement merit-based funding provisions, which would require both charter and traditional public schools to compete for public funds similar to what has been implemented in the recent *Race to the Top* incentive created by the United States Department of Education.²⁴

Part I of this Note provides the necessary foundation for understanding charter schools. In particular, Part I discusses the origin of charter schools, charter school success rates, and how charter schools are funded. Part II examines the various failed litigation efforts to

23. *Sugar Creek Charter Sch., Inc. v. Charlotte-Mecklenburg Bd. of Educ.*, 673 S.E.2d 667 (N.C. Ct. App. 2009); see also discussion *infra* Part II.B.

24. See *Race to the Top for Charter Schools*, PR NEWSWIRE (June 15, 2009), <http://www.prnewswire.com/news-releases/race-to-the-top-for-charter-schools-62110867.html> (“*Race to the Top for Charter Schools: 2009 Ranking and Scorecard* finds that the most important factors influencing the creation of a high number of successful charter schools are independent authorizing entities, *fiscal equity*, and operation independence.”) (emphasis added); see also U.S. DEP’T. OF EDUC., *RACE TO THE TOP EXECUTIVE SUMMARY 2* (2009), available at <http://www2.ed.gov/programs/racetothetop/executive-summary.pdf> (explaining that this is a new federal program that will “reward States that have demonstrated success in raising student achievement”).

advance the equal funding cause on behalf of charter schools, and highlights successful litigation strategies that may provide a remedy for disparate funding. Part II also takes a close look at pertinent case law, policy debates, and societal concerns that have been asserted for and against equal funding efforts. Part III analyzes the major arguments for and against equal funding of charter schools, and highlights flaws in the arguments against equal funding for charter schools. Finally Part IV proposes some solutions to the equal funding debate. On one hand, Part IV argues that a new litigation strategy may be implemented to yield success in charter school finance litigation. On the other hand, Part IV argues for a new interdisciplinary policy rationale to support the proposal for a change in funding legislation and public policy.

I. BACKGROUND: THE CHARTER SCHOOL EXPLOSION

A. A Brief History of Public Charter Schools in America and the Problems they Were Created to Ameliorate

In 1991, Minnesota enacted the first charter school law,²⁵ and in 1992, the first charter school opened in St. Paul, Minnesota.²⁶ Since then, charter schools have grown rapidly in America.²⁷ Charter school laws exist in forty-one states and the District of Columbia,²⁸ and there are currently over 5,000 charter schools that serve over 1.6 million children.²⁹ Despite this surge in charter schools, there are still nine remaining states that do not have charter school laws.³⁰

25. See *Origins of Chartering Timeline*, *supra* note 1.

26. See *Resources on Minnesota Issues: Charter Schools*, MINN. LEGIS. REFERENCE LIBR., <http://www.leg.state.mn.us/lrl/issues/issues.aspx?issue=charter> (last reviewed Sept. 2010) (“Minnesota was at the forefront of the nation in passing legislation to create the first legislated charter school.”); see also CITY ACAD. HIGH SCH., <http://www.cityacademy.org/> (last visited Feb. 23, 2012) (explaining that City Academy, a high school located in St. Paul, Minnesota, was established in 1992 and is the nation’s first public charter school.).

27. See *New Report Finds Number of Students Enrolled in Charter Schools Has Nearly Quadrupled Since 1999*, AM. INST. RES., http://www.air.org/reports-products/index.cfm?fa=ViewContent&content_id=842 (last visited Mar. 1, 2012) (“From 1999 to 2008, the number of students enrolled in charter schools has nearly quadrupled, from 340,000 to 1.3 million students. During this period, the percentage of all public schools that were charter schools increased from 2 to 5 percent.”).

28. See *Frequently Asked Questions: What Role Do State Governments Play in the Development of Charter Schools?*, *supra* note 12.

29. See W. Holmes Finch, *Foreword to* MEAGAN BATDORFF ET AL., CHARTER SCHOOL FUNDING: INEQUITY PERSISTS i (2010), available at <http://cms.bsu.edu/Academics/CollegesandDepartments/Teachers/Schools/Charter/CharterFunding.aspx> (Charter schools have grown by more than 50% in the past five years.).

30. See *Laws & Legislation: Charter School Law*, CTR. FOR EDUC. REFORM, <http://www.edreform.com/issues/choice-charter-schools/laws-legislation/> (last visited Mar. 4, 2012) (discuss-

A charter school is:

[A] nonsectarian public school of choice that operate[s] with freedom from many of the regulations that apply to traditional public schools. The ‘charter’ establishing each such school is a performance contract detailing the school’s mission, program, goals, students served, methods of assessment, and ways to measure success. . . . Charter schools are accountable to their sponsor—usually a state or local school board—to produce positive academic results and adhere to the charter contract.³¹

Charter schools are granted more flexibility and freedom in the way they operate,³² “in exchange for increased accountability and scrutiny.”³³ Also, charter schools are typically not bound by the same strict districting guidelines as traditional public schools and can therefore “enroll any student in the district, rather than being limited to students living in the school’s immediate vicinity.”³⁴ Charter schools are not allowed to screen for student acceptance or select students based on certain criteria; further, most states require that students be selected for admission into limited capacity charter schools through a lottery system.³⁵

Charter schools can be created by converting a traditional public or private school into a charter school, or by starting an entirely new

ing that Alabama, Kentucky, Montana, Nebraska, North Dakota, South Dakota, Vermont, Washington and West Virginia do not have charter school laws).

31. *U.S. Charter Schools: An Overview and History of Charter Schools*, INFO USA, http://usinfo.org/enus/education/overview/charter_schools_history.html (last visited Mar. 4, 2012); see, e.g., DEL. CODE ANN. tit. 14, § 501 (West 2011) (stating that the purpose of the Delaware public charter school law is to “create an alternative to traditional public schools . . . and improve public education”); see also Deana R. Peterson, *Leaving No Child Behind: Why Were Charter Schools Formed and What Makes Them Successful?*, 12 J. GENDER RACE & JUST. 377, 377-80 (2009) (providing a brief explanation of charter schools).

32. See Kevin S. Huffman, *Charter Schools, Equal Protection Litigation, and the New School Reform Movement*, 73 N.Y.U. L. REV. 1290, 1291 (1998) (“[Charter] schools receive considerably more autonomy from state and local regulation in terms of student recruitment, curriculum, budget, and staffing.”).

33. Susan Harper, *Funding Our Future: Charter School Finance 101*, FED. RES. BANK OF SAN FRANCISCO, <http://www.frbsf.org/publications/community/investments/0405/article4.html> (last visited Feb. 24, 2012); see also Rubio, *supra* note 19, at 1649 (explaining that charter schools receive greater autonomy “at the price of increased accountability”).

34. Huffman, *supra* note 32, at 1294; see also Note, *The Limits of Choice: School Choice Reform and State Constitutional Guarantees of Educational Quality*, 109 HARV. L. REV. 2002, 2002 n.2 (1996) (citing CTR. FOR EDUC. REFORM, *SCHOOL REFORM IN THE UNITED STATES: STATE BY STATE SUMMARY 3* (1995) (on file with the Harvard Law School Library)) (“Eleven states permit students to choose schools anywhere throughout the state (‘interdistrict choice’), and nine other states allow public school choice within some districts (‘intradistrict choice’).”).

35. See Huffman, *supra* note 32, at 1299. Some schools use a first-come-first-served admissions policy. *Id.*

school.³⁶ When creating a new school, an organization or individual will apply for a charter in the state, and once the charter is granted, the school will operate for a fixed period of time according to that charter agreement.³⁷ Typically, charter schools are started and run by nonprofit organizations;³⁸ however, sometimes these nonprofit organizations partner with for-profit organizations “for the operation and management of the schools.”³⁹ Further, approximately five states do not restrict charter schools to nonprofit management, thus some charter schools are completely run by for-profit entities.⁴⁰

Charter schools were created to help remedy many of the public school system’s failures.⁴¹ According to a recent news report, the failures of public education are unacceptable.⁴² Therefore, charter schools “serve as choice schools”⁴³ and are designed to increase equal access to an adequate education, provide parents and children with alternatives to their current public schools, serve as a system and model for accountability in the education world, encourage innovation and flexibility in the classroom for teachers and administrators, and promote community involvement.⁴⁴

36. See Rubio, *supra* note 19, at 1648.

37. See Harper, *supra* note 33. In Washington D.C., charters are granted by the D.C. Board of Education or the D.C. Public Charter School Board for 15 years with unlimited renewals. See District of Columbia School Reform Act of 1995, D.C. CODE § 38-1802.12(a)(1)-(2) (1996); see also CTR. FOR EDUC. REFORM, CHARTER SCHOOL LAWS ACROSS THE STATES: RANKINGS AND SCORECARD (Alison Consoleti ed., 12th ed. 2011), available at <http://www.edreform.com/2012/01/17/ce-rcer-charter-laws-2011/> (outlining basic information on all state charter school laws).

38. See Rubio, *supra* note 19, at 1664-65.

39. *Id.* at 1665; see also Forman, Jr., *supra* note 19, at 843.

40. See Rubio, *supra* note 19, at 1664-65, 1665 n.149 (citing PRESTON C. GREEN III & JULIE F. MEAD, CHARTER SCHOOLS AND THE LAW: ESTABLISHING NEW LEGAL RELATIONSHIPS 5-8 (2004)) (noting that Arizona, Colorado, New York, Virginia, and Wisconsin do not restrict charter school operation to non-profit organizations); see also Driscoll, *supra* note 19, at 505-06 (providing a brief explanation of “The Basics” of the process for establishing a charter school).

41. See Peterson, *supra* note 31, at 383. Parents choose charter schools for their high academic standards, small class sizes, innovative approaches, educational philosophy which is in line with their own, and small school size which is associated with a feeling of safety. *Id.*

42. See ABIGAIL THERNSTROM & STEPHAN THERNSTROM, NO EXCUSES: CLOSING THE RACIAL GAP IN LEARNING 12 (2003) (“NAEP [(National Center for Education Statistic)] results consistently show a frightening gap between the basic academic skills of the average African-American or Latino student and those of the typical white or Asian American. By twelfth grade, on average, black students are four years behind those who are white or Asian. Hispanics don’t do much better.”) (footnote omitted); see also Peter Enrich, *Leaving Equality Behind: New Directions in School Finance Reform*, 48 VAND. L. REV. 101, 103 (1995) (“The quality of the educational opportunities offered in the public schools of most American urban centers, and in many other underfinanced districts as well, remains shockingly poor.”).

43. See THERNSTROM & THERNSTROM, *supra* note 42, at 265 (providing a discussion on school choice); see also Huffman, *supra* note 32, at 1294.

44. *Charter School FAQ: Why Are Charter Schools So Popular?*, PBS, <http://www.pbs.org/closingtheachievementgap/faq.html#q4> (last visited Mar. 4, 2012) (explaining that charter

Specifically, public schools have fallen behind and received criticism for a number of academic failures.⁴⁵ Students in high-poverty communities, usually minorities, consistently achieve less than students in low-poverty communities and are less likely to attend college.⁴⁶ Further, on average, students in high-poverty communities have lower scores in reading, mathematics, and music and visual arts.⁴⁷ Currently, sixty-eight percent of eighth graders read below grade level, and thousands of students drop out of school every day.⁴⁸ These failing results have dire consequences and necessitate a promising alternative like charter schools.⁴⁹ In spite of the poor state of public education in America, it is still important to note that some traditional public schools have achieved notable improvements and have been considered just as, or more, successful than charter schools.⁵⁰

schools provide more “child-centered education” and encourage the rest of the public education system to do better).

45. See generally NAT'L CTR. FOR EDUC. STATISTICS, *THE CONDITION OF EDUCATION* (2011), available at <http://nces.ed.gov/programs/coe/> (summarizing the important developments and trends in education through the use of the latest available data.).

46. Valerie Strauss, *1 in 6 U.S. Students in High-Poverty Schools*, WASH. POST (May 28, 2010, 12:07 PM), <http://voices.washingtonpost.com/answer-sheet/equity/1-in-6-students-in-high-povert.html> (noting that one in six public school students is now in high-poverty schools).

47. See *Closer Look 2010: High-Poverty Public Schools*, NAT'L CTR. EDUC. STAT., <http://nces.ed.gov/programs/coe/analysis/2010-section3a.asp> (last visited Mar. 6, 2012).

48. See Joann M. Weiner, *Charter School Lottery Gambles with Kids' Futures – and Often Loses*, POL. DAILY (July 15, 2010), <http://www.politicsdaily.com/2010/07/14/charter-school-lottery-gambles-with-kids-futures-and-often-l/> (stating that the word “failed” most accurately describes the current state of public education in America).

49. See EDELMAN, *supra* note 21, at 81 (“[I]ncarceration is becoming the new American slavery and poor children of color are the fodder.”); SCHOOLTOPRISON, <https://www.schoolto-prison.org/> (last visited Mar. 1, 2012) (providing a forum which encourages attorneys and advocates to share strategies and ideas of ways to challenge the pushing out of children from schools into the criminal justice systems). See generally *School to Prison Pipeline*, ACLU, <http://www.aclu.org/racial-justice/school-prison-pipeline> (last visited Mar. 3, 2012) (documenting and challenging America’s public education establishment which systematically sends children from public school into the criminal justice system).

50. For instance, in the nation’s capital, the tension between equal charter school funding and keeping with the status quo is further complicated by the fact that both charter and traditional public schools have seen improvements in math and reading at the secondary school level. Cane, *supra* note 1 (“Over the past three years, charters raised student proficiency . . . from 43 to 57 percent in math and 43 to 52 percent in reading. . . . [and the] regular school system raised . . . proficiency from 29 to 42 percent in reading and 26 to 43 percent in math.”). But see Ben Wildavsky, *Relax, America. Chinese Math Whizzes and Indian Engineers Aren’t Stealing Your Kids’ Future*, FOREIGN POL’Y (Mar./Apr. 2011), http://www.foreignpolicy.com/articles/2011/02/22/think_again_education (providing a more relaxed response to the typical panic that accompanies gloomy statistics on America’s dwindling position in the international education race and suggesting that the nationality factor is not as important as it used to be when considering who wins the education race worldwide).

B. Understanding How Charter Schools Are Funded Throughout the States

As previously discussed, charter schools are products of state law.⁵¹ Therefore, each state creates its own charter school laws and includes funding provisions for how much money it will allocate to charter schools.⁵² These funding schemes are usually similar to the funding systems for traditional public schools, however, on unequal terms and with some exceptions. It is also important to note that studies about both traditional and charter school finance lack uniformity because funding guidelines vary from state to state and even district to district.⁵³

However, in general, traditional public schools are financed through three standard sources: federal, state, and local government funding.⁵⁴ In great part, these sources consist of state grants and locally raised property taxes.⁵⁵ Likewise, charter schools receive most

51. See *Laws & Legislation: Charter School Law*, *supra* note 30.

52. See Chester E. Finn, Jr. & Eric Osberg, *Foreword* to THOMAS B. FORDHAM INST., CHARTER SCHOOL FUNDING: INEQUITY'S NEXT FRONTIER vii (Chester E. Finn, Jr. & Eric Osberg eds., 2005), available at http://www.edexcellence.net/detail/news.cfm?news_id=344 ("As everyone who has spent time in the charter-school world knows, the answer to every policy question begins with the sentence, 'It depends on the state.'"); see, e.g., District of Columbia School Reform Act of 1995, D.C. CODE § 38-1804.01(b)(2) (1996) ("Formula calculation . . . the amount of the annual payment . . . shall be calculated by multiplying a uniform dollar amount used in the formula . . . by the number of students calculated under [other sections in the code].").

53. See Rubio, *supra* note 19, at 1649 ("Any discussion of charter schools must therefore keep in mind both the variety that characterizes the national charter movement and the role of state statutes in determining the nature of these variances.").

54. See *id.* at 1650.

States rely primarily on income and sales taxes to fund elementary and secondary education. State legislatures generally determine the level and distribution of funding, following different rules and procedures depending on the state.

. . . Many states use funding formulas that provide funding based on the number of pupils in a district. Some formulas are weighted based on different factors such as the number of students with disabilities, the number of students living in poverty, or the number of students for whom English is a second language. The allocation for students with different types of needs can vary significantly depending on the funding formula. Additionally, in some states the formula is designed so that higher poverty school districts with less access to local funding receive additional assistance.

The share of total education funding provided by the state government differs from state to state. In some states the state share is as high as 86 percent, while in others it is as low as 31 percent. States that rely heavily on local property taxes instead of state funding to fund elementary and secondary education, often have larger funding disparities between school districts in the state.

Background & Analysis: School Finance, NEW AM. FOUND. FED. EDUC. BUDGET PROJECT, <http://febp.newamerica.net/background-analysis/school-finance> (last visited Feb. 24, 2012).

55. See Enrich, *supra* note 42, at 104 ("Because of wide variations in the property wealth of the districts within a state, the [local] property tax [model for public school finance usually] provides sharply disparate levels of support for the various districts, resulting in dramatic disparities in the total funding available for education in the different communities.").

of their funding (often on unequal terms when compared to traditional public schools) from federal, state, and local government sources.⁵⁶ Charter schools may also receive private grants and loans.⁵⁷

Accordingly, since charter schools are public schools, they are eligible to receive money from state or district operating funds based on the average daily attendance (“ADA”) of the students enrolled.⁵⁸ So, the charter school is paid, or reimbursed according to how many students attend the school, on average, each day.⁵⁹ Therefore, the charter school will receive per pupil funding, allocated by the state or local district according to the average amount of children that attended the school during the month or year.⁶⁰

Further, funding for traditional public school facilities or capital accounts is often supplied through “local revenue streams.”⁶¹ That is, “[t]ypically, public school districts cover facility costs by selling tax-exempt bonds, accessing funds from local taxes, or collecting state appropriations.”⁶² However, again, charter schools are either completely denied access to these revenue streams or allowed partial access.⁶³ In sum, charter school finance is primarily composed of per pupil funding, little to no facilities and capital costs funding, and no private or government grants and loans.

C. The Effects of Disparate Funding on Charter Schools

Studies have shown that “[n]ationwide, on average, charter schools are funded at 61[%] of their district counterparts, averaging \$6,585 per pupil per school year compared to \$10,771 per pupil at

56. *See id.*

57. *See id.*; *see also* MEAGAN BATDORFF ET AL., CHARTER SCHOOL FUNDING: INEQUITY PERSISTS 11 (2010), available at <http://cms.bsu.edu/Academics/CollegesandDepartments/Teachers/Schools/Charter/CharterFunding.aspx>; Forman, Jr., *supra* note 19, at 869-73 (explaining the role of private philanthropy in charter school success and identifying specific schools noted for their fundraising efforts).

58. *See Charter School FAQ: How Are Charter Schools Funded?*, *supra* note 16.

59. *See id.* Per pupil funding is a standard amount of money assigned to each pupil that attends public school. *See id.* For example, state X may allocate \$9,000 per pupil, per year for every charter school. Accordingly, a charter school would also potentially receive \$9,000 multiplied by the ADA – 150 students, which would equal \$1,350,000 for one school year.

60. *See* Harper, *supra* note 33. This does not mean that charter schools receive funding based on the number of students enrolled. For example, if there are 200 students enrolled, and only 150 students attend school on average, then charter schools will only receive per pupil funding for 150 students.

61. *Id.*

62. Rubio, *supra* note 19, at 1663.

63. *See id.* (“[C]harter schools often could not access these sources of facilities funding because they operated outside the school district”); *see also* Harper, *supra* note 33.

traditional district public schools.”⁶⁴ The most recent studies confirm that charter schools are significantly underfunded, with the average state disparity being 19.2% or over a \$2,000 difference for per pupil funding between charter schools and traditional public schools.⁶⁵ Further, the studies conclude that these disparities are not caused by differences in students’ needs between the schools.⁶⁶ That is, the studies controlled for factors which could be viewed as a legitimate reason for the disparate funding, including: differences in the number of students with disabilities, the number of free or reduced lunch services provided to students, and differences in grade levels provided by the schools.⁶⁷ The studies indicate that funding disparities are mostly attributed to the fact that *no* state provides charter schools with access to all of the funding sources granted to traditional public schools.⁶⁸ Instead, most states provide less funding to charter schools by giving them less per pupil funding and little to no facilities funding.⁶⁹ As discussed below, this trend in disparate funding is often attributed to politics, inadequate funding provisions in charter school laws, and an on-going policy of skepticism toward charter schools.⁷⁰

Although, some states have attempted to fund charter schools on par with traditional public schools, there remains a huge gap in funding between the two school factions.⁷¹ One author concluded that there are four major charter school spending areas that require more adequate resources: (1) start-up funds, (2) per pupil funding, (3) facilities funding, and (4) technical support.⁷² Most charter schools do not

64. *Laws & Legislation: Charter School Law*, *supra* note 30.

65. See CHARTER SCHOOL FUNDING: INEQUITY PERSISTS, *supra* note 57, at 11; see also Jonathan Kantowitz, *Disparity in Public Funding of Public Charter, Traditional Schools*, EDUC. RES. REP. (May 25, 2010), <http://educationresearchreport.blogspot.com/2010/05/disparity-in-public-funding-of-charter.html> (noting that on average America’s public charter schools receive \$2,247 less in funding than traditional public schools).

66. See CHARTER SCHOOL FUNDING: INEQUITY PERSISTS, *supra* note 57, at 5-9.

67. See *id.* at 7-9 (finding that funding differences still exist even when controlling for differences in student special education need, students’ family economic need, or differences in grades serviced by different schools).

68. See *id.*

69. See discussion *supra* Part I.C.

70. See discussion *supra* Part III.A.

71. See *Charter School FAQ: How Are Charter Schools Funded?*, *supra* note 16; see also CTR. FOR EDUC. REFORM, *Charter School Funding State-by-state Funding Comparison* (2006) (on file with author) (comprehensive state survey outlining the per pupil funding gap between conventional public schools and public charter schools).

72. See Jamie Gottlieb, *Harmonizing No Child Left Behind’s Restructuring Provision and State Charter School Laws: The Need for Autonomy, Flexibility, and Adequate Resources*, 39 SETON HALL L. REV. 191, 218-23 (2009); see also Rubio, *supra* note 19, at 1662 (identifying four sources of underfunding to charter schools including: federal, state, local, and facilities funding).

receive funding to cover facility costs, start-up costs, or other capital costs.⁷³ Further, studies have indicated that facilities funding is the biggest cause of the funding disparity, ultimately creating a significant problem for charter school development and sustainability.⁷⁴

State laws typically do not grant charter schools funding to acquire facilities in which to house their schools.⁷⁵ Therefore, where states do not provide facilities or funding to lease or purchase facilities, charter schools must usually seek loans, lease facilities on their own, and/or use a portion of their per pupil funding, which would otherwise go to instructional costs.⁷⁶ Although sometimes charter schools receive state or federal grants to acquire facilities,⁷⁷ the facilities funding source represents yet another major hurdle charter schools must overcome while racing to academic success.⁷⁸ As a result, charter school officials must concentrate additional energy and resources on obtaining and maintaining facilities, instead of on student performance.⁷⁹

In order to account for many of these facilities funding disparities, charter schools have to “improvise.”⁸⁰ To provide facilities, charter schools often start out by converting alternative spaces like former churches or warehouses, into school spaces.⁸¹ In addition, it is important to note that charter schools may also apply for and receive federal grant money for start-up costs; they may also receive other

73. See *Charter School FAQ: How Are Charter Schools Funded?*, *supra* note 16; see also *Laws & Legislation: How Are Charter Schools Funded?*, CTR. FOR EDUC. REFORM, <http://www.edreform.com/issues/choice-charter-schools/laws-legislation/> (last visited Mar. 4, 2012).

74. See Rubio, *supra* note 19, at 1662 (noting that none of the surveyed jurisdictions with charter school laws allowed for “full access” to facilities funding). In fact, “[a]ll facilities and capital funding [disparities are] widely recognized as the most acute problem[s] facing many charter schools.” *Id.* Unfortunately, “[f]acilities funds . . . are the source to which charter schools enjoy the least access.” *Id.*; see also MEGAN BATDORFF ET AL., *supra* note 57, at 3.

75. See Gottlieb, *supra* note 72, at 221; see also District of Columbia School Reform Act of 1995, D.C. CODE § 38-1805.52 (1996) (noting that the Mayor shall “consider the facilities needs of all public school students” but not allocating actual facilities to public charter schools in the District of Columbia).

76. See Gottlieb, *supra* note 72, at 221.

77. See *id.*

78. See Rubio, *supra* note 19, at 1663 (“Facilities funding is thus critical to the operation of most charter schools.”).

79. See *id.* (“[T]he primary alternative [facilities funding] source for many charter schools was the per-pupil allotments from the district and state.”).

80. See *About ACS: How Do Charter Schools Manage If They Are Underfunded?*, ATLANTIS, <http://www.atlantiscs.org/faq.php> (last visited Mar. 4, 2012); see, e.g., *About KIPP DC*, KIPP DC, <http://www.kippdc.org/about/about-kipp-dc/> (last visited Feb. 5, 2012) (noting that KIPP DC improvised by starting out in a church basement with its first school).

81. See *About ACS: How Do Charter Schools Manage If They Are Underfunded?*, *supra* note 80.

federal monies, which help supplement the lack of equal funding.⁸² For example, a charter school may receive Title I and Special Education monies.⁸³ Charter schools may also apply for private grants.⁸⁴ Specifically, many charter schools have been able to leverage private funding from philanthropists or other sources as a result of their significant academic achievements.⁸⁵ Although these supplemental revenue sources help, charter schools still require access to facilities funding or resources.⁸⁶

Unlike most traditional public schools, charter schools must use their per pupil funding, in addition to whatever grants or private funding they secure to finance all of the schools' operating expenses.⁸⁷ Personnel expenses account for 50-70% of a charter school's operating budget.⁸⁸ Student-based needs such as curriculum materials, school supplies, and books account for up to 15% of the operating budget.⁸⁹ And, facilities costs account for up to 20% of a charter school's budget,⁹⁰ even though charter schools typically are not granted facilities funding.

As a result of disparate funding systems, charter schools are obligated to take additional steps in order to ensure the financial viability of their schools. Financial instability places charter schools at risk of losing their charters and closure.⁹¹ Therefore, like any public institu-

82. *See id.* ("Also significant in operational expenses are categorical federal education grant funds. These funds generally . . . (1) [are] distributed directly by the U.S. Department of Education through its own application process, or (2) channeled through state education agencies . . .").

83. *See Equitable Operational Funding and Equal Access to All State and Federal Categorical Funding*, NAT'L ALLIANCE FOR PUB. CHARTER SCH., <http://www.publiccharters.org/law/ViewComponent.aspx?comp=21> (last visited Mar. 4, 2012).

84. *See* Terence Chea, *Charter Schools Expand with Public, Private Money*, HUFFINGTON POST (Jan. 21, 2011 6:05 AM), http://www.huffingtonpost.com/2011/01/21/charter-schools-expand_n_812183.html?view=screen (discussing the private funds that assist charter schools).

85. *See* Harper, *supra* note 33.

86. *See* Tanya Hutchins, *Debate Continues Over Charter School Funding*, NBC4i (Nov. 16, 2010), <http://www2.nbc4i.com/news/2010/nov/16/debate-over-charter-school-funding-ar-292569/>. Columbus, Ohio charter schools do not receive equal state funding or facilities funding. *Id.* The Director of Horizon Science Academy Middle School explains that access to unused public school buildings or at least monies for facilities "will help a whole lot." *Id.*; *see also Facilities Funding*, BEFAIRDC, www.befairdc.org (last visited Feb. 25, 2011). In D.C., although traditional public schools received approximately \$3,200 per pupil for facilities costs in 2010, public charter schools only received approximately \$2,800. *Id.*

87. *See* Harper, *supra* note 33.

88. *See id.*

89. *See id.*

90. *See id.*

91. *See* Forman, Jr., *supra* note 19, at 866, 871 (arguing that charter school dependence on unstable private funding, "is possibly the Achilles heel of the quasi-market reform," and leaves them "financially vulnerable").

tion, financial support is a major component of a charter school's overall success and the reality of disparate funding should be treated seriously.⁹²

D. Do Charter Schools *Really* Work?

Initially, charter schools were met with skepticism. Seemingly, the education establishment lacked confidence in charter schools for various reasons, including the arguments that: charter schools are not accountable, charter schools steal funding from traditional public schools, charter schools promote profiteering and misusing funds, and various other reasons related to performance and sustainability.⁹³ In sum, all of these stereotypes, albeit some based in truth, have contributed to some of the negative publicity surrounding charter schools. Thus, when the equal funding debate arose, as a matter of policy and smart spending, it was understandable why most state legislatures were hesitant to provide equal funding to charter schools. However, it is still important to examine the data regarding where charter schools stand on the platform of academic successes and improvements.

Although, an overwhelming amount of evidence supports a finding that, on average, charter schools push student achievement rates up to par; overall, studies revealed that the answer regarding whether all charter schools are successful, is still debatable.⁹⁴ A recent Fordham Institute report indicates that:

Some charter schools are superb, others dismal. But this institutional innovation has proven hugely popular with parents, children, educators, and communities because it provides an outlet for committed citizens and entrepreneurial educators to do something

92. See generally BEFAIRDC, *supra* note 86 (describing disparities in per pupil funding, facilities funding, and facilities access in Washington, D.C., and advocating that the legislature adhere to the equal funding mandates of D.C. charter school laws for "fair funding").

93. See Bruno v. Manno, *The Case Against Charter Schools*, BUS. LIBR. (May 2001), http://findarticles.com/p/articles/mi_m0JSD/is_5_58/ai_76880214/?tag=content;coll.

94. See *Charter Schools*, EDUC. WEEK, <http://www.edweek.org/ew/issues/charter-schools/> (last updated May 25, 2011); see also Huffman, *supra* note 32, at 1300-02. Proponents identifying the positive impacts of charter schools propose that the schools are successful and important contributors to education reform because they: (1) provide increased competition amongst schools, entrepreneurial opportunities for teachers, and accountability for results; (2) provide increased innovation, which in turn creates a ripple effect to pressure traditional schools to improve; (3) minimize a monopolistic public school system by providing school options for students, similar to the options available to the wealthy; (4) can be terminated for failure, and therefore removed as a dead expense to the state; and (5) they meet the needs of more low-income students than traditional public schools. *Id.*

about the appalling school options facing hapless children and desperate families in far too many places.⁹⁵

Essentially, even though the conclusion as to whether charter schools are successful is debatable, several authorities agree that they are a welcomed innovation among many communities, and there are a number of exceptional charter schools that have made significant improvements to the state of education, pedagogical practices, and communities.⁹⁶

In retrospect, the greatest cause of charter school failure has been “financial or management deficiencies.”⁹⁷ Typically, school closures have been attributed to either a lack of financial footing, a failure to meet the charter school accountability standards required to renew the charter contract, or an inability to attract students to attend.⁹⁸ The first charter school was closed in 1995.⁹⁹ Since then, approximately eleven-percent of over 5,000 charter schools ever created (550 charter schools) in the United States have closed.¹⁰⁰

On the other hand, since the inception of charter school laws, a number of charter school franchises have nearly perfected the charter school model, creating efficient spending models, hiring quality teachers, achieving outstanding student results, and ultimately complying with and exceeding performance standards required in state charter laws. For example, KIPP schools—the Knowledge is Power Program¹⁰¹—has been widely acclaimed for its excellence and student performance in education by educators, communities, and school gov-

95. Finn, Jr. & Osberg, *supra* note 52, at v.

96. For instance, in a study performed on fourth grade students, results showed that charter school students were four-percent more likely to be more proficient in reading and two-percent more likely to be proficient in math. See *Choice and Charter Schools: Do Charter Schools Work?*, CTR. FOR EDUC. REFORM, <http://www.edreform.com/2011/09/25/do-charter-schools-work/> (last visited Feb. 23, 2012); see also Peterson, *supra* note 31, at 385 (identifying 2003 NAEP report statistics that support that charter schools improve student achievement in several states including Arizona, California, and Colorado). In addition, in Washington, D.C., charter schools hold the title of “highest student test scores” in both high school and middle school, and have surpassed traditional public schools in raising high school graduation rates and college acceptance rates even though they service more students with demanding needs. See Cane, *supra* note 1 (“[P]ublic charter schools have pushed high-school graduation and college-acceptance rates above the level that the reforming school system has achieved while serving a greater share of economically disadvantaged and minority students than D.C. Public Schools.”).

97. CTR. FOR EDUC. REFORM, *CHARTER SCHOOLS: TODAY CHANGING THE FACE OF AMERICAN EDUCATION PART 3: CHARTER SCHOOL CLOSURES THE OPPORTUNITY FOR ACCOUNTABILITY* 1 (Jeanne Allen et al. eds., 2006).

98. See *id.*

99. See *id.*

100. See *id.*

101. See *About KIPP*, KIPP, <http://www.kipp.org/about-kipp> (last visited Mar. 23, 2012). KIPP is a “national network” of high performing public charter schools. *Id.*

erning bodies alike. Similarly, Urban Prep,¹⁰² an all boy's public charter school in Chicago, Illinois marked its first graduation in 2010 by sending 100% of its students, all inner-city boys from destitute neighborhoods and with slim chances of success,¹⁰³ to college.¹⁰⁴

II. LEGAL ARGUMENTS CONCERNING INEQUITIES IN CHARTER SCHOOL FUNDING

A. Failed Litigation Efforts to Cure Inequities in Charter School Funding

In a recent New Jersey Supreme Court case, the court refused to apply the state's equal protection standard to inequities in charter school funding.¹⁰⁵ In *Scipio-Derrick v. Davy*, four students attending charter schools in Newark, New Jersey, brought a class action against the state on behalf of all students attending Newark charter schools.¹⁰⁶ The students claimed that per pupil funding provisions in the N.J. Charter School Program Act, and funding provisions in the N.J. Construction and Financing Act denied students at charter schools the right to equal per pupil funding and facilities funding.¹⁰⁷ Thus, the statutes violated students' equal protection rights under the New Jersey Constitution.¹⁰⁸

The trial and appellate courts dismissed the action for failure to state a claim, and the New Jersey Supreme Court affirmed, holding that the equal protection clause was not applicable to school funding issues.¹⁰⁹ Further, the court held that the plaintiffs' contention was

102. See generally URBAN PREP ACADS., 2009 URBAN PREP ACADEMIES ANNUAL REPORT (2009), available at http://www.urbanprep.org/about/pdf/Urban_Prep_Year_In_Review_2008_to_2009.pdf (providing general information about the charter school including: the school's purpose, model, academic successes, finances, and other critical aspects).

103. Before attending Urban Prep, Krishaun Branch "was getting D's, smoking reefer a lot, skipping school twice a week . . . [H]e liked to fight and hang out in the streets; having relatives in gangs was his armor." Associated Press, *The 100 Percenters: Inner-city Boys School Marks First Graduation, Sends 107 to College*, FOX NEWS (Jun. 28, 2010), <http://www.foxnews.com/us/2010/06/28/percenters-inner-city-boys-school-marks-graduation-sends-college-1568150205/>. Urban Prep services students from "the poorest, gang-ravaged neighborhoods." *Id.*

104. See *id.*

105. J.D. *ex rel.* Scipio-Derrick v. Davy, 2 A.3d 387, 401 (N.J. Super. Ct. App. Div. 2010).

106. See *id.* at 388.

107. See *id.*; see also Construction and Financing Act, N.J. STAT. ANN. § 18A:7G-1 (West 2008); Charter School Program Act of 1995, N.J. STAT. ANN. §§ 18A:36A-10, -12 (West 2000) (barring charter schools from receiving state or local facilities funding and providing 90% per pupil funding for operation costs).

108. See *Scipio-Derrick*, 2 A.3d at 388.

109. See *id.* at 392, 401.

better suited for petitioning the legislature, not the judiciary.¹¹⁰ The court explained that although certain cases opened the door to equal protection claims in education; the overwhelming authority leaned toward “thorough and efficient”¹¹¹ (“T & E”)¹¹² claims to resolve funding discrepancies in schools.¹¹³

The New Jersey Supreme Court recognized many of the common arguments against equal funding for charter schools. Primarily, the court’s ruling was based on a legislative intent argument that focused on the language in the existing charter school statute.¹¹⁴ However, the court also included a number of policy arguments to support its ruling.

First, the court supplied a statutory interpretation argument and identified that the New Jersey law was “deliberately” designed to enhance the education of *all* students.¹¹⁵ As such, the court found that the law applied equally to all students; therefore, it did not violate plaintiffs’ equal protection rights because they chose to attend charter schools.¹¹⁶ Next, the court supplied several policy arguments to support its ruling.

As part of its analysis, the court recognized the following four policy arguments in favor of disparate funding. First, the court considered the need to allocate scarce resources between two school factions and the need to budget in favor of traditional public schools, which were first in line.¹¹⁷ Second, the court considered the need to address

110. *See id.* at 400-01.

111. *See* N.J. CONST. art. VIII, § 4 ¶ 1 (“The Legislature shall provide for the maintenance and support of a thorough and efficient system of free public schools for the instruction of all the children in the State between the ages of five and eighteen years.”); N.J. STAT. ANN. § 18A:7A-10 (explaining that the purpose of the “thorough and efficient” standard is to “ensure that all districts are operating at a high level of performance” based on “instruction and program; personnel; fiscal management; operations; and governance”).

112. *See* Enrich, *supra* note 42, at 183 (“[A]dequacy arguments should be the tools of choice for further efforts at education finance reform.”).

113. *See* *Scipio-Derrick*, 2 A.3d at 393-95, 400-01; *see also* Enrich, *supra* note 42, at 103 (concluding in support of “thorough and efficient” litigation). Enrich also indicates that “the rhetoric of adequacy shows greater promise than the rhetoric of equality for overcoming the significant legal and political hurdles confronting challenges to existing systems for financing public education.”).

114. *See* *Scipio-Derrick*, 2 A.3d at 400-01.

115. *See id.*

116. *See id.* at 399-400.

117. *See id.* at 398-99; *see also* Note, *supra* note 34, at 2004-05 (“[If a school’s per pupil funding declines because it loses students, then a school that loses] a significant portion of its student body to ‘skimming’ by other schools . . . actually suffer[s] a disproportionate loss of funding because of economies of scale.”). This can affect “school resources, such as computers and gym equipment, [which] are shared by all students in a school. As a result, if a school loses a fraction of its funding, it can afford fewer resources for all of its remaining students, and the overall quality of education at the school may thus decline.” *Id.* at 2004 n.8; *see also* Driscoll,

concerns that charter schools would detract from public school funds and other governmental purposes.¹¹⁸ Third, the court supported the view that charter school students always have the option and right to return to traditional public schools.¹¹⁹ Finally, the court explained that students at charter schools receive an education that is “largely exempt from regulation”; therefore, where the school is not bound by the restraints of the public school system, neither should it be privy to all of the benefits of public education.¹²⁰

The New Jersey Supreme Court’s reasoning is generally representative of current arguments provided against charter schools’ claims for equal funding. In these instances where plaintiffs assert equal protection claims against disparate funding, the court typically only looks at the plain language of the charter school laws and the intent of the legislature. Generally, the courts will not attempt to create a new judicially mandated remedy for charter school funding by legislating from the bench. The New Jersey court has provided strong legal and policy arguments in favor of disparate funding for charter schools; however, disparate funding claims have been successful in some jurisdictions.

B. Successful Litigation Efforts to Cure Inequities in Charter School Funding

Charter school disparate funding claims have been successfully litigated in some cases. In a 2007 Maryland Court of Appeals case, *Baltimore City Board of School Commissioners v. City Neighbors Charter School*,¹²¹ the highest court in Maryland granted great deference to the local School Board of Education’s determination that, with few exceptions, the state charter school law allowed for equal funding between traditional public schools and public charter schools.¹²² In *City Neighbors Charter School*, the court addressed

supra note 19, at 506 (highlighting opponents’ political argument that charter schools will actually “worsen the state of the public education system” by sending “scarce resources and talented students and teachers to schools in which not every student is *eligible to enroll*”) (emphasis added). *But see* Note, *supra* note 34, at 2005 (noting that there is “limited evidence” to support the skimming theory); discussion, *supra* Part I.A (identifying that all students are “eligible” to enroll in charter schools even though not all students are able to enroll due to the limited capacity at most charter schools).

118. *See Scipio-Derrick*, 2 A.3d at 399.

119. *See id.*

120. *See id.* at 397.

121. *Balt. City Bd. of Sch. Comm’rs v. City Neighbors Charter Sch.*, 929 A.2d 113, 131-32 (Md. 2007).

122. *See id.* at 115.

three different appeals for charter school applications—two from Baltimore City public charter schools and one from a Prince George’s County charter school.¹²³

The first case concerned City Neighbors, a non-profit community group that applied for a charter with the Baltimore City Board of School Commissioners.¹²⁴ City Neighbors applied for a charter, and anticipated funding in the amount of \$7,500 per pupil.¹²⁵ However, the Baltimore City Board of School Commissioners granted City Neighbors’ school charter on the condition that the school received funding in “the form of services rather than cash, both of which were unacceptable to City Neighbors.”¹²⁶ City Neighbors filed a petition with the School Board of Education (“SBE”), claiming that they were unable to open on their expected fall 2005 date due to the dispute over funding with the local school board.¹²⁷

In two similar cases, Patterson Park Public Charter School in Baltimore City, and Lincoln Public Charter School in Prince George’s County Maryland experienced almost identical scenarios.¹²⁸ Again, with Patterson Park, the school was denied funding disbursements in the form of cash in order to prepare for its anticipated open date.¹²⁹ Similarly, Lincoln was refused funding due to unresolved negotiations regarding the amount of funding, amongst other things.¹³⁰

In all three scenarios, the charter schools argued that the Maryland law governing charter school funding allowed for equal funding.¹³¹ Under the Education Article of the Maryland Code,¹³² the law provides that the state “shall disburse to a public charter school an amount . . . *commensurate* with the amount disbursed to other public schools in the local jurisdiction.”¹³³ The court upheld the SBE’s equal funding interpretation of the Maryland law. The court found that: (1) the law required a disbursement of cash rather than compensation in services; (2) the law required that school districts provide charter

123. *See id.* at 117.

124. *See id.*

125. *See id.*

126. *Id.* at 118.

127. *See id.*

128. *See id.* at 118-19.

129. *See id.*

130. *See id.* at 119. Lincoln anticipated that it would require the full \$8,554 per pupil funding while the school board proposed to pay the school \$5,495. *Id.*

131. *See id.* at 118-19.

132. MD. CODE ANN., EDUC. §9-109(a) (West 2003).

133. *Id.*; *see also City Neighbors*, 929 A.2d at 117 (emphasis added).

schools with per pupil funding equal to the average funding of local traditional schools; and (3) the funding scheme only required a two-percent deduction from the total per pupil funding provided to charter schools in order to account for administrative services that could only be rendered by the local school board.¹³⁴ The court provided that according to the legislative history, the legislature intended that the charter school funding scheme be based on a per pupil standard, and that the authority for creating a funding formula be placed in the hands of the broader governing body—the SBE, instead of with the local school boards.¹³⁵

This case demonstrates a different approach to the funding dispute. This case shows that when state legislatures are granted great deference in determining the outcome of their funding models and have intended to create an equal funding regime, a court is likely to rule in favor of charter schools because they have the necessary legislative authority to do so. Essentially, this case indicates that there is a choice to be made regarding funding models for charter schools—state legislatures can *choose* to enforce policies, which support equal funding.

Similar to the case in Maryland, a recent North Carolina Court of Appeals case ruled in favor of a charter school's claim for equal funding. In *Sugar Creek Charter School, Inc. v. Charlotte-Mecklenburg Board of Education*, plaintiffs alleged that their local Board of Education denied them the appropriate per pupil funding, and a pro rata share of the Charlotte-Mecklenburg school district's local current expense fund pursuant to a North Carolina statute.¹³⁶ The lower court ruled in favor of Sugar Creek Charter School granting them over one million dollars in back pay that had not been distributed to them in accordance with the statute.¹³⁷ The North Carolina Court of Appeals reversed the trial court in part regarding textbook funds, affirmed in part regarding a majority of the funds granted, and remanded in part.¹³⁸ Even though the Charlotte-Mecklenburg Board of Education argued that it had sole jurisdiction to decide funding issues, the Court of Appeals held that the school board only had authority to supervise

134. See *City Neighbors*, 929 A.2d at 132.

135. See *id.* at 127-31.

136. *Sugar Creek Charter Sch., Inc. v. Charlotte-Mecklenburg Bd. of Educ.*, 673 S.E.2d 667, 669 (N.C. Ct. App. 2009) (citing N.C. Gen. Stat. § 115C-238.29H(b) (West 2006)).

137. See *id.*

138. See *id.* at 677.

and administer educational funds.¹³⁹ Here, unlike the Maryland *City Neighbors* case, the court looked closely at the language of the state's charter laws without giving much deference to the administrative bodies in charge of implementing the laws.

Further, the court looked to the language of the state charter school law to conclude that the legislature intended that charter schools have “access to the same level of funding as children attending the regular public schools of [the] State.”¹⁴⁰ According to the North Carolina charter school law, if a student transfers to a charter school, then “an amount equal to the per pupil *local current expense*”¹⁴¹ follows them to the charter school.¹⁴² Further, the court indicated that the “local current expense fund” language required that charter schools have equal access to all monies contained in the local current education expense fund.¹⁴³ As such, the court granted Sugar Creek Charter School access to all funds including: fund balances, which carried over from the previous fiscal year;¹⁴⁴ the Hurricane Katrina Relief Fund; the sales tax reimbursement fund; a preschool programs and facilities fund; and a donations fund.¹⁴⁵

The North Carolina and Maryland rulings on equal funding for charter schools represent the beginning of a line of litigation that has the potential to grant charter schools funding on par with traditional public schools. However, it is important to note that the major difference between these successful cases and the New Jersey *Scipio-Derrick* case is that here the courts' rulings hinged in great part on the courts' interpretation of the state charter school statutes, which already provided the requisite intent to enforce equal funding. In essence, the legislature already imbedded the intent for equal funding of charter schools in the law, thus the courts were not required to create or impose a judicial remedy on other grounds (*i.e.* equal protection arguments proposed in *Scipio-Derrick*).

139. *See id.* at 670-73.

140. *Id.* at 673.

141. N.C. GEN. STAT. § 115C-238.29H(b) (West 2006) (emphasis added) (“If a student attends a charter school, the local school administrative unit in which the child resides shall transfer to the charter school an amount equal to the per pupil local current expense appropriation to the local school administrative unit for the fiscal year.”).

142. *Sugar Creek Charter Sch., Inc.*, 673 S.E.2d at 674 (emphasis added).

143. *Id.* (finding that charter schools are entitled to funds in the school board's local current expense fund).

144. *See id.* at 675.

145. *See id.* at 676 (noting that access to the donation funds was contingent on it being held within the local current expense fund).

In sum, according to the previous cases, it appears that the judiciary is not the most effective venue for pursuing equal funding claims for charter schools. However, if the legislature has already provided a clear intent or unambiguous statutory language, which lends authority to the judiciary to interpret an equal funding regime, then charter schools may be successful. Essentially, when the state charter school law can be interpreted to allow equal funding, then litigation is a good strategy for achieving equal funding.

Further, although a number of states continue to support disparate funding, there are a number of cases on the rise, which could result in more equal funding regimes. For example, as of May 2010, charter school advocates in Washington, D.C. threatened to sue outgoing Mayor Adrian Fenty if he did not increase per pupil funding for charter schools.¹⁴⁶ This tension arose as a result of a deal brokered with D.C. teachers' unions, which would increase D.C. Public School teacher salaries but excluded charter schools from the funding formula.¹⁴⁷ Under this program, public schools would have greater bargaining power to attract more qualified teachers. Charter schools would be forced to compete with less money to recruit teachers who play a major role in a charter school's success or failure. However, under the new D.C. government administration, Mayor Vincent Gray, an advocate for charter schools, fully supports a move toward equal funding.¹⁴⁸

Additional battles have arisen in Georgia, where a supreme court decision on whether state funds follow students that transfer to charter schools, could have major implications for the structure of Georgia's charter schools.¹⁴⁹ Finally, in Arizona, seven families have asserted another equal protection claim in an effort to achieve equal funding for charter schools.¹⁵⁰ These new cases will likely have major

146. See Deborah Simmons, *Charter Schools Threaten to Sue D.C. for Funding*, WASH. TIMES (May 3, 2010), <http://www.washingtontimes.com/news/2010/may/03/charter-schools-threaten-to-sue-dc-for-funding/>.

147. See *id.*

148. Gray pledged "to equalize longstanding public funding inequities so that charters, which are public schools that are independently run, receive the same per-student public funds as" D.C. public schools. Cane, *supra* note 1.

149. See D. Aileen Dodd, *High Court Hears School Arguments; Districts Challenge Funding Authority of Charter School Board.; Ruling with Big Impact Could Take Sixth Months*, ATLANTA J. - CONST. Oct. 13, 2010, at 1B., available at <http://www.ajc.com/news/state-supreme-court-hears-679416.html>.

150. See *Charter Advocates Challenge School Finance Systems in Arizona and North Carolina*, ACCESS, <http://www.schoolfunding.info/news/litigation/09-10-16%20Charter%20Litigations.php3> (last visited Feb. 21, 2012).

implications for how charter schools across the nation attack unequal funding systems.

III. ANALYSIS OF CHARTER SCHOOL FUNDING ARGUMENTS

There are several arguments in support of states' decisions to allocate unequal funding to public charter schools. However, a careful analysis of each argument ultimately leads to the conclusion that the basis for these funding disparities is economic and political, rather than fair. This section analyzes the various arguments in support of unequal funding for charter schools, and identifies other legal, economic, political and philosophical arguments in support of equal funding opportunities.

A. Arguments that Support Inequities in Charter School Funding

According to one argument found in *Scipio-Derrick*, the state maintains an interest in the unequal distribution of public funds between traditional and charter public schools.¹⁵¹ Under one argument, the court contends that there is the need to properly budget scarce resources between two school factions, and ultimately budget in favor of traditional public schools, because they remain within the power of the state.¹⁵² In addition, according to the New Jersey Supreme Court, charter schools will detract monies from traditional public schools.¹⁵³ As a result, traditional public schools will not be able to serve students at the same capacity.¹⁵⁴ This argument is premised on the assumption that there is not enough money to completely finance both types of schools.

Assuming that the state is correct in that financial resources are scarce (as is typically the case in any government), this argument is still flawed. Charter schools provide families with a new school option that essentially replaces the public school. Therefore, when a student leaves a traditional public school, that student should no longer be accounted for as an expense in the traditional public school's budget. Instead, according to *City Neighbors* and *Sugar Creek Charter School*, the student expense transfers with the student, and so should the

151. *See* J.D. *ex rel* Scipio-Derrick v. Davy, 2 A.3d 387, 393 (N.J. Super. Ct. App. Div. 2010).

152. *See id.* at 398.

153. *See id.*

154. *See id.*

funding. If the per pupil funding is allowed to stay with the traditional public school even after students transfer to a charter school, then logically there would be a per pupil budget surplus, which is unfair to the local charter schools that will not have access to the same surplus.

Among other arguments, some states and education authorities contend that traditional public schools must account for additional administrative expenses, which charter schools do not incur.¹⁵⁵ For example, as mentioned above, traditional schools provide services such as transportation to school, or a higher volume of special education services.

In response, charter schools are denied the opportunity to provide additional services to students partly because they do not receive equal funding. Arguably, charter schools would be able to provide additional services to students *if* they could expect to receive the funding to do so. Since this is not the case, charter schools are often unable to provide the additional services for the very same reason that states claim the need to preserve its scarce resources for traditional public schools.

Finally, charter schools do not detract funds from public schools. In one instance, charter schools detract students from traditional public schools because they take on students that were originally educated in the traditional setting. However, this does not equate to charter schools creating a new expense to burden government spending. Instead, charter schools take on an expense for which traditional schools are no longer responsible. Therefore, charter schools should not necessarily be viewed as detracting funds from traditional public schools.

The New Jersey Supreme Court also argued that students could always return to traditional public schools if they are not satisfied with the funding schemes provided for charter schools.¹⁵⁶ Essentially, if charter school students believe that their schools are receiving inadequate funding, then those students always have the option to transfer back into the traditional school setting. This argument is flawed because it incorrectly assumes that traditional public schools serve as a valid option to which students may return.

155. See League of Women Voters of Ala., *Charter Schools: Facts and Issues, Charter Schools Funding and Expenses*, LWVAL.ORG, <http://www.lwval.org/learn-vote/charter-schools/page265/page265.html> (last visited Mar. 6, 2012); see also *Equitable Operational Funding and Equal Access to All State and Federal Categorical Funding*, *supra* note 83 (identifying that in Colorado and Maine, charter schools receive per pupil funding minus a limited percentage for administrative costs).

156. See *Scipio-Derrick*, 2 A.3d at 397.

The purpose of a charter school is to provide an adequate alternative to the many traditional public schools that are failing to meet students' needs.¹⁵⁷ Specifically, in the case previously mentioned, Anthony's default school was insufficient to meet students' academic needs; therefore, returning to the local traditional public school was not a plausible option for Anthony because he would be choosing to return to a less adequate or likely failing school.¹⁵⁸

There is a reason why students choose to attend charter schools. In Anthony's case, his choice was to attend a charter school where he had a legitimate opportunity to gain an excellent education instead of attending the failing local school. In essence, Anthony, like many other students seeking to attend charter schools, did not have the option of returning to the traditional public school system because the traditional public school system was not a legitimate option for obtaining a quality education.

The last argument identified in *Scipio-Derrick*, supports the notion that less restraints and regulation somehow justify less funding to charter schools. Charter schools are not required to operate or teach students according to specific state mandated requirements. Instead, as mentioned above, charter schools must meet rigorous financial and student performance accountability standards in order to remain in good standing and remain open. Therefore, there is already an even exchange—flexibility and less governmental control in exchange for rigorous accountability and the high risk of termination. This is the policy behind charter school laws; however, it should not lead to the conclusion that less control justifies less funding.

Further, states enacted charter school laws with a goal in mind—student achievement through innovation. Charter schools' independence from traditional school systems allows them to achieve that goal. Therefore, states should not financially burden the charter schools they created to carry out state goals simply because those charter schools maintain increased autonomy. This policy burdens charter schools, leads to an increased likelihood of charter schools' failure, and results in a waste of state resources.

In addition, several educational organizations provide valuable opinions and input on the issue of charter school finance and in sup-

157. See Finn, Jr. & Osberg, *supra* note 52, at v (“[M]illions of children are now more or less trapped long-term in schools acknowledged to be ‘in need of improvement’ and, for the many low-income families within that population, few decent education alternatives are at hand.”).

158. See TakePart LLC, *About the Children—Anthony*, *supra* note 4.

port of disparate funding. First, some authorities and opponents argue that charter schools create a “cream-skimming” effect,¹⁵⁹ where they “siphon the wealthiest and best-educated families from traditional public schools.”¹⁶⁰ As a result, traditional public schools are left with the most difficult students to service, thus making the task of educating these students insurmountable. Eventually, traditional public schools would “deteriorate,” and cause greater harm to lower class students and families;¹⁶¹ therefore, charter schools should not receive equal funding because they will ultimately lead to the demise of traditional public schools. However, authorities claim that statistics and evidence do not validate this concern.¹⁶²

Second, opponents argue that there is a need to decrease charter school competition with traditional public schools in order to maintain and ensure the survival of regular public schools. However, in response, traditional schools can benefit from the ideas, methods, and successes of competent charter schools.¹⁶³ States enacted charter school laws, in part, so that students in public schools would not be

159. Cream skimming occurs when “the educational choice system created by charter schools privileges those students and parents whose race, class, or educational background afford them a better position to navigate the market for schools.” Forman, Jr., *supra* note 19, at 839 (identifying “cream skimming” as a “central concern” of charter school opponents); *see also id.* at 851-56 (discussing the “cream skimming” debate).

160. Huffman, *supra* note 32, at 1302.

161. *See id.* at 1302, 1328 (concluding that charter school legislation creates a risk that only “well-informed” families will receive information about and take advantage of charter school choice opportunities, leaving “uninformed” families ghettoized and “poor”); *see also* Note, *supra* note 34, at 2005 (concluding that cream skimming reduces the “quality of teaching,” leaving other students “less motivated”).

162. Results from the NAEP 2003 Pilot Study 5 (2004) suggested that, although the evidence disconfirming cream-skimming may be disputable and has limits, the facts demonstrate that: (1) charter schools do not “consistently draw less privileged students;” (2) they do serve a disproportionate population of black students; (3) “poor students are distributed fairly equally between” traditional and charter schools; and (4) the students “are of roughly equal academic ability.” *See* Forman, Jr., *supra* note 19, at 862 (referencing statistics and findings from the National Center for Education Statistics, U.S. Department of Education, *America’s Charter Schools*); *see also* Driscoll, *supra* note 19, at 506-07 (quoting another source) (rebutting the cream skimming and drained resources arguments with statistics that charter schools were created to “target . . . at-risk, language minority, and racial minority students.”). Opponents have also voiced concerns that charter schools “will be run by unqualified nonprofessionals;” therefore, public funds would be allocated to methods and educators that potentially have no track record of success. *See* Huffman, *supra* note 32, at 1303.

163. *See* Huffman, *supra* note 32, at 1290 (“School choice activists have argued for nearly three decades that opening the public school market will both stimulate competition and increase school quality.”); *see also* Alan Olkes, *Charter Schools: Equal Funding, Equal Accountability*, ORLANDO SENTINEL (Apr. 28, 2008), http://articles.orlandosentinel.com/2008-04-28/news/myword28_1_charter-schools-traditional-public-schools-schools-in-florida (identifying a Florida teacher of 50 years, who agreed that charter schools encourage all schools “to refine their best practices in order to compete in an open market of parent choice”).

constrained by the monopoly of traditional public school methods.¹⁶⁴ Where students cannot afford to pay for expensive private schools, or their parents lack the time and resources to properly home school them, charter schools introduce an effective alternative and healthy competition into the market of education.

Further, from an economic standpoint, this competition breeds increased quality and productivity. That is, as charter schools are required to meet rigorous accountability standards, they must constantly improve their teaching methods and practices in order to meet students' needs, to ensure academic achievement, and to ensure that they survive as a charter school. Therefore, this additional pressure to perform stimulates a plethora of new ideas that can be shared and used by traditional public schools in order to bring about overall improvements in education.

B. Arguments that Support Equal Funding for Charter Schools

Where legislatures have enacted statutes that provide for equal funding standards for charter schools, it is assumed that state policies and arguments support equal funding. However, there are other significant reasons why students and parents flock to charter schools, and why they should receive the same funding as traditional public schools. This interdisciplinary approach is based on: (1) economics; (2) politics; and (3) philosophy.

1. Economic Reasons

Basic economic and accounting principles dictate that per pupil funding should follow the student. In essence, per pupil funding allocated for a student to attend a traditional public school should follow that student if he/she transfers to a charter school. This conclusion is based on the logic that a per pupil expense no longer exists at a traditional public school once a student leaves. Therefore, traditional public schools should not have the authority to retain per pupil funding or portions of per pupil funding for student expenses that are transferred to a charter school. When traditional public schools retain per pupil funds for expenses that no longer exist, they ostensibly create a budget surplus for traditional public schools, which leads to incidental

164. See Forman, Jr., *supra* note 19, at 843 (“Charter schools are, therefore, a move away from the bureaucratic model of service provided by a single monopolistic government entity.”). Therefore, those in support of charter schools “make claims that inefficiently organized monopoly schools will simply waste any extra money.” *Id.* at 878.

budget decreases for charter schools that receive less than 100% of the per pupil funds required to serve new students. Charter schools were established to create better educational opportunities and not to create economic or accounting loopholes. Thus, the question is—*where do the withheld per pupil funds go?* If they are no longer used to fund student education at traditional public schools, then for what are they being used? This question, which is commonly unanswered, further supports the simple economic and accounting solution that per pupil funding should follow the student.

2. Political Reasons

With respect to states' governance of education, one viewpoint is that the state has an interest in seeing charter schools succeed and flourish. Again, charter schools are products of state law; they were created to enhance opportunities for students.¹⁶⁵ Therefore, ensuring the success of every school, regardless of its status as a charter or traditional public school, constitutes good policy because it will further the state's interest by achieving the charter school law's goal—student achievement. Specifically, states benefit when charter schools enhance educational opportunities and prepare students to function in the world. As such, equal funding is a fair and logical policy because it increases the likelihood that charter schools will succeed, and thus helps states achieve their education goals.

3. Philosophical Reasons

Although education is not a fundamental right in America, it has always been identified as an important value that is essential to achieving the “American Dream.”¹⁶⁶ The purpose of education is to provide citizens with knowledge and skills so that they can function and thrive in society. Where citizens are not educated, the state risks the creation of a society that cannot contribute to its own operation and growth. When this happens, individuals can become burdensome on society because they are unable to achieve and provide for themselves.

With respect to charter schools, states enact charter school laws with the hope that these innovative schools will provide an *education*

165. See *supra* text accompanying note 157.

166. See generally Beverly Moran & Stephanie M. Wildman, *Race and Wealth Disparity: The Role of Law and the Legal System*, 34 FORDHAM URB. L.J. 1219, 1238 (2007) (“Access to education develops human capital and is another form of unevenly distributed wealth in [America].”).

to children. A strong argument lies in the fact that any funding scheme, which lacks the means to support a thorough education to students, is not in line with the objectives of charter school laws. In essence, the philosophy is—place children’s educational needs above any arbitrary economic or political arguments for disparate funding. If the purpose of the education system is to provide the *best* tools for educating all children, then this objective should be the focal and starting point from which any legislative decision regarding charter school funding evolves.¹⁶⁷ In conclusion, equal funding to support all public schools is the best policy in support of our nation’s education philosophy.

In addition to this interdisciplinary approach, several educational organizations provide additional valuable opinions and input in support of equal funding for charter schools. First, charter school advocates argue for equal funding in order to sustain and ensure continued success and growth of these school options. Specifically, the National Alliance for Public Charter Schools (“NAPCS”) concluded that charter schools should have the opportunity to receive the same local and state funds and grants that are available to traditional public schools,¹⁶⁸ because the lack of funding creates an “uneven playing field,” and unduly burdens charter schools that have to supplement funding with learning funds.¹⁶⁹ Further, according to other education experts, the current regime calls for a “bold new reform” and policy changes to ensure that charter schools receive the funding that state and district charter school laws often already guarantee them in order to place them on the same footing as traditional public schools.¹⁷⁰ In sum, proponents argue that charter schools deserve equal funding in

167. See Forman, Jr., *supra* note 19, at 880 (“[Since charter schools] appear to promote access [to quality education] for the disadvantaged . . . perhaps it is worth turning down the volume a bit in the shouting match over markets versus government in education.”).

168. Press Release, Nat’l Alliance for Pub. Charter Sch., Nat’l Alliance for Pub. Charter Sch. Issues Statement & Policy Recommendations on New Ball State Report (May 25, 2010), *available at* http://www.publiccharters.org/files/pressreleases/Ball%20State%20Report%20FINAL_0510.pdf.

169. *Id.* Recently, Nelson Smith, President and CEO for the National Alliance for Public Charter Schools, added fire to the flame growing around the funding issue by stating that “[t]his persistent pattern of unequal funding for public charter schools threatens to impede their continued growth, That means opportunity denied for several hundred thousand children now on charter-school waiting lists” *Id.*

170. See Cane, *supra* note 1 (“A bold new reform [is needed] to end the policy of the [Fenty] administration that prevented most charters from buying or leasing surplus school system buildings and instead sold them for condos or letting them rot.”). It was also noted that “D.C.’s public charter school law wisely insists upon [equal funding].” *Id.*

order to have a fighting chance at succeeding in the market of public education.

Finally, according to some authorities, charter schools should be granted equal funding, to the benefit of traditional public schools, because then they can add to the “clamor” of lobbying for overall increases to public education budgets.¹⁷¹ According to proponents, if, and once charter schools receive equal funding, they will then “have every incentive to join traditional public school advocates and argue for increased funding for all schools.”¹⁷² Thus, all schools can benefit from charter schools receiving equal funding because there will be a greater force lobbying for larger public education budgets.

IV. SOLUTIONS TO THE CHARTER SCHOOL FUNDING DISPARITY

Based on the arguments and analysis above, the following discussion provides a variety of suggestions to help remedy inequities in charter school funding. These proposals include: (a) pursuing equal funding litigation under certain circumstances; (b) amending charter school legislation to include equal funding provisions or graduated funding provisions; and (c) developing and implementing a merit-based competition for both traditional and charter public schools.

A. Equal Funding Litigation Presents a Challenging Option for Charter School Litigants¹⁷³

State or federal equal protection challenges to charter school funding laws have failed, as demonstrated in the New Jersey Supreme Court case,¹⁷⁴ because federal and many state courts refuse to deem education a constitutional right for which an equal protection analysis

171. Forman, Jr., *supra* note 19, at 876-78 (citing ERIC ROFES & LISA M. STULBERG, *Conclusion: Toward a Progressive Politics of School Choice*, in *THE EMANCIPATORY PROMISE OF CHARTER SCHOOLS: TOWARD PROGRESSIVE POLITICS OF SCHOOL CHOICE* 293 (2004)).

172. *Id.*

173. See Enrich, *supra* note 42, at 183 (concluding that “a quarter century’s experience suggests” that equality arguments in education finance litigation, although “understandable,” are not the best “tool[s] for the task” of achieving equal funding regimes in public education in general).

174. See discussion *supra* Part III.A.; cf. Enrich, *supra* note 42, at 128 (identifying that, even though the school funding legal debate has become a state issue, most litigants and scholars continue to frame the issue based on an equal protection argument).

applies.¹⁷⁵ However, charter school plaintiffs should pursue equal funding litigation under certain circumstances.

Historically, legal funding battles to ensure adequate education to students with the most need have failed in courts, even though the Supreme Court has set a strong tone for education policy in America with its rationale in *Brown v. Board of Education*.¹⁷⁶ In *Brown*, the Court held that the separate but equal doctrine is unconstitutional in the realm of public education.¹⁷⁷ Moreover, the Court supplied the following rationale with this infamous language regarding the importance and impact of education on society:

Today, education is perhaps the most important function of state and local governments. Compulsory school attendance laws and the great expenditures for education both demonstrate our recognition of the importance of education to our democratic society. It is required in the performance of our most basic public responsibilities, even service in the armed forces. It is the very foundation of good citizenship. Today it is a principal instrument in awakening the child to cultural values, in preparing him for later professional training, and in helping him to adjust normally to his environment. In these days, it is doubtful that any child may reasonably be expected to succeed in life if he is denied the opportunity of an education. Such an opportunity, where the state has undertaken to provide it, is a right which must be made available to all on equal terms.¹⁷⁸

In deciding *Brown*, the Court identified that education is “a right which must be made available to all on equal terms.”¹⁷⁹ As such, this rationale should be the guiding principle for education funding across traditional and charter schools.

175. See generally Huffman, *supra* note 32 (providing a thorough explanation of the Fourteenth Amendment guarantee to equal protection of the laws and outlining the components of an equal protection legal analysis as applied in public schools). Further, Huffman concludes that “[e]qual protection challenges to public schools will most likely be saddled with the burden of overcoming the more lenient rational basis standard of review.” *Id.* at 1311; see also Rubio, *supra* note 19, at 1645.

176. See generally *Brown v. Bd. of Educ.*, 347 U.S. 483 (1954) (holding that a separate but equal philosophy is unconstitutional as applied to public education).

177. See *id.* at 495.

178. *Id.* at 493; see also Rubio, *supra* note 19, at 1652 (opining that the Court’s “sweeping description” of public education as a State responsibility “recognized school expenditures as a lever of equality”).

179. *Brown*, 347 U.S. at 493; see also Enrich, *supra* note 42, at 117 (“The invitation to pursue this clearly stated right to equal educational opportunity into settings other than segregation was both obvious and difficult to decline.”).

Nevertheless, funding issues continue to serve as a major factor behind disparities in public education opportunities, due in part to the Supreme Court's refusal to apply equal protection arguments or to take any other judicial actions to cure these inequalities.¹⁸⁰ Specifically, in *San Antonio Independent School District v. Rodriguez*, the Court held that school funding schemes based on local property taxes are constitutional, reasoning that the Constitution does not require absolute equality or equal advantages in public education.¹⁸¹ As a result, school funding issues are typically not addressed successfully in the courtroom.

Accordingly, equal funding litigation has been an uphill battle for those challenging state and local governments' authority to set funding schemes for their school districts.¹⁸² The New Jersey Supreme Court has indicated that the challenge is no different when addressing charter school and traditional public school funding disparities.¹⁸³ Therefore, litigation presents a challenging option for charter school plaintiffs who seek equal funding unless the state charter school statute can be interpreted to allow for equal funding. Further, under the circumstances where state charter school laws can be interpreted to allow for equal funding, litigants should look to the North Carolina Court of Appeals case—*Sugar Creek Charter School* and the Mary-

180. See Rubio, *supra* note 19, at 1643 (proposing that even though the Court has seemingly refused to cure inequities in school funding through judicial equal protection remedies, more recent Supreme Court cases, specifically *Papasan v. Allain*, 478 U.S. 265 (1986), and *Plyer v. Doe*, 457 U.S. 202 (1982), “present alternative avenues that would allow charter school plaintiffs to circumvent the *Rodriguez* barriers”).

181. Rubio further identified that in *San Antonio Independent School District*, the Court seemingly closed “the doors to the federal courthouse,” essentially closing the door “to equal protection litigants protesting inequities in school funding.” See *id.*

182. See Enrich, *supra* note 42, at 143 (“Despite its powerful attractiveness, and despite its continuing preeminence, equality has proven a disappointing tool in the struggles over education funding.”); see also Huffman, *supra* note 32, at 1328 (“[F]ederal school finance cases demonstrate a general unwillingness to apply high levels of scrutiny to education policies . . .”). But see Rubio, *supra* note 19, at 1659 (arguing that charter schools still have a fighting chance to survive motions to dismiss equal protection challenges to unequal funding regimes even though a charter school receives some private funding). Rubio relies on *Papasan v. Allain*, 478 U.S. 265 (1986), to conclude that charter schools would have to meet the exception laid in the case:

[A] plaintiff needs to identify some revenue stream generally available to some or most public schools that is denied to plaintiff's school by a State decision. Where a charter school plaintiff successfully alleges such a decision as the source of the funding inequity, *Papasan* indicates that she will survive a motion to dismiss based on *Rodriguez*. It remains, therefore, to consider those characteristics of charter schools that will be relevant to any charter school plaintiff's equal protection funding challenge, including the precise nature and extent of the funding inequity in question.

Id. at 1658-59. See generally Kamina Aliya Pinder, *Federal Demand and Local Choice: Safeguarding the Notion of Federalism in Education Law and Policy*, 39 J.L. & EDUC. 1 (2010) (providing background information on school equal access litigation and adequacy litigation).

183. See *supra* Part II.A.

land Court of Appeals case—*City Neighbors Charter School*,¹⁸⁴ for guidance on pursuing the appropriate remedy—*i.e.* transfer of the local current expense fund.

B. Equal Funding Legislation.

States should endorse equal funding provisions or graduated funding provisions in charter school laws. In general, traditional public schools are typically financed from three major sources—federal, state, and local government funding; they also receive facilities funding.¹⁸⁵ And, despite the many arguments that charter schools are private institutions, charter schools are public schools that should be privy to the same federal, state, local, and facilities funding granted to traditional public schools.¹⁸⁶

To achieve this goal, states should amend their school funding laws to include provisions that fund public charter schools equally to traditional public schools, in effect, ensuring that charter schools are treated as public schools, rather than as completely separate school factions or as private schools.¹⁸⁷ Education experts have examined the funding disparity between charter schools and traditional schools and proposed a variety of legislative amendments as solutions to the funding gap. The Center for Education Reform (“CER”) published a report that identifies the most pertinent flaws found in charter school legislation generally and provides helpful solutions. The following key areas have been identified in school funding legislation, as requiring immediate attention and change: clarifying statutory language;¹⁸⁸

184. See discussion *supra* Part II.B.

185. See MEAGAN BATDORFF ET AL., *supra* note 57, at 11.

186. See Press Release, Nat’l Alliance for Pub. Charter Sch., *supra* note 168 (“Charter schools are public schools. There is no excuse for the continuing gap in funding between a charter school student and the child who attends the district-run public school down the street.”); see also Finn, Jr. & Osberg, *supra* note 52, at v (“[C]harter schools are no less public than their traditional counterparts and typically serve needier students.”).

187. The National Alliance for Public Charter Schools provided the following policy recommendations: 1) “[a]ll students attending all public schools should be receiving fair and equitable funding[;]” and 2) “[i]t is imperative that facilities funding and/or access to existing public school facilities be provided for public charter schools.” See Press Release, Nat’l Alliance for Pub. Charter Sch., *supra* note 168.

The principal bases for short-funding of charter schools—above all, the denial of access to local resources and facilities dollars—could be rectified in every jurisdiction by amending the state charter law. Either charter schools can be given full access to those funds or compensatory payments can be made to them by states,

Finn, Jr. & Osberg, *supra* note 52, at x.

188. See CTR. FOR EDUC. REFORM, SOLVING THE CHARTER SCHOOL FUNDING GAP: THE SEVEN MAJOR CAUSES AND WHAT TO DO ABOUT THEM 5 (Shaka L.A. Mitchell & Jeanne Allen

eliminating disparities based on fixed costs;¹⁸⁹ including provisions for equal access to facilities and facility funding;¹⁹⁰ and allowing access to public debt markets.¹⁹¹

First, the CER identified that ambiguous funding provisions in state laws allow school districts to negotiate deals with charter schools without specific direction from state legislatures.¹⁹² Often times, this leads to charter schools that lack “equal bargaining power” and school districts that go unsanctioned for “withholding [necessary] funds from charter schools.”¹⁹³ In response, several charter school advocates, including the CER have recommended clearer and stronger statutory language that provides for equal funding.¹⁹⁴

Next, the CER identifies that local school boards sometimes retain a portion of per pupil funding (which should follow students to their new school), in an effort to meet fixed costs that do not change based on the number of students attending a particular traditional public school.¹⁹⁵ According to the CER, this practice is referred to as “Impact Aid and ‘Hold Harmless’ Clauses,” which states typically allow.¹⁹⁶ To remedy the problem, states will sometimes provide additional funding to charter schools to compensate for monies withheld due to Impact Aid.¹⁹⁷ To resolve this issue, the CER proposes that school districts completely dispense with Impact Aid.¹⁹⁸

Next, the lack of facilities funding and access to public debt markets has been identified as the leading cause in funding disparities between traditional and charter public schools.¹⁹⁹ This lack in funding diverts significant amounts of per pupil and instructional resources away from students in order to secure facilities and manage capital costs.²⁰⁰ The CER suggests again that, equal per pupil funding for

eds., 2005) [hereinafter SOLVING THE CHARTER SCHOOL FUNDING GAP] (on file with the author).

189. *See id.* at 7.

190. *See id.* at 8.

191. *See id.* at 9.

192. *See id.* at 6.

193. *Id.*

194. A sample law provides that “the State shall pay \$7,500 or an amount equal to the per pupil expenditure for students in all public schools including charter schools, whichever is greater for the current school year.” *Id.*

195. *See id.* at 7.

196. *See id.*

197. *See id.*

198. *See id.* at 8.

199. *See discussion supra* Part I.C.

200. *See SOLVING THE CHARTER SCHOOL FUNDING GAP, supra* 188, at 8.

charter schools will provide the necessary facilities funds and access to public debt markets will provide financing for capital costs.²⁰¹

In the alternative, another solution to cure inequities in charter school funding legislation is a graduated equalization scheme. Here, a merit-based system to achieve equal funding presents a viable option. As a result, opponents' concern about the lack of guaranteed academic success of charter schools can be addressed by: (1) improving fiscal reporting so that states and communities know exactly what happens with school funding; and (2) providing an avenue through which charter schools receive equal funding after demonstrating their viability and sustainability as innovative alternatives to conventional public schools.

In order to implement these proposals, experts conclude that first, states must significantly improve fiscal reporting for all public schools because the lack of organized and consistent financial data prevents legislatures and communities from making informed decisions about where money goes and where it is most needed.²⁰² As a result of this improvement, charter schools can improve public confidence through transparency.²⁰³ Second, by building more confidence in decision makers through reliable financial reporting and successful academic programs, charter schools can arguably increase their bargaining power, using their success to demand better funding systems. Arguably, it is difficult to deny a charter school funding once it has proven to succeed over failed conventional education.

C. *Race to the Top* Program – Another Solution

“It’s time to stop just talking about education reform and start actually doing it. It’s time to make education America’s national mission.”²⁰⁴ With this decree from President Barack Obama, the United

201. *See id.* at 8-9; *see also* NAT’L ALLIANCE FOR PUB. CHARTER SCH., A NEW MODEL LAW FOR SUPPORTING THE GROWTH OF HIGH-QUALITY PUBLIC CHARTER SCHOOLS 23, 46-52 (2009), available at http://www.capitol.hawaii.gov/session2011/studies/NAPCS-New_Model_Law.pdf (providing a template for model charter school laws that address the major concerns regarding disparate per-pupil and facilities funding discussed by the Center for Education Reform).

202. *See* Finch, *supra* note 29, at ii; *see also* MEAGAN BATDORFF ET AL., *supra* note 57, at 17 (“[Q]uality [funding] data are not always available.”). *See generally* SOLVING THE CHARTER SCHOOL FUNDING GAP, *supra* note 188 (providing an overview of the various areas of legislative proposals).

203. Finch, *supra* note 29, at ii (“In such fiscally perilous times, educators must be prepared to fully open their financial books to reassure the public that their money is being well spent.”).

204. U.S. DEP’T OF EDUC., *supra* note 24, at 2 (citing a statement made by President Barack Obama).

States Department of Education (“ED”) implemented the *Race to the Top* program to encourage and incentivize education reform amongst the states.²⁰⁵ *Race to the Top* spun out of the education reform component of the American Recovery and Reinvestment Act of 2009 (“ARRA”), which among other things, was “designed to . . . invest in critical sectors, including education.”²⁰⁶ The *Race to the Top Fund* is “a competitive grant program designed to encourage and reward States that are creating the conditions for education innovation and reform[, and] achieving significant improvements in student outcomes.”²⁰⁷ Under the program, states that seek to be rewarded for improvements in education have endorsed major innovations in public education.²⁰⁸ As such, *Race to the Top* has effectively become the nation’s premier program for incentivizing and creating public school reform.

Under *Race to the Top*, ED awards grants to states that have applied to the program, have “demonstrated success in raising student achievement, and have the best plans to accelerate their reforms in the future.”²⁰⁹ State school system performance evaluations are centered on a number of selection criteria for which there is a point scale for scoring states and determining the amount of the reward, if any at all.²¹⁰ In addition, the program prioritizes different goals. For example, there are six major priorities—the first, the *Absolute Priority*, is a Comprehensive Approach to Education Reform, which must be demonstrated by the state.²¹¹

Under the federal *Race to the Top* program, only states may apply and be considered for reward money; however, this Note suggests that a similar program should and can be implemented at the state level to encourage reform amongst school districts and public schools. As described above, ED has already constructed a comprehensive program for encouraging school reform and student achievement as a means to gain award money to be used in state schools.²¹² Similarly, where states are still torn between providing equal funding to charter

205. See U.S. Dep’t of Educ., *Race to the Top Fund*, ED.GOV, <http://www2.ed.gov/programs/racetothetop/index.html> (last modified Jan. 24, 2012) (outlining the *Race to the Top* program).

206. U.S. DEP’T OF EDUC., *supra* note 24, at 2.

207. *Id.*

208. *Id.*

209. *Id.*

210. See *id.* at 3.

211. See *id.*

212. See U.S. Dep’t of Educ., *Race to the Top Fund*, *supra* note 205.

schools, they can adopt a replica program at the local level to raise healthy competition for equal funds and encourage the same focus on student achievement.

Even though there are a number of concerns regarding the viability and success of many charter schools, the *Race to the Top* program provides a workable solution. Under this model, charter and traditional public schools alike would receive merit and reform reward funds based on their schools' innovative operations schematic and academic outcomes. Similar to Congress, state legislatures could use funds received from the federal *Race to the Top* program, or reorganize existing funds in state budgets to create this state-based incentive program. Here, states would create a fund, which would reward schools regardless of their traditional or charter status, for (1) developing innovative and student achievement centered programs, and (2) effecting outstanding performances and accomplishments in student achievement.

In conclusion, the *Race to the Top* program incentivizes education reform and improvement, which has actually occurred for the benefit of students in many states. Similarly, states could incentivize education reform and improvement at the local level through programs similar to *Race to the Top*. Therefore, states should adopt local versions of the *Race to the Top* program because they would be able to effect the same positive changes to educational opportunities at the state and local level.

CONCLUSION

*"In this era of educational accountability, such inequity [in charter school funding] is tantamount to providing charter schools with only one oar, and then asking them to paddle as fast as other schools that have two oars in the water."*²¹³

There are a variety of funding schemes for charter and traditional schools at the state level; however, this Note focuses generally on the fundamental principles that underlie those funding schemes. Reliable data and statistics are integral to achieving the best funding systems for all public schools; however, the end goal to every funding scheme should always be the same—to ensure that every student attending a state public school receives the funding assigned to their per pupil sta-

213. Finch, *supra* note 29, at ii.

tus regardless of whether they attend a traditional public school or a public charter school.

As previously discussed, there are a number of valid arguments for and against equal funding for charter schools, and based on the current case law and numerous studies and arguments from education experts, charter schools should be provided equal funding, or at least be provided the opportunity to achieve funding equal to traditional public schools. Public schools are available to the community at no charge and are funded by the state based on a per pupil formula. Even though charter schools serve as an innovative alternative within the public school system, charter schools are still public schools nonetheless. Therefore, a student attending this innovative form of public school—charter school—should be provided equal per pupil funding in accordance with the per pupil funding formula.

Moreover, the greater policy surrounding public school funding is desperately in need of a change. Based on various economic, political, and philosophical arguments, the primary focus of all state legislatures should not be how to appease the status quo; rather, the focus should be on how to best provide for children's educational needs, and how to support and replicate programs that work. Finally, the resources and tools for equal funding legislation and performance incentive programs already exist; therefore, states should take advantage of these ideas to improve their public school funding schemes in order to give public charter schools a fighting chance at survival and success.

NOTE

America's Religious Values at Crossroads: Lifting the Veil on Zoning Decisions to Ensure Victory for the America of the Constitution and Religious Tolerance

NURUDEEN ELIAS*

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INTRODUCTION

There are two Americas. The first America celebrated religious liberty; the second America persecuted Mormons and discriminated against Catholics. The first America does not care what language you speak or what God you worship; loyalty to the Constitution trumps all differences. The second America views itself as a Protestant nation and is suspicious of whatever does not fit into Anglo-Saxon mores. These two Americas are having an intense debate over the proposed building of mosques around the country. For instance, the first America, represented by the likes of President Obama, asserts, “[t]his is America and our commitment to religious freedom must be unshakeable.” The second America does not agree. It sees the [New York Mosque] project as an affront to the memory of 9/11, and is concerned that Islam in any form is incompatible with the American way of life.¹

The American Civil Liberties Union (“ACLU”) and the Pew Research Center for Religious and Public Life (“Pew Research Center”) have documented dozens of mosque zoning permit denials across the country.² In most cases, intense anti-Muslim community opposition was responsible for permit denials that would otherwise be routine.³ The second America is directly undermining the values of the first America. The question becomes, which version of America should prevail? For the first America—that of the law and the Constitu-

1. Ross Douthat, *Islam in Two Americas*, Op-Ed., N.Y. TIMES, Aug. 16, 2010, at A19. The author comes to a different conclusion from that reached in this Note. He argues that immigrants, especially Muslim immigrants, should seek to “appease” the Second America by aligning their ideals to that of the Second America. In my opinion, the author fails to see the real issue, which is the right of Muslim immigrants to practice their religion freely.

2. See *Map—Nationwide Anti-Muslim Activity*, ACLU.ORG, <http://www.aclu.org/maps/map-nationwide-anti-mosque-activity> (last visited Jan. 10, 2012) [hereinafter *ACLU Study*]; see also PEW RESEARCH CTR. FOR RELIGIOUS & PUB. LIFE, *CONTROVERSIES OVER MOSQUES AND ISLAMIC CENTERS ACROSS THE U.S. passim* (2010)[hereinafter *PEW RESEARCH*], available at <http://features.pewforum.org/muslim/assets/mosque-map-all-text-10-5.pdf>.

3. See *id.*

tion—to prevail, the courts must take into account the second America.

The United States Constitution protects freedom of religious exercise and eschews the domination of one religion over another through the levers of government.⁴ These protections apply to the states by incorporation through the Fourteenth Amendment.⁵ Furthermore, statutory law provides added protection for religious groups against discrimination. One of such laws is the Religious Land Use and Institutionalized Person's Act ("RLUIPA"),⁶ which prohibits discrimination against religious organizations in land use regulation.⁷

This Note focuses on the land use provisions of RLUIPA's Section 2. Under Section 2(a), governments can neither impose nor implement a land use regulation in a manner that imposes a *substantial burden* on the religious exercise of a person, including a religious assembly or institution.⁸ Accordingly, the law requires federal courts to nullify such regulations, unless the local government demonstrates that the imposition of the burden on that person, assembly, or institution "(A) is in furtherance of a compelling governmental interest; and (B) is the least restrictive means of furthering that compelling governmental interest."⁹ Thus, the government has to meet the burden of strict scrutiny once the plaintiff proves a substantial burden.¹⁰ Section 2(b) of RLUIPA focuses on other forms of discrimination and exclusionary claims.¹¹ Specifically, Section 2(b)(1) guarantees that in zoning matters, religious and secular organizations are treated equally,¹² and Section 2(b)(2) guarantees that religious minorities and religious majorities are treated alike.

4. The Free Exercise Clause of the First Amendment of the United States Constitution provides that "Congress shall make no law . . . prohibiting the Free Exercise [of religion]; and the Establishment Clause under the same Amendment declares: "Congress shall make no laws respecting an establishment of religion." U.S. CONST. amend. I.

5. See *Cantwell v. Connecticut*, 310 U.S. 296, 303 (1940) (holding that a state law that deprives a person of liberty without due process of the law is in contravention of the Fourteenth Amendment and the fundamental concept of liberty in the Fourteenth Amendment embraces the liberties guaranteed in the First Amendment).

6. Roman P. Storzer & Anthony R. Picarello, Jr., *The Religious Land Use and Institutionalized Persons Act of 2000: A Constitutional Response to Unconstitutional Zoning Practices*, 9 GEO. MASON L. REV. 929, 930 (2001).

7. See 42 U.S.C. § 2000cc (2000).

8. *Id.* at § 2(a).

9. *Id.*

10. Strict scrutiny is the highest level of scrutiny the Supreme Court applies in analyzing constitutional issues. See generally *U.S. v. Carolene Prods.*, 304 U.S. 144, n.4 (1938).

11. 42 U.S.C. § 2000cc(2)(b).

12. 42 U.S.C. § 2000cc(2)(b)(1).

Congress passed RLUIPA to undo the Supreme Court's erosion of free exercise of religion. Two decades ago, the Court ended the automatic use of strict scrutiny in evaluating government decisions that placed an incidental burden on the free exercise of religion.¹³ RLUIPA emerged out of Congress' opposition to that decision. Through RLUIPA, Congress reinstated the old strict scrutiny test for discrimination in religious exercise but limited it to institutionalized persons and land-use regulation. Hence, this Note proceeds with the assumption that RLUIPA is a more efficient means of achieving the objectives of the First Amendment in land use matters because it: 1) specifically protects religious exercise in land use regulation, and 2) is intended to guarantee use of strict scrutiny for land use matters that substantially burden religious exercise, unlike the current interpretation of the First Amendment.

However, RLUIPA has not achieved its stated goals. Among reasons for this shortfall are the following: 1) Section 2(a) does not define a substantial burden; 2) appellate courts have not adopted a uniform definition of a substantial burden; and 3) discrimination has not been recognized as a substantial burden.¹⁴ Congress intended RLUIPA to end local zoning discrimination against religious organizations.¹⁵ According to the legislative history, the goal of RLUIPA is to "remedy the well-documented discriminatory and abusive treatment suffered by religious individuals and organizations in the land use context"; although Section 2(a) does not directly refer to discrimination, its objective is to prevent "unjustified hardships."¹⁶ When popular discrimination leads to a zoning decision that creates an unjustified hardship, then the purpose of RLUIPA is to ensure that a court overturns the zoning decision if it does not satisfy strict scrutiny.

RLUIPA has failed in fulfilling this purpose because proving a substantial burden has become an insurmountable hurdle. A hurdle

13. See generally *Emp't Div. v. Smith*, 494 U.S. 872 (1990) (holding that Oregon law prohibiting the use of peyote did not violate the First Amendment).

14. For examples of cases where discrimination was not recognized as a substantial burden, see generally *Vision Church v. Vill. of Long Grove*, 468 F.3d 975 (7th Cir. 2007), *en banc reh'g denied, cert. denied*, 128 S. Ct. 77 (2007); *Petra Presbyterian Church v. Vill. of Northbrook*, 489 F.3d 846 (7th Cir. 2007), *cert. denied*, 128 S. Ct. 914 (2008); *Living Water Church of God v. Charter Twp. of Meridian*, 258 F. App'x 729 (6th Cir. 2007), *cert. denied*, 128 S. Ct. 2903 (2008); *Lighthouse Inst. for Evangelism, Inc. v. City of Long Branch*, 100 F. App'x 70 (3d Cir. 2004) (unpublished) *cert. denied*, 543 U.S. 1120 (2005); *Civil Liberties for Urban Believers v. City of Chicago*, 342 F.3d 752 (7th Cir. 2003), *cert. denied*, 542 U.S. 1096 (2004).

15. 146 CONG. REC. 1,234-35 (2000).

16. *Id.*

that exists as a result of the appellate courts' interpretation of RLUIPA. To remedy this discrepancy between Congress's intent and the interpretation of the courts, this Note proposes that courts should accept evidence of popular discrimination in a community as a *prima facie* substantial burden, after which the burden of proof should shift to the government to show that its decision meets strict scrutiny.

Under the current interpretation of RLUIPA's Section 2(a), courts often do not reach the strict scrutiny portion of the test because religious organizations cannot meet the mutating substantial burden standard. By ensuring that the government more than likely would have to carry its burden of proof, this proposed burden-shifting mechanism ensures a just outcome. Specifically, it puts the onus on the government to demonstrate that prejudice towards Muslims was not the motivation behind its decision. It guarantees the judiciary's use of strict scrutiny in protecting fundamental rights of minorities in a majoritarian democracy, which is one of the important checks and balances of constitutional design aided by judicial interpretation in the last sixty years. Finally, it addresses directly the issue of popular discrimination. Moreover, scholars that believe RLUIPA's protection of free exercise rights is overbroad have also proposed similar burden-shifting mechanisms because such a mechanism would separate the issue of discrimination from other issues that may plague religious organizations, thereby serving Congress' stated intent.¹⁷

The remainder of this Note proceeds in four parts. Part I explores the roots of increased hostilities towards Muslims in the United States. Part II analyzes RLUIPA, examining both its structure and its history. Part III discusses why RLUIPA is not working through a detailed exploration of case law. Lastly, Part IV demonstrates how a burden-shifting mechanism for incorporating popular discrimination into the analysis of RUILPA's Section 2(a) might work.

17. Daniel Lennington, *Thou Shalt Not Zone: The Overbroad Applications and Troubling Implications of RLUIPA's Land Use Provisions*, 29 SEATTLE U. L. REV. 805, 838 (2006).

I. THE GENESIS OF POPULAR DISCRIMINATION
AGAINST MUSLIMS

A. America at War in the Muslim World

The seed of contemporary animosity towards Muslims was sown eleven years ago.¹⁸ On September 11, 2001 (“9/11”), Americans woke up to planes flying into the twin towers of the World Trade Center in New York City, causing the deaths of over 3,000 people.¹⁹ Simultaneously, another plane was flown into the pentagon building in Northern Virginia, killing more people.²⁰ A fourth plane crashed in the wilderness near Pittsburg, killing everyone on board.²¹ The entire country was shocked, angered, and wanted the perpetrators of these acts brought to justice.²² As we now know, Al-Qaeda in Afghanistan, led by Osama bin Laden, claimed responsibility.²³ We also now know that Al-Qaeda is a group of extremist Muslims who claim grievances against the United States for its policies towards the Middle East, especially its close relationship to Israel.²⁴ Consequently, a month after the 9/11 attacks, the United States military, along with the North At-

18. Arguably, the second America developed an animosity towards Muslims in the 1950s. It started with the Nation of Islam (“NOI”), a group of black Muslims of which Malcolm X, the hard line civil rights activist, was a member. The group was confrontational and explicit in its rejection of the American mainstream. Members of NOI like Muhammed Ali, the heavyweight-boxing champion, openly challenged the U.S. government’s policies. See *Clay v. United States*, 397 F.2d 901 (5th Cir. 1968) (holding that Cassius Clay, a.k.a. Mohammed Ali, was guilty of willfully dodging the draft). Ali’s defiance reached a climax when he was jailed for refusing to don American colors in the war against Vietnam, insisting that he had no grievances against the Vietnamese. *Id.* His famous retort to the media was “no Vietcong ever called me ‘Nigger.’” *No Vietnamese Ever Called Me Nigger (1968)*, N.Y. Times, Apr. 10, 2012, available at <http://movies.nytimes.com/movie/159515/No-Vietnamese-Ever-Called-Me-Nigger/overview>. A combination of Malcolm X’s hard line civil rights tactics; Muhammad Ali’s open defiance of the government; NOI leaders—Elijah Muhammad and Louis Farrakhan—pronouncements that were critical of the U.S. government; and misconceptions about NOI created a relatively hostile environment for NOI members. See generally JAMES CONYERS, *ENGINES OF THE BLACK POWER MOVEMENT* (2007) (discussing NOI’s contribution to black resistance in 1950s and 60s). However, for almost four decades before 9/11, Muslims were not part of the national consciousness.

19. Mohamed Nimer, *Muslims in America After 9-11*, 7 J. ISLAMIC L. & CULTURE 1, 1 (2002) (arguing that the lives of Muslims have become difficult after 9/11 because of the vitriol from the far right of American politics).

20. Serge Schmemmann, *U.S. Attacked; President Vows to Exact Punishment for ‘Evil’*, N.Y. TIMES, Sept. 12, 2001, at A1.

21. *Id.*

22. *Id.*

23. Tony Karon, *Eight Years After 9/11: Why Osama Bin Laden Failed*, TIME (Sept. 11, 2009), <http://www.time.com/time/nation/article/0,8599,1921758,00.html>.

24. See Daveed Gartenstein-Ross, *Al-Qaeda’s False Offer of Truce*, WKLY. STANDARD (Aug. 10, 2005, 12:00 AM), <http://www.weeklystandard.com/Content/Public/Articles/000/000/005/942belym.asp> (reporting that Ayman Al-Zawahiri released a tape on August 4, 2010, in which he stated that the United States can reach a truce with Al-Qaeda if the United States withdraws from Iraq, ends its support for Israel, and disengages militarily from the Middle East).

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lantic Treaty Organization (“NATO”), invaded Afghanistan, a predominantly Muslim country. The stated mission was to kill or capture members of Al-Qaeda and ensure that Afghanistan would never be a staging ground for another attack on the United States.²⁵

Before Americans could come to grips with this new “enemy,” the Bush administration announced that the intelligence community had discovered that the leader of Iraq, another Muslim majority country, conspired with Al-Qaeda to carry out the 9/11 attack.²⁶ An intelligence report erroneously claimed that Iraq had weapons of mass destruction, further amplifying the perceived threat of another attack on the United States.²⁷ The U.S. government concluded that it was intolerable for an enemy bold enough to attack the homeland to have weapons that could wreak greater havoc than what occurred on 9/11. In March 2003, the U.S., along with the United Kingdom and a few other countries, invaded Iraq.²⁸

As a result, three years into the new millennium, Americans found their country at war with two predominantly Muslim countries.²⁹ To make matters worse, the U.S. government constantly reported foiled attacks by Al Qaeda and other extremist groups, claiming the banner of Islam, on the U.S. homeland.³⁰ In 2009, a Muslim member of the United States army killed, in the name of Islam,

25. Douglas Jehl, *Pentagon Reportedly Skewed C.I.A.'s View of Qaeda Ties*, N.Y. TIMES, Oct. 22, 2004, at A10.

26. *See id.* (citing a document prepared by Douglas J. Feith, Under-Secretary of Defense for Policy, that claimed C.I.A. intelligence reports showed a connection between Saddam Hussein, former President of Iraq, and Al-Qaeda).

27. *Cf.* Joseph Wilson, *What I Didn't Find in Africa*, N.Y. TIMES, July 6, 2003, § 4, at 9 (arguing that the Bush administration might have manipulated intelligence about weapons of mass destruction in Iraq to justify invading the country).

28. *See generally* VICTOR HANSON, *BETWEEN WAR AND PEACE: LESSONS FROM THE WAR IN IRAQ AND AFGHANISTAN* (2004) (author uses his understanding of classical history to explain the future ramifications of the wars in Iraq and Afghanistan).

29. *Id.*

30. *See, e.g.*, Tony Karon, *Time Square Bomb Arrest Raises U.S. Security Question*, TIME (May 5, 2010), <http://www.time.com/time/nation/article/0,8599,1987126,00.html> (noting that, in 2010, Faisal Shahzad, an American of Pakistani descent, planted a car bomb in Times Square, New York but the bomb failed to detonate); Michael Powell & William K. Rashbaum, *Plot Suspects Described as Short on Cash and a Long Way From Realizing Goals*, N.Y. TIMES, June 4, 2007, at B1 (reporting that investigators discovered some homegrown Islamic terrorist that planned to set fire on Kennedy International Airport in New York); Joe Sharkey, *Please Take Off Your Shoes, and Is the Parrot Loaded?*, N.Y. TIMES, Jan. 5, 2010, at B6 (reporting that a would be suicide bomber was prevented from detonating a bomb in his underwear on a flight from Amsterdam to Detroit).

fellow officers in an attack at a U.S. military base.³¹ These are among the events that shaped Americans' perception of Muslims and Islam. Prior to 9/11 and the invasions of Afghanistan and Iraq, most Americans knew little about Islam.³²

Thus, many Americans have developed a negative perception of Muslims and Islam. Numerous polls after 9/11 showed this trend.³³ For example, a 2004 Cornell University poll suggested that a substantial number of Americans view Islam as a violent religion and are willing to curtail the rights of American Muslims for that reason.³⁴ In that poll, forty-four percent of Americans believed that the civil liberties of Muslim Americans should be curtailed.³⁵ Twenty-seven percent said Muslims should be required to register their whereabouts with the government.³⁶ In addition, twenty-nine percent thought it was a good idea to profile Muslims as potential threats based on their religion.³⁷

Eleven years after 9/11, Americans' attitudes towards Muslims and Islam have not changed. In a recent Gallup poll, forty-three percent of Americans admitted to having "prejudice towards Muslims."³⁸ Thirty-one percent said their views of Islam were "not favorable at all."³⁹ Another twenty-two percent said their views of Islam were "not too favorable."⁴⁰ Only nine percent admitted to having a favorable view of Islam.⁴¹ Not surprisingly, this distrust has translated into attempts to deny Muslim Americans their constitutional rights.

31. Clifford Krause & James Dao, *Details Trickle Out as Army Tests Sole-killer Theory*, N.Y. TIMES, Nov. 7, 2009, at A1 (reporting that Major Nidal Hassan, an Army psychiatrist, shot and killed thirteen people at Fort Hood Army military base).

32. Cf. Nimer, *supra* note 19, at 35 ("[N]ever before 9-11 has the small community of Muslims in America been the center of public attention.").

33. See *Fear Factor, 44 Percent of Americans Queried in Cornell National Poll Favor Curtailing the Civil Liberties of Muslim Americans*, CORNELL NEWS (Dec. 17, 2004, 11:59 PM), <http://www.news.cornell.edu/releases/Dec04/Muslim.Poll.bfp.html> [hereinafter *Fear Factor*]; *In US, Religious Prejudice Stronger Against Muslims*, GALLUP (Nov. 5, 2010, 4:30 PM), <http://www.gallup.com/poll/125312/religious-prejudice-stronger-against-muslims.aspx>.

34. *Fear Factor*, *supra* note 33.

35. *Id.*

36. *Id.*

37. *Id.*

38. *In US, Religious Prejudice Stronger Against Muslims*, *supra* note 33.

39. *Id.*

40. *Id.*

41. *Id.*

B. Violence Towards Muslims and Challenges to Mosque Projects Across the Country

Animosity towards Muslims has manifested into not only violence against Muslims, but also concerted efforts to deny Muslim organizations permits to build mosques and Islamic centers.⁴² The ACLU⁴³ and the Pew Research Center⁴⁴ have chronicled hundreds of attacks on mosques and Muslim organizations and dozens of suspicious zoning permit denials for mosques throughout the nation.

In Madera, California, an unknown assailant threw a brick at a local mosque and left signs outside the mosque that read “[w]ake-up America, the enemy is here.”⁴⁵ In the same state, arsonists burned down a mosque after threatening the congregation.⁴⁶ On the other side of the country, a group of teenagers in Carlton, NY, hurled insults at mosque congregants; side swiped them with cars; and, fired gunshots to intimidate them.⁴⁷ In Glendale, AZ, an acid bomb was the weapon of choice for those who sought to prevent a group of Muslims from praying in a mosque.⁴⁸ All across the country, there are hundreds of similar stories of people acting violently towards Muslims, especially when they gather for worship.

As documented by the Pew Research Center and ACLU studies, people trying to deny Muslims their free exercise rights have not stopped at intimidation and violence; they are actively trying to coerce the levers of government to suppress the rights of Muslims. The most prevalent method has been to influence permit decisions by local zoning boards. In some cases, they have been successful.

Pew Research reported that thirty-seven proposed mosques and Islamic centers around the country have encountered community opposition to their zoning permit applications in the last three years.⁴⁹ In most cases, the opposition has cited innocuous concerns such as traffic, noise, parking, and depreciation of property values, but there

42. See PEW RESEARCH, *supra* note 2.

43. ACLU Study, *supra* note 2.

44. PEW RESEARCH, *supra* note 2.

45. Diana Marcum, *Vandalism May Be Hate Crime; U.S. Attorney Says Investigating Acts Like the One at a Madera Mosque Is a Priority*, L.A. TIMES, Sept. 8, 2010, at AA4.

46. Henry Lee & Marisa Lagos, *Muslim Leaders Call Antioch Fire ‘Act of Terror,’* S.F. CHRON., Aug. 13, 2007, at B3.

47. Jay Tokasz, *Incident Worries Members of Mosque*, BUFFALO NEWS, Sept. 2, 2010, at B1.

48. *Arizona Bomb Targeted in “Acid Bomb” Attack*, REUTERS (Aug. 8, 2007, 2:58 PM), <http://www.reuters.com/article/2007/08/08/us-crime-usa-mosque-idUSN0833871920070808>.

49. PEW RESEARCH, *supra* note 2.

have also been overt protests of Islam.⁵⁰ The U.S. Justice Department reported that it intervened in eight cases of mosque permit denials in six months compared to one church permit denial for the same period.⁵¹ The U.S. Justice Department only intervenes in cases of national significance.

Some Mosque permit cases have captured the attention of the nation because of the intense opposition to the permits by the local communities. For example, in New York City, citizens groups,⁵² politicians,⁵³ and religious leaders⁵⁴ tried to stop a Muslim organization from building an Islamic center four blocks from the site of the 9/11 attacks on the World Trade Center. The debate gained a lot of national attention;⁵⁵ polling showed that about seventy percent of Americans were opposed to the proposed site because of its proximity to the World Trade Center.⁵⁶ It also became an issue in the 2010 mid-term elections, both in and outside New York. For example, a Republican Party congressional candidate from North Carolina released a campaign advertisement accusing Muslims of trying to build a victory mosque near the World Trade Center.⁵⁷ She claimed that when Muslims conquered Jerusalem, around the Sixth Century, and Constantinople, after the fall of the Roman Empire, they built victory mosques to commemorate their conquests, insinuating that the Islamic Center project in New York was a victory mosque commemorating the attacks on 9/11.⁵⁸

50. *Id.*

51. U.S. JUSTICE DEP'T, REPORT ON THE TENTH ANNIVERSARY OF RLUIPA 12 (2010).

52. A group composed of family members of the victims of the attack on the World Trade Center on September 11, 2001 has organized an online campaign against the mosque project in New York. See Tim Summer, *Renee Elmers for Congress: No Mosque at Ground Zero*, 9-11 FAMILIES FOR A SAFE AND STRONGER AM. (Oct. 5, 2010, 9:11 PM), <http://www.911families-foramerica.org/>.

53. Sheryl G. Stolberg, *Obama Says Mosque Remarks Were About Rights*, N.Y. TIMES, Aug. 15, 2010, at A4. Former Republican Speaker of the House of Representatives, Newt Gingrich and Rep. John Boehner criticized President Obama for supporting the rights of Muslims to build a Mosque near the site of the World Trade Center. *Id.*

54. Paul Vitello, *Amid Furor on Islamic Center, Pleas for Orthodox Church Nearby*, N.Y. TIMES, Aug. 24, 2010, at A16. Leaders of a Greek Orthodox church seeking a permit to build a church criticized government officials for paying more attention to issuing the Mosque permit and also made known their opposition to building the mosque. *Id.* They claimed that no one knew where the funding for the mosque was coming from and that that should be cause for concern. *Id.*

55. Anne Barnard, *Outraged and Outrageous*, N.Y. Times, Oct. 10, 2010, at MB1.

56. *Id.*

57. Nick Wing, *North Carolina Congressional Candidate, Links Opponent to Park 51 "Victory Mosque"*, HUFFINGTON POST (Sept. 23, 2010, 09:32 AM), http://www.huffingtonpost.com/2010/09/23/renee-elmers-gop-congres_n_735585.html.

58. *Id.*

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In Murfreesboro, Tennessee, a citizen group sued to stop the building of a mosque under the pretext of inadequate notice for a zoning board hearing while emphasizing its distrust of Muslims.⁵⁹ The site of the proposed mosque was firebombed, and members of the congregation heard nine gunshots when they went to inspect the site of the arson.⁶⁰ This violent opposition occurred despite the Baptist Church sitting on the plot next to the proposed mosque plot.⁶¹

In Wayne, New Jersey, a Muslim group, the Albanian Associated Fund, was denied a conditional use permit to build a mosque on rural property despite the zoning ordinance allowing religious building in that zone. To ensure that the organization never built the mosque, the township condemned the property under its eminent domain powers.⁶²

In Sheboygan, Wisconsin, a zoning board hearing for a permit to convert an industrial use building to a mosque became an avenue for the community to express its fears of Islam.⁶³ At the town planning commission's meeting, members of the community opposed granting the permit, giving reasons such as the community "is on Christ and Christ alone," Islam has "not [had] a very good track record . . . nation[ally] [and] worldwide," and "[Islam's] goal is to wipe out Christianity around the world."⁶⁴

59. Christian Grantham, *U.S. Attorneys Make Presence Known in Murfreesboro Mosque Trial*, MURFREESBORO POST (Oct. 22, 2010, 11:26 PM), <http://www.murfreesboropost.com/u-s-attorneys-make-presence-known-in-murfreesboro-mosque-trial-cms-24817>. The local zoning board eventually approved the mosque project but the community is still against it. *Id.* However, as the trial indicates, the reason for the lawsuit is far from procedural. *Id.* Reports paint a picture of a community with deeply rooted animosity towards Islam. *Id.* The lawyer for the plaintiff used the trial to expound on his clients' view of Islam. *Id.* For instance, a witness testified that "when someone is not native born and we don't know what their message is, we should investigate and bring in the Homeland Security and the FBI before any permit is allowed." *Id.* The plaintiff attorney asked another witness, if his idea of an afterlife is strapping a bomb to his chest and blowing himself up, so that he can get some virgins. *Id.* In the opinion of the plaintiffs, the right of Muslims to practice their religion should not be protected. *Id.*

60. Mealand Ragland-Hudgins, *Shots Fired Near Murfreesboro Mosque Site*, DAILY NEWS J. (Aug. 29, 2010, 10:31 PM), <http://www.knoxnews.com/news/2010/aug/29/shots-fired-near-murfreesboro-mosque-site/>.

61. *Id.*

62. *Wayne Sued by Muslim Group*, W. MILFORD MESSENGER (July 21, 2006), available at http://www.strausnews.com/articles/2006/07/27/west_milford_messenger/news/8.txt. The township settled the case after the federal district court denied the township's motion to dismiss. *Id.* In its motion to dismiss, the township argued that the use of eminent domain does not implicate RLUIPA because RLUIPA deals with zoning issues but not the Takings Clause. *Id.*

63. Barbara Abel & Julia Leiblich, *Rural Controversy: A Mosque in Sheboygan*, TIME (Aug. 19, 2010, 6:35 PM), <http://www.time.com/time/nation/article/0,8599,2011842,00.html>.

64. *Id.*

Some of these cases were resolved after the Muslim organizations and organizations like the ACLU threatened litigation. However, given the current state of the law, it is not clear that the Muslim organizations would have triumphed in court. To illustrate further the impact of popular discrimination on zoning decisions, we would consider next an unresolved case from Naperville, Illinois.

C. A Paradigmatic Case: *Irshad Learning Center v. DuPage County*

Irshad Learning Center (“ILC”), an Islamic organization filed a complaint against DuPage County in the United States District Court for the Northern District of Illinois alleging that the county violated RLUIPA and the First Amendment when it denied the organization a conditional use permit to expand the use of its property.⁶⁵ It all started in March of 2008 when ILC purchased a property in unincorporated DuPage County for use as a place of religious worship and education.⁶⁶ The previous owner operated a private school on the premises for fourteen years.⁶⁷ In 2005, the County Board granted a conditional use permit for the property, allowing the operation of that private school with up to sixty-five students.⁶⁸ The permit limited the school hours to 7:30 a.m. to 12:30 p.m., Monday to Friday.⁶⁹ Neither party disputes that ILC could use the property under the exact same conditions that the DuPage County Board approved for the private school.

However, ILC applied for a “conditional use permit”⁷⁰ to expand the use of the property to allow 100 individuals to use the property for religious services, including twenty-seven parking spaces and twelve

65. *Irshad Learning Ctr. v. Cnty. of DuPage*, 804 F. Supp. 2d 697, 700-01 (N.D. Ill. 2011).

66. *Id.* at 701.

67. *Id.*

68. *Id.*

69. *Id.*

70. A conditional use permit is a permit granted to a property owner to make use of property in a manner allowed under current zoning regulations, but only in accordance with conditions to be applied by the zoning authority. Other types of land-use proposals also receive individual assessments—special-use permits and variances. Special-use permits are “legislatively authorized, but administratively issued.” See DONALD G. HAGMAN, URBAN PLANNING AND LAND DEVELOPMENT CONTROL LAW 195 (1971). That is, the legislature makes a type of building or use part of the master plan but authorizes the zoning board to determine if each project fits that master plan. For instance, the legislature may envision churches in a zone but would require each proposed church project to satisfy some criteria before building in the zone. Variances, on the other hand, are departures from the master plan that are granted only after a showing of unnecessary hardship. *Id.* at 195-96.

additional parking spaces if twenty-seven spaces were insufficient. To ensure support from the community, ILC held “open door” meetings with neighbors at the property.⁷¹ After seventeen months of protracted hearings, multiple denials and multiple appeals, DuPage County Zoning Board of Appeals (“ZBA”) denied ILC’s application.⁷² ILC contended that it satisfied all of the requirements of a conditional use permit and was ready and willing to abide by any limitations of use.⁷³

Furthermore, ILC contended that ZBA’s denial of its permit was due to pressure from anti-Muslim elements in DuPage County, citing as evidence two members of the zoning board that changed their vote from yes to no after anti-Muslim elements in the community raised a storm.⁷⁴ To support its claim, ILC pointed to allegations from community members that linked ILC to terrorist organizations. At a ZBA “special public hearing,” one woman testified that the application should be denied because of ILC’s link to the Alavi Foundation.⁷⁵ The Alavi Foundation, a New York based non-profit foundation, was under investigation by the U.S. Attorney for the Southern District of New York for allegedly violating U.S. government sanctions against Iran.⁷⁶ Because the Alavi Foundation had provided partial financing that helped ILC purchase the property, some citizens of DuPage County insisted that ILC was guilty of the same offense.⁷⁷ ILC noted, however, that the Alavi Foundation also had provided funding to organizations including Doctors Without Borders, Mercy Corps, Harvard Law School, and Columbia University.⁷⁸

However, community members kept insisting that ILC and the Alavi Foundation were linked. At another ZBA hearing, a Naperville resident e-mailed all board members regarding ILC’s link to the Alavi Foundation, and warned: “You MUST NOT GRANT APPROVAL on this conditional use of residential property to [ILC], UNTIL YOU HAVE COMPLETE AND ABSOLUTE clearance from our local

71. *Irshad*, 804 F. Supp. 2d at 702.

72. *Id.* at 702-03.

73. *Id.*

74. *Id.* at 704-05.

75. *Id.* at 704.

76. *Id.* at 703-04.

77. *Id.*

78. *Id.*

FBI and Homeland Security. Again . . . as President Obama said last week . . . PLEASE connect the dots.”⁷⁹

The “Naperville Tea Patriots” also posted information on their website regarding ILC’s link to the Alavi Foundation.⁸⁰ They posted a letter dated January 4, 2010, addressed to Naperville City Council members, suggesting that the conditional use application was a form of “Stealth Jihad” and that ILC intended to spread “Radical–Jihadist Islamic Ideology.”⁸¹ The Tea Patriots asserted that ILC was “synonymous with [the] Alavi Foundation” and “synonymous with or connected to a variety of national and international Islamic and terrorist organizations.”⁸² Individuals from the “Naperville Tea Patriots and Act for America” protested outside the final county board meeting when the application was denied.⁸³ A representative from the organization also testified at the meeting that ILC was a terrorist “front group.”⁸⁴

The District Court denied the county’s motion to dismiss in this case, and the case is still pending in court.⁸⁵ However, in the court’s order denying the motion to dismiss, the analysis of the substantial burden on ILC’s RLUIPA claim did not go to the heart of ILC’s complaint. ILC contended in its complaint that the community’s anti-Muslim sentiments were directly responsible for the denial of its conditional use permit; according to the record, the county board was leaning towards approving ILC’s application until the community pressured the board to deny the permit by insisting that ILC was a terrorist organization.⁸⁶ This is popular discrimination in action. The community took undue advantage of the zoning process, which requires the zoning board to consider legitimate concerns of the community.⁸⁷ Legitimate concerns that can affect a decision are traffic,

79. *Id.* at 704.

80. *Id.*

81. *Id.*

82. *Id.* at 704-05.

83. *Id.* at 705.

84. *Id.*

85. *Id.* at 722.

86. *See id.* at 702-05.

87. Multiple factors subject the functioning of the board to the influence of the community’s prejudices. Zoning boards are required to incorporate legitimate concerns of the community into its decisions, but illegitimate concerns find their way into decisions as well. PETER W. SALSICH, JR. & TIMOTHY J. TRYNIECKI, *LAND USE REGULATION: A LEGAL ANALYSIS & PRACTICAL APPLICATION OF LAND USE LAW* 226-28 (1998). In most jurisdictions, the Board has to hold hearings with advance notice to the community. *Id.* at 227. At these hearings, the board listens to the concerns of community members and comes to a decision that takes into account those concerns. *Id.* at 227-28. (“A . . . purpose of the public hearing is to require debate among

noise, sanitation, and even property values.⁸⁸ Concerns about ILC's religion are illegitimate. Here, the vocal majority used its numerical power to bully the zoning board into suppressing the rights of the minority.

Congress wanted RLUIPA to remedy situations like this. However, because popular discrimination is not a recognized substantial burden nor incorporated into the analysis of a substantial burden, the court may never resolve the dispute in a way that would put other communities on notice. This Note proposes that courts should accept evidence of popular discrimination in a community as *prima facie* evidence of a substantial burden, after which the burden of proof should shift to the government to show that the permit denial was the least restrictive means of achieving a compelling governmental interest. If this mechanism was used in the ILC case, ILC would be able to make a *prima facie* case of a substantial burden by showing a causal link between the community opposition and the permit denial. This would shift the burden to DuPage County to show that the permit was denied for a legitimate reason and not because of the discriminatory animus expressed by the Tea Party Patriots. Most likely, the county would fail, and ILC's right would be vindicated. Part IV provides details on and support for this proposed burden shifting mechanism. The next section, however, explores the nuts and bolts of RLUIPA.

II. THE RELIGIOUS LAND USE AND INSTITUTIONALIZED PERSON'S ACT

A. Origin of RLUIPA

The road to RLUIPA began with the Supreme Court's unpopular decision in *Employment Division v. Smith*.⁸⁹ For three decades before *Smith*, the Court applied a strict scrutiny test to governmental actions

opposing views.”). *Id.* at 228. In addition, members of the Board in most jurisdictions are political appointees that can be hired or fired at the will of the City Mayor or County Executive. *See Zoning Board Members*, AMERICAN PLANNING ASSOCIATION (last visited Apr. 9, 2012), <http://www.planning.org/education/zoning/index.htm>. These factors increase the likelihood that a seemingly permissible decision may be reached for impermissible reasons.

88. *See Civil Liberties for Urban Believers v. Chicago*, 342 F.3d 752, 766-67 (7th Cir. 2003) (illustrating that the court speaks approvingly of the Chicago ordinance that requires the zoning board to limit overcrowding, street congestion, and depletion of taxable value of city land).

89. *See generally* *Emp't Div. v. Smith*, 494 U.S. 872 (1990). The ruling in the case was unpopular because religious leaders feared that the Court was interpreting the First Amendment in ways that would leave religious organizations subject to intrusive government regulations. MARCI A. HAMILTON, *GOD VS. THE GAVEL: RELIGION AND THE RULE OF LAW* 223 (2005).

that had an “incidental burden on the free exercise of religion.”⁹⁰ However, long before *Smith*, the Court started showing discomfort with its own doctrine.⁹¹

Smith presented the Court with the perfect set of facts to narrow its free exercise jurisprudence. In that case, two Native Americans were fired from their jobs and denied unemployment benefits after ingesting peyote, a hallucinogen, for religious purposes.⁹² Under Oregon law, consumption of peyote was a crime and the government was required to deny unemployment benefits to anyone fired for committing a crime.⁹³ The Native Americans challenged the law that criminalized peyote, arguing that it infringed on their religious freedom.⁹⁴

Writing for the majority, Justice Scalia distinguished between neutral laws and laws that directly regulate religious beliefs.⁹⁵ He noted that the old First Amendment test was “developed in a context that lent itself to individualized government assessment” of a person’s conduct.⁹⁶ In *Smith*, however, an “across-the-board . . . prohibition on a particular form of conduct” was at issue.⁹⁷ In other words, the Court would no longer apply strict scrutiny to religiously neutral and generally applicable government actions that burden religious conduct.⁹⁸

The *Smith* decision created panic in religious communities.⁹⁹ Pressure mounted on Congress to redress the situation. In response, Congress promulgated the Religious Freedom and Restoration Act (“RFRA”). The Act required strict scrutiny of any government action that “substantially burden[ed] a person’s exercise of religion even if the burden result[ed] from a rule of general applicability.”¹⁰⁰ But the

90. *Sherbet v. Verner*, 374 U.S. 398, 403 (1963).

91. *United States v. Lee*, 455 U.S. 252, 261-63, n.3 (1982) (Stevens, J., concurring) (reasoning that neutral laws of general applicability should be treated differently from laws targeted at a group of individuals).

92. *Smith*, 494 U.S. at 874.

93. *Id.*

94. *Id.*

95. *Id.* at 877-78.

96. *Id.* at 884.

97. *Id.*

98. *Id.* at 885. Significantly, Justice Scalia noted that “[t]o make an individual’s obligation to obey [generally applicable laws] contingent upon the law’s coincidence with his religious beliefs . . . permit[s] him . . . to become a law unto himself.” *Id.* (citation omitted).

99. See generally HAMILTON *supra* note 89 (stating that religious leaders believed the Court had “overturned a long-settled doctrine that required strict scrutiny of any law, no matter how neutral, that substantially burdened religious conduct.”).

100. Religious Freedom and Restoration Act, 42 U.S.C. § 2000bb-1 (1993) (repealed 1997). The Religious Freedom and Restoration Act (“RFRA”) required government to provide a com-

Court found RFRA unconstitutional in part, reasoning that the Act improperly redefined constitutional protections.¹⁰¹

RLUIPA was Congress' response to the Court's invalidation of RFRA.¹⁰² Congress designed RLUIPA "to protect the free exercise of religion from unnecessary governmental interference" and "to protect one of the most fundamental aspects of religious freedom—the right to gather and worship."¹⁰³ RLUIPA was also intended to "remedy the well-documented discriminatory and abusive treatment suffered by religious individuals and organizations in the land use context."¹⁰⁴ Senator Orrin Hatch of Utah and Senator Edward Kennedy of Massachusetts championed it through Congress,¹⁰⁵ and President Clinton signed RLUIPA into law on September 22, 2000.

Supporters argued that zoning boards frequently denied permits for "places of worship . . . under the guise of discretionary land use purposes, such as 'traffic, aesthetics, or uses not consistent with the . . . land use plan,'"¹⁰⁶ the same reasons given by the zoning boards in some of the earlier discussed mosque permit denials. Congress also suggested that zoning boards deny permits, especially in downtown areas, to places of worship to protect the tax base because houses of worship are generally tax exempt.¹⁰⁷ However, opponents of the law believe that land use decisions belong solely in the hands of local zon-

elling justification for any action that imposed a substantial burden on religious exercise. Ad-Marie Walsh, *Religious Land Use and Institutionalized Persons Act of 2000: Unconstitutional and Unnecessary*, 10 WM. & MARY BILL RTS. J. 189, 191 (2001). According to RFRA, the "[g]overnment may substantially burden a person's exercise of religion only if it demonstrates that application of the burden to the person is in furtherance of a compelling governmental interest; and is the least restrictive means of furthering that compelling governmental interest." *Id.* at 191-92.

101. See *City of Boerne v. Flores*, 521 U.S. 507, 533-36 (1997). In *City of Boerne*, a Catholic church wanted to enlarge its building. *Id.* at 511-12. The church applied for a permit but the historic landmark commission denied the permit. *Id.* The church sued the commission under the RFRA. *Id.* The issue was whether the RFRA could be considered enforcement legislation under the Fourteenth Amendment and if so did Congress exceed its power. *Id.* The Supreme Court held that Congress exceeded its power because most of the state laws that RFRA applied to were not ones motivated by religious bigotry. *Id.* at 534-36. For RFRA to be constitutional, it had to be remedial. *Id.* at 532. Also, Congress did not put forth any evidence showing that states were infringing on people's free exercise of religion. *Id.* at 524.

102. Walsh, *supra* note 100, at 189.

103. 146 CONG. REC. 7,190-91 (2000).

104. 146 CONG. REC. 1,235 (2000).

105. See Walsh, *supra* note 102, at 193.

106. *Id.* at 194 (citing 146 CONG. REC. 7,774 (2000)).

107. Jane Lampman, *Religion in America—A Test of Faith*, DESERET NEWS, Sept. 23, 2000, at A1.

ing boards and not in the hands of federal courts.¹⁰⁸ They argued that the local zoning boards have the expertise and connection with the community to determine the zoning plan that is best for communities.¹⁰⁹ The Eleventh Circuit rejected this argument in *Midrash Sephardi Inc. v. Town of Surfside*, opining that RLUIPA “is a proper exercise of Congress’s power under [Section] five of the Fourteenth Amendment, [so it does not violate] the Tenth Amendment.”¹¹⁰ In other words, RLUIPA does not raise states rights issues because in passing RLUIPA, Congress used its primary authority under section five of the Fourteenth Amendment to redress the documented discrimination of religious organizations by zoning boards. The solution proposed in this Note takes into account the local nature of zoning decisions by suggesting that the analysis of popular discrimination as a substantial burden should be community focused.

B. The Structure of the Statute

Section 2 of RLUIPA protects land use as an exercise of religious freedom. It has two sub-parts. Section 2(a) seeks to protect persons and organizations against land use decisions that substantially burden religious exercise. Section 2(b) focuses on discrimination, specifically when a religious organization is treated differently from secular organizations or other religious organizations. This Note focuses on the interpretation of Section 2(a).

Under Section 2(a), it is unlawful for the government to implement a land use regulation that imposes a substantial burden on the religious exercise of a person or organization,¹¹¹ unless that burden “is in furtherance of a compelling governmental interest, and is the least restrictive means of furthering that interest.”¹¹² Jurisdiction under Section 2(a) can come from: (A) a program that receives federal finance assistance, even if the burden results from a rule of general applicability; or (B) if the substantial burden affects, or its removal

108. Walsh, *supra* note 100, at 195. The author argues that RLUIPA is unnecessary because the Constitution and federal civil rights statutes already provide mechanisms for religious organizations to challenge land use decisions. *Id.* at 190. In addition, she argues that RLUIPA violates the Establishment Clause of the First Amendment, the Commerce Clause, and the Tenth Amendment’s separation of powers. *Id.*

109. *Id.* at 195

110. *Midrash Sephardi Inc. v. Town of Surfside*, 366 F.3d 1214, 1242 (11th Cir. 2004) (holding that RLUIPA is an appropriate exercise of Congress’s power under section five of the Fourteenth Amendment).

111. 42 U.S.C. § 2000cc(a)(1) (2006).

112. *Id.* § 2000cc(a)(1)(A)-(B).

would affect interstate commerce; or (C) the substantial burden is imposed in a land use program that requires individual assessments.¹¹³

The implication of this sub-section is broad. Under (A) and (B), a person or religious organization can challenge a land use law that applies to everyone irrespective of religion, if they can prove that the manner of implementation resulted in a substantial burden.¹¹⁴ The only caveats are that either the dispute must affect interstate commerce or the program must receive federal dollars.¹¹⁵ Sub-section (C), however, is the most limited application of the statute because it applies only to programs that require an individual assessment. Most zoning challenges brought under RLUIPA find jurisdiction under sub-section (C) because most local governments have procedures for individualized assessments of proposed uses of property.¹¹⁶ This system of individualized assessment is subject to the whims and caprices of members of the zoning boards and strong influence from the community because zoning board members are products of the political process.¹¹⁷ Hence, when there is widespread animosity towards a specific group of people, it can manifest itself in the process of assessing zoning permits.

III. WHY RLUIPA IS NOT WORKING

Since the passage of RLUIPA, religious organizations have brought a substantial number of lawsuits against municipal zoning boards.¹¹⁸ Hence, federal appellate courts have had opportunities to interpret RLUIPA regarding its land use provisions.¹¹⁹ However, no uniform definition has emerged for a substantial burden. Furthermore, the Supreme Court has not granted *cert* in any RLUIPA case dealing with land use regulations.¹²⁰ In other words, RLUIPA is not working because 1) Section 2(a) does not define a substantial burden; 2) appellate courts have not adopted a uniform definition of a substantial burden; and 3) courts do not treat discrimination as a substantial burden.

113. *Id.* § 2000cc(a)(2)(A)-(C).

114. *Id.* § 2000cc(a)(2)(A)-(B).

115. *Id.*

116. *Id.* § 2000cc(a)(2)(C).

117. *See id.*

118. Karla L. Chaffee & Dwight H. Merriam, *Six Fact Patterns of Substantial Burden in RLUIPA: Lessons for Potential Litigants*, 2 ALB. GOV'T L. REV. 437, 449-52 (2009).

119. *See id.* at 452-53.

120. *See* discussion *supra* note 14.

A. No Uniform Definition of a Substantial Burden

It is difficult to predict an outcome in a RLUIPA case because there is no uniform definition of a substantial burden.¹²¹ Circuits have adopted mostly narrow definitions of a substantial burden. For example, the Seventh Circuit defined a substantial burden as something that renders religious exercise “effectively impracticable.”¹²² Similarly, the Eleventh Circuit defined a substantial burden as “pressure that directly ‘coerces’ individuals to modify their religious belief.”¹²³ Following suit, the Ninth Circuit defined a substantial burden as something “oppressive to a significantly great extent . . . and [that] must impose a significantly great restriction or onus.”¹²⁴ However, a Seventh Circuit case adopted a considerably broad definition, holding that “delay, uncertainty, and expense” might impose a substantial burden.¹²⁵ These definitions create difficulty in gauging the weight of evidence needed to prove a substantial burden.

1. Most Courts Define a Substantial Burden Narrowly

As expected, narrow definitions of a substantial burden usually guarantee a negative outcome for plaintiffs. In one of the first appellate RLUIPA cases, the Seventh Circuit laid out a considerably narrow definition of a substantial burden. The court in *Civil Liberties for Urban Believers* (“C.L.U.B.”) held that the City of Chicago had not imposed a substantial burden on a group of churches challenging the city’s zoning ordinance because the ordinance required churches to apply for a costly special use permit to build in some designated zones.¹²⁶ In reaching its decision, the court laid down a framework for analyzing a substantial burden that is almost impossible to surmount and that effectively allows a zoning board to discriminate against a religious organization.¹²⁷ The court held that “a substantial burden on religious exercise is one that necessarily bears direct, primary, and fundamental responsibility for rendering religious exercise—including

121. Chaffee & Merriam, *supra* note 118, at 437.

122. *Civil Liberties for Urban Believers v. City of Chicago*, 342 F.3d 752, 761 (7th Cir. 2003).

123. *Midrash Sephardi Inc. v. Town of Surfside*, 366 F.3d 1214, 1227 (11th Cir. 2004).

124. *San Jose Christian Coll. v. City of Morgan Hill*, 360 F.3d 1024, 1034 (9th Cir. 2004) (relying on Merriam-Webster’s Collegiate Dictionary to define “substantial burden”).

125. *Sts. Constantine & Helen Greek Orthodox Church, Inc. v. City of New Berlin*, 396 F.3d 895, 901 (7th Cir. 2005).

126. *Civil Liberties*, 342 F.3d at 755-56.

127. *Id.* at 761.

the use of real property for the purpose thereof within the regulated jurisdiction generally—effectively impracticable.”¹²⁸

The decision in *C.L.U.B.* was right but it created bad law. It was right because the churches were challenging an ordinance that did not automatically deny them the ability to build in the challenged zones. They only had to apply for a modestly priced special use permit. However, in denying the claim, the court set a bad precedent. If the court had adopted a definition that allowed the burden of proof to shift to the government at some point, the government would have been able to carry the burden. Hence, we would have had the same result and left room for future plaintiffs to make their case.

Congress did not intend RLUIPA to give religious organizations blanket immunity on zoning issues.¹²⁹ However, Congress wanted to ensure that zoning boards did not get away with covert discrimination. Defining a substantial burden as something that makes religious exercise “effectively impracticable” defeats congressional intent because the religious organization would have to demonstrate that unless the zoning board’s decision is overturned, it would be impossible for its adherent to practice their religion. At least one court saw fit to point out that the effectively impracticable standard finds no support in the language or purpose of the statute.¹³⁰ Notwithstanding, the Third,¹³¹ Ninth,¹³² and Eleventh¹³³ Circuits have adopted similarly narrow definitions.

The effect of this narrow definition of a substantial burden played out in *Petra Presbyterian Church v. Town of Surfside*, another Seventh

128. *Id.*

129. 146 CONG. REC. 7,776 (2000) (joint statement of Senator Hatch and Senator Kennedy) (“This Act does not provide religious institutions with immunity from land use regulations, nor does it relieve religious institutions from applying for variances, special permits or exceptions, hardship approval, or other relief provisions in land use regulations, where available without discrimination or unfair delay.”).

130. *Guru Nanak Sikh Soc’y of Yuba City v. Cnty. of Sutter*, 326 F. Supp. 2d 1140, 1153 (E.D. Cal. 2003) (“This test reads quite a bit more into the word “substantial” than is warranted by the text, purpose, or history of the statute.”).

131. *San Jose Christian Coll. v. City of Morgan Hill*, 360 F.3d 1024, 1034-35 (9th Cir. 2004) (reasoning that “the government is prohibited from imposing or implementing a land use regulation in a manner that imposes a ‘significantly great’ restriction or onus on ‘any exercise of religion’”).

132. *Lighthouse Inst. for Evangelism, Inc. v. City of Long Branch*, 100 F. App’x 70, 77 (3d Cir. 2004) (unpublished) (holding that substantial burden meant that government action rendered religious exercise “effectively impracticable”).

133. *Midrash Sephardi Inc. v. Town of Surfside*, 366 F.3d 1214, 1227 (11th Cir. 2004) (holding that “a ‘substantial burden’ is akin to significant pressure which directly coerces the religious adherent to conform his or her behavior accordingly”).

Circuit case. There, the court acknowledged that the government could not carry its burden of proof but decided that the government need not carry that burden because the church could not scale the hurdle the court had erected. In *Petra*, a church purchased property in an industrial zone in a village with a zoning ordinance that excluded churches from industrial zones but not secular membership organizations.¹³⁴ In September of 2000, before buying the property, the church submitted an informal request to have the zoning board amend the ordinance to enable the church to use the property for worship.¹³⁵ The board considered the request favorably without making a ruling.¹³⁶ The church then signed a contract to purchase the property contingent on getting a permit from the zoning board.¹³⁷

At a zoning board hearing, landowners in the industrial zone expressed opposition to the church's application.¹³⁸ Without taking a vote, the board directed its staff to prepare documents consistent with a denial of the church's application.¹³⁹ The church withdrew its application without receiving a denial but proceeded with the purchase of the property.¹⁴⁰ After the passage of RLUIPA, concerns about the village 1988 ordinance's conflict with the new law led the village to revise its ordinance to ban all membership organizations.¹⁴¹ However, membership organizations that were already operating in the industrial zone were grandfathered in.¹⁴² Relying on RLUIPA, the church brought a claim against the village; despite the church's strong claim of unequal treatment, the district court held that the village's denial of the church's application did not violate RLUIPA.¹⁴³

On appeal to the Seventh Circuit, the church claimed that it "reasonably relied" on the invalidity of the village ordinance when it pur-

134. *Petra Presbyterian Church v. Vill. of Northbrook*, 489 F.3d 846, 847 (7th Cir. 2007).

135. *Id.* at 848. The church bought the property soon after the enactment of RLUIPA and immediately began using the property to hold church services. One of the church's main arguments is that it has a vested right in using the property as a church because a doctrine of Illinois law allows a land use to continue after a zoning change was made that would have banned it. *Id.*

136. *Id.* at 847.

137. *Id.*

138. *Id.* This is an example of the influence community opposition can have on the decision of a zoning board. According to the record, the zoning board gave the initial application a favorable hearing but the favorability of the application changed once the landowners and factory owners opposed the church in the industrial zone. *Id.* at 847-48. In this case, it is unknown whether the landowners opposed the church for legitimate or illegitimate reasons. *Id.*

139. *Id.*

140. *Id.* at 848.

141. *Id.*

142. *Id.*

143. *Id.*

chased the property, since the ordinance violated RLUIPA and the Free Exercise Clause.¹⁴⁴ The court reiterated that, under RLUIPA, the church had to show that the village's action created a substantial burden on the church; after which, the burden of proof shifted to the village to show a compelling governmental interest behind its action.¹⁴⁵

The village contended that it had a compelling interest in reducing tort liability that may arise from the lack of sidewalks and the presence of toxic waste in the industrial zone.¹⁴⁶ However, the court concluded that the village did not have a compelling interest in excluding the church from the industrial zone because other non-religious membership organizations functioned in the zone.¹⁴⁷ Despite the court's conclusion, it held that the church was not substantially burdened because it could not show the "paucity of other lands," to be built on.¹⁴⁸ However, the court did not specify how the church could prove a "paucity of other lands."¹⁴⁹ In order to satisfy the court in this case, the church would have to produce a detailed analysis of the real estate market in the village. It is unlikely that the intention of Congress was to allow zoning boards to escape accountability, especially when they are obviously wrong, because of an organizations inability to show that land is scarce.

One other important observation in this case was the change in the zoning board's attitude towards the church application after land-owners in the industrial zone voiced opposition to the permit. While zoning decisions are designed to incorporate the community's voice, it can be hijacked to serve illegitimate ends. It is not clear whether that was the situation in this case. However, it is obvious that a court

144. *Id.* at 848-49.

145. *Id.* at 851.

146. *Id.* at 851-52.

147. *Id.*

148. *Id.* Here, the court's analysis of substantial burden centered on the church's ability to show that there was a scarcity of land on which to build churches. Clearly, the court found that the showing of a substantial burden was the most important component of the rule. The court stated that

the 'substantial burden' provision backstops the [Act's] explicit prohibition of religious discrimination If a land-use decision . . . imposes a substantial burden on religious exercise . . . and the decision maker cannot justify it, the inference arises that hostility to religion, or more likely a particular sect, influenced the decision. Unless the requirement of substantial burden is taken seriously, the difficulty of proving a compelling governmental interest will free religious organizations from zoning restrictions of any kind.

Id. (internal quotations omitted).

149. *Id.* at 851.

should consider the effect of a community's attitude towards a permit application when reviewing a challenged decision because of the impact a community can have on the zoning board's decision.

Most courts use narrow definitions of a substantial burden. In *Midrash Sephards Inc. v. Town of Surfside*, the Eleventh Circuit reasoned that a substantial burden is akin to significant pressure which directly coerces the religious adherent to conform his or her behavior accordingly.¹⁵⁰ State courts have adopted this definition. A court in Oregon held that a "government regulation imposes a substantial burden on religious exercise only if it 'pressures' or 'forces' a choice between following precepts and forfeiting certain benefits, on one hand, and abandoning one or more of those precepts in order to obtain the benefits, on the other."¹⁵¹ Like the effectively impracticable standard, this definition is almost impossible to surmount because the religious organization would have to show that the regulation in question prevents it from practicing a tenet of its faith. In other words, a substantial burden can only occur from a rule of general applicability and not from denying a religious organization's land-use application. It is not surprising that some courts have rejected this definition. A United States district court reasoned that construing "substantial burden" to reach only those government actions that coerce conduct prohibited by the claimant's religious faith runs contrary to the purpose and language of the statute.¹⁵²

2. Effects of a Sufficiently Broad Definition

While sufficiently broad definition of a substantial burden leaves plaintiffs with a fighting chance, it still falls short of guaranteeing predictable outcomes. As earlier mentioned, the Seventh Circuit has also defined a substantial burden in ways that would lead to diametrically opposite conclusions with *Petra*. The *Sts. Constantine* court held that a state that has a method for granting individual exemptions from a general rule must have a compelling reason to deny a religious organi-

150. *Midrash Sephardi Inc. v. Town of Surfside*, 366 F.3d 1214, 1227 (11th Cir. 2004).

151. *Church of Jesus Christ of Latter-Day Saints v. City of West Linn*, 111 P.3d 1123, 1130 (Or. App. 2004).

152. See *Cottonwood Christian Ctr. v. Cypress Redevelopment Agency*, 218 F. Supp. 2d 1203, 1226 (C.D. Cal. 2002) (noting that the church proposed to build on a vacant lot where the city had hoped a commercial retail center would materialize, but the city denied church's proposal, then initiated eminent domain condemnation proceedings against church).

zation an exemption that is sought based on hardship.¹⁵³ The court was effectively defining a land use hardship as a substantial burden. The court assumed a substantial burden based on the nature of the church's initial application without inquiring about the effect of the application denial.¹⁵⁴

The court further reasoned, "If a land-use decision . . . imposes a substantial burden on religious exercise . . . and the decision maker cannot justify it, the inference arises that hostility to religion or, more likely to a particular sect, influenced the decision."¹⁵⁵ The court's reasoning here captures the importance of the proper analysis of a substantial burden. That is, if the analysis of a substantial burden is less exacting and the court concludes that there is no substantial burden, then it will be impossible for the court to reach the government's reasons for denying a permit even though the denial may be due to hostility.

The court appreciated that the proper burden of proof belongs to the government, not the plaintiffs. Hence, to be able to reach the government's argument, the court recognized exemptions sought on hardship as a substantial burden. The hardship application of the church was in essence a *prima facie* showing of a substantial burden. Applying a burden shifting mechanism such as that used in this case will cure the problems with the statute's inability to protect against discrimination, but it will not make it impossible for zoning boards to deny permits on legitimate grounds so long as they have a compelling governmental interest. The only shortcoming of this decision was that it did not call discrimination by its name.

B. Discrimination Is Not Recognized as a Substantial Burden

As earlier discussed, the purpose of RLUIPA is to stop discrimination in the area of land use. However, courts have failed to label discriminatory conduct as discriminatory. The language of RLUIPA itself is responsible for this handicap. The phrase "substantial burden" evokes a secondary effect meaning. That is, the government took an action and that action has substantially burdened religious conduct. The rule does not present the tools to analyze situations

153. *Sts. Constantine & Helen Greek Orthodox Church, Inc. v. City of New Berlin*, 396 F.3d 895, 897 (7th Cir. 2005).

154. *Id.*

155. *Id.* at 900.

where the action itself is the burden. This Note argues that discrimination, in itself, is a burden and should be treated as such.

In a Ninth Circuit case where discrimination was the burden, the court did not overtly recognize it as such. In *Guru Nanak Sikh Society of Yuba City v. County of Sutter*, a Sikh religious society applied for a conditional use permit to build a temple in a residential zone but the county denied the application citing concerns of noise, traffic, and other similar issues.¹⁵⁶ After the denial, the society bought land in an agricultural zone and applied for a new permit.¹⁵⁷ The county denied the new application, despite the society agreeing to all conditions imposed on the permit, partly because neighbors opposed granting the permit.¹⁵⁸ Moreover, the county board never explained why the religious society agreeing to all the conditions imposed on the permit was not sufficient to mitigate the board's concerns.¹⁵⁹ The county only cited "[a] right to farm" as reason for the second permit denial.¹⁶⁰

The *Guru Nanak* court defined a substantial burden as a regulation that is oppressive to a significantly great extent.¹⁶¹ The court reasoned that the county's unconvincing excuses for the two permit denials and its rejection of the religious society's agreement to meet all conditions imposed on the second permit combined to meet the substantial burden standard.¹⁶² The court, therefore, held that the county's actions to "a significantly great extent lessened the prospect of Guru Nanak being able to construct a temple in the future."¹⁶³

156. *Guru Nanak Sikh Soc'y of Yuba City v. Cnty. of Sutter*, 456 F.3d 978, 981-82 (9th Cir. 2006). The first application was in 2001 when the Guru Nanak Society applied for a Conditional Use Permit in a low-density residential zone where churches and temples were allowed. *Id.* at 982. The Sutter County Planning Division recommended that the zoning board grant the permit, especially if the society agreed to specified conditions. *Id.* However, the zoning board denied the permit unanimously because residents of the neighborhood opposed the temple on the grounds that noise and traffic from the temple would interfere with the existing neighborhood. *Id.*

157. *Id.* at 983. In 2002, the society bought a 28.6 acre property that enclosed an orchard and a 2,300 square foot single family home. *Id.* at 982. The society applied for a permit to use the building for a temple and to increase the size of the building by 500 square feet. *Id.* at 983. The Planning Commission held a hearing and approved the permit 4-3. *Id.* However, neighbors started filing appeals against the Commission's findings. Eventually, the Zoning Board denied the permit. *Id.* at 983-84.

158. *Id.*

159. *Id.* at 991.

160. *Id.* at 983-84.

161. *Id.* at 988-89 (citing *San Jose Christian Coll. v. City of Morgan Hill*, 360 F.3d 1024, 1034 (9th Cir. 2004)).

162. *Id.* at 981.

163. *Id.* at 992 (holding that the zoning board violated RLUIPA in denying the society's conditional use permit because the board imposed a substantial burden on the society's free

America's Religious Values at Crossroads

The court's reasoning here is instructive. When permit denials occur because of covert discrimination, unless the discriminators attitude change, it is more likely than not that every permit application by the same person or organization discriminated against would result in another denial. Therefore, to guard against covert discrimination, the analysis of a substantial burden must take that into account. The *Guru Nanak* court understood this but did not: 1) propose an objective framework for applying its reasoning to varying facts; or 2) label the county's behavior as discriminatory.

Other courts have also considered discrimination in their analyses of a substantial burden, albeit indirectly. For instance, the Seventh Circuit's concern of "delay, uncertainty, and expense" in *Sts. Constantine* was a nudge towards fairness. Similarly, the Second Circuit's finding in *Westchester Day School* that a permit denial was "arbitrary and capricious" shows that the court was concerned about fairness.¹⁶⁴ There, the reasons for the permit denial were not supported by the record and were based on improper considerations, such as fear of future expansion.¹⁶⁵

While it is commendable that the courts have gone in a broader direction, we need a more predictable analysis for what constitutes a substantial burden. The best approach would incorporate *Guru Nanak's* fairness and *Sts. Constantine's* burden shifting mechanism. That is, it would acknowledge the difficulty of ferreting out covert discrimination and put the onus on the government to demonstrate that it had a compelling reason for denying a permit.

Muslim organizations are subject to similar issues that plague secular and other religious organizations. As documented in Part I of this Note, they are also subject to popular discrimination. Hence, the analyses in the above-cited cases may be insufficient in capturing the burden Muslim organizations face. In recognizing this added burden, popular discrimination alone does not have to be equated to a substantial burden. However, it should be factored into the analysis.

exercise of religion, and the board advanced no compelling governmental interest that the denial furthered).

164. *Westchester Day Sch. v. Vill. of Mamaroneck*, 504 F.3d 338, 351 (2d Cir. 2007).

165. *Id.*

IV. A NEW FRAMEWORK TO ACHIEVE THE GOALS OF RLUIPA

The goal of RLUIPA is to ensure that zoning boards do not exercise their power in a way that denies individuals the freedom to practice their religions.¹⁶⁶ Opposition to mosques around the country has not been limited to the type of oppositions religious organizations regularly face. Moreover, it is not sufficient to rely on Section 2(b) of RLUIPA because not all claims of discrimination can be supported by showing that a Muslim organization has been treated differently compared to a secular organization or another religious organization. Therefore, to guarantee Muslims their constitutional rights, an analysis of a substantial burden that recognizes the added difficulty of the effects of popular discrimination is necessary.

Although some studies show that religious organizations—especially minority religious organizations—do not suffer in the hands of zoning boards, these studies have not focused on Muslim organizations. For instance, a study of zoning exemptions of the New Haven Board of Zoning Appeals (“BZA”) revealed that between 1992 and 2000, BZA granted over 76% of its exemption requests for religious organizations, compared to 80% for secular organizations.¹⁶⁷ Furthermore, minority religious organizations had a 77% success rate while majority religions had a 75% success rate.¹⁶⁸ Arguably, Muslims have nothing to fear when confronting zoning boards. This conclusion is misleading because the study did not specify any rate of success for Muslim organizations. The data used is pre-September 11, 2001, and the study was conducted only in New Haven, Connecticut. On the other hand, other studies have found that “small religious groups and nondenominational churches are greatly over-represented in zoning cases.”¹⁶⁹ More than 49% of zoning cases involved religious groups

166. 146 CONG. REC. 6,688 (2000) (Senator Kennedy stated that “the evidence is clear that local land use laws often have the discriminatory effect of burdening the free exercise of religion.”)

167. Stephen Clowney, *An Empirical Look at Churches in the Zoning Process*, 116 YALE L.J. 859, 863 (2007). The New Haven Board of Zoning Appeals is the governmental entity responsible for hearing and ruling on zoning decisions in New Haven, Connecticut. *See Id.* at 859-60. The author conducted the study to lend empirical support to the view that RLUIPA is unnecessary because churches in the United States do not encounter discrimination from state and local governments in land use matters. *Id.* at 859.

168. *Id.* at 865.

169. 146 CONG. REC. 7774, 7777 (2000) (citing a study produced by professors from Bingham Young University and attorneys from Mayer, Brown & Platt LLP).

that represent only 9% of the population.¹⁷⁰ Thus, the more logical conclusion is that religious minorities face harsher treatment with zoning boards, thereby leading them to seek justice in the courts.

Moreover, the consideration of popular discrimination in the analysis of a substantial burden should be community-focused. There are legitimate reasons that would lead a municipal zoning board to deny a zoning application; hence, in the quest to find the truth, the focus should be on the facts in each specific situation and community, and not on other communities' view of Muslims.

A. Popular Discrimination Exists

As documented in Part I of this Note, Muslim organizations are experiencing hardship in obtaining zoning permits. The debates on the proposed Islamic center near the site of the World Trade Center captures the argument that Muslim organizations are facing a harder time in securing permits for buildings. Although the New York City Council voted to allow the proposed Islamic center, the vehement opposition to the project before and after the approval demonstrated that there was more to the issue than the location. Since then, dozens of mosque projects around the country have faced substantial opposition from the communities surrounding properties intended for the mosque projects.¹⁷¹

In the mosque controversies examined earlier, the communities' perception of Muslims had a direct effect on the land use decision of zoning boards. It is imperative that the law ensures that such prejudice does not stand. Throughout the history of the United States, there has been a tension between the country's ideals represented by the first America, in the Declaration of Independence and the U.S. Constitution, and the negative treatment of minorities by the second America.

Like most religions, it is important for Muslims to congregate and pray together. Muslims are required to pray five times a day, preferably in a congregation.¹⁷² In addition, Muslims are required to attend congregational prayers every Friday.¹⁷³ So the inability of a Muslim

170. *Id.*

171. See PEW RESEARCH, *supra* note 2.

172. CEASAR E. FARAH, ISLAM: BELIEFS AND OBSERVANCES 136 (7th ed. 2003) ("The act of prayer is not left to the whim of the believer to perform; it constitutes rather a well-defined ritual, faithfully executed according to a prescribed pattern. Five times a day, at dawn, midday, mid afternoon, sunset, and nightfall . . .").

173. *Id.* (citing QURAN 62:9-10).

organization to procure a space to congregate is a substantial burden because it hinders a member's ability to practice the religion. Even the Supreme Court has recognized Muslims' right to congregate on Fridays.¹⁷⁴

Nonetheless, the inability to congregate alone cannot be the basis for a legal claim because most religions have similar mandates to congregate. However, the inability to congregate as a result of an illegitimate permit denial should be adequate to prove a substantial burden.

B. Recognizing Popular Discrimination

Federal courts should consider the following factors as a *prima facie* showing of a substantial burden on Muslim organizations: (1) records of the zoning boards on the permit at issue, including public hearings; (2) the community's reaction to that specific mosque project; and (3) a causal link between the alleged discrimination and the permit denial. The second factor can be evidenced using op-ed columns, local papers letters to the editors, interviews, newspaper reports, polls, and other similar documentation.

Once a court determines that these factors show *prima facie* discrimination against the Muslim organization, then the burden will shift to the government to show that there is a compelling governmental interest for denying the permit and that the permit denial is the least restrictive means for achieving that interest. If the government is able to meet this burden, then the burden shifts back to the religious organization to provide evidence that the reasons proffered by the government are false. This burden shifting approach ensures that there is equal opportunity for both the government and the plaintiff to make their case. It also recognizes that the purpose of RLUIPA is to guard against discrimination and that indirect discrimination is hard to prove.

This framework is similar to the *McDonnell-Douglas* burden shifting mechanism courts use in Title VII cases.¹⁷⁵ Under Title VII of the Civil Rights Act, courts recognize that race discrimination is generally hard to prove without direct and overt evidence.¹⁷⁶ Hence, courts employ an indirect method to reach the covert discrimination

174. *O'lane v. Estate of Shabazz*, 482 U.S. 342, 345 (1987) (acknowledging that a Muslim prisoner has sincerely held beliefs that compel him to attend Jumua'ah—the Friday congregational prayers at mid-day).

175. *McDonnell Douglas Corp. v. Green*, 411 U.S. 792 (1973).

176. *Lenington*, *supra* note 17, at 838.

alleged. While the mechanism casts a wide net, it does not reach conduct that is not discriminatory.

The *McDonnell-Douglas* burden shifting mechanism in employment discrimination works by allowing a plaintiff employee to present a rebuttable *prima facie* case of discrimination from which a fact finder could infer that the plaintiff was a victim of discrimination.¹⁷⁷ Then the burden shifts to the employer to rebut the claim by articulating a non-discriminatory reason for its action.¹⁷⁸ If the employer is able to meet this burden, then the burden shifts back to the employee to show that the employer's rebuttal was mere pretext to cover discriminatory intent.¹⁷⁹ This mechanism has worked to uncover covert discrimination, and it has also worked to bar frivolous claims.¹⁸⁰ In fact, scholars that believe RLUIPA is overbroad have also suggested implementing the burden-shifting mechanism of Title VII to rectify the statute's perceived weaknesses.¹⁸¹

177. *Green*, 411 U.S. at 802.

178. *Id.* at 802-03.

179. *Id.* at 804.

180. Lennington, *supra* note 17, at 838.

181. *Id.* (arguing that RLUIPA Section 2(a) is overbroad and recommending that Congress amend the statute using a burden shifting mechanism).

The goal of the amendment proposed in this Article is twofold. First, this proposal will scale back the size of Congress' net, in order to reach only intentional discrimination. Second, this proposal will still be aimed at the covert, hard-to-catch discrimination that is sometimes present in local zoning decisions. This proposed amendment to subsection (a) is listed as follows:

(a)(1) No government shall impose or implement a land use regulation in an intentionally discriminatory manner that imposes a substantial burden on the religious exercise of a person, including a religious assembly or institution, unless the government demonstrates that the imposition of the burden on that person, assembly, or institution

(A) is in furtherance of a compelling governmental interest; and

(B) is the least restrictive means of furthering that compelling governmental interest.

(a)(2) To prove liability under this subsection, a plaintiff shall first establish a *prima facie* case of intentional discrimination by showing that (A) the government has imposed or implemented a land use regulation; (B) the regulation has placed a substantial burden on the plaintiff's religious exercise; and (C) there is record evidence giving rise to an implication that the government's decision was discriminatory. If the plaintiff can make this showing, then the burden of production shifts to the defendant to proffer a legitimate, nondiscriminatory reason for the decision. If the defendant can meet its burden, then the final burden rests with the plaintiff to prove that the defendant's stated reason for the decision is a mere pretext for discrimination.

(a)(3) At any time, the defendant may escape liability by demonstrating that the imposition of the burden on that person, assembly, or institution (A) is in furtherance of a compelling governmental interest; and (B) is the least restrictive means of furthering that compelling governmental interest.

This revision is based, in large part, on the way courts handle claims of race discrimination in the employment context. Courts have often said that claims of race discrimination are generally not easy to prove with direct, or "overt," evidence of discrimination. Accordingly, courts have used this same indirect method of proving discrimination that reaches "covert" discriminatory decisions.

Id. at 837-39.

Furthermore, the popular discrimination factors proposed here are narrowly tailored to a specific community and a specific project to avoid generalizing people's view of Islam and Muslims, and to avoid risking the invalidation of legitimate permit denials. Further, the main function of these factors would be to allow courts to reach the issue of a compelling governmental interest by allowing Muslim organizations to prove a *prima facie* substantial burden. These factors conform to Supreme Court jurisprudence on the First Amendment Free Exercise Clause and the Fourteenth Amendment Equal Protection Clause.¹⁸² They fulfill the legislative intent behind RLUIPA, and further the Ninth Circuit's fairness rationale in *Guru Nanak*. Most importantly, they ensure that the judiciary fulfills its role in protecting minority rights, especially when the United States is at war with people that look like some of its minority citizens.¹⁸³

The Supreme Court used similar factors in analyzing religious discriminatory laws in *Church of the Lukumi Babalu Aye v. City of Hialeah*.¹⁸⁴ There, the Supreme Court invalidated a city ordinance that prohibited the sacrifice of animals because it found that the ordinance was passed to target the animal sacrifice practice of the Church of the Lukumi.¹⁸⁵ The Court held that the law violated the First Amendment's Free Exercise Clause because it was a non-neutral law that substantially burdened the Church's religious practice, and the city did not have a compelling interest in imposing the burden.¹⁸⁶ Of the most importance is the Court's analysis in reaching its conclusion on the ordinance's lack of neutrality.¹⁸⁷ The Court examined the text of the

182. See generally *Church of the Lukumi Bablu Aye, Inc. v. City of Hialeah*, 508 U.S. 520 (1993) (holding that a city's ordinance violated the First Amendment, by incorporation through the Fourteenth Amendment). In its holding, the Court considered the attitude of the city's citizens toward the religious denomination that was targeted by the ordinance. *Id.* at 534-35.

183. See Stephen P. Croley, *The Majoritarian Difficulty: Elective Judiciaries and the Rule of Law*, 62 U. CHI. L. REV. 689, 719 (1995). The author argues that one of the most important roles of the judiciary is to protect the right of minorities, which is hard to ensure if the judges are elected. Electing judges creates an incentive for a judge to make decisions that favor the majority so as to garner the majority's support. *Id.*

184. *Church of the Lukumi*, 508 U.S. at 534-35.

There are further respects in which the text of the city council's enactments discloses the improper attempt to target Santeria. Resolution 87-66, adopted June 9, 1987, recited that '*residents and citizens of the City of Hialeah* have expressed their concern that certain religions may propose to engage' in practices which are inconsistent 'with public morals, peace or safety,' and 'reiterate[d] the city's commitment to prohibit any and all [such] acts of any and all religious groups.' No one suggests, and on this record it cannot be maintained, that city officials had in mind a religion other than Santeria.

Id. (emphasis added).

185. *Id.* at 545-47.

186. *Id.*

187. *Id.* at 541.

law and the legislative record.¹⁸⁸ Therefore, it is a valid legal analysis in the area of First Amendment jurisprudence to lift the veil to determine the legitimacy of government action.

Although, no RLUIPA case has directly recognized popular discrimination as a substantial burden, the Ninth Circuit came close in *Guru Nanak*. There, the court concluded that the zoning board had shown a pattern that it might never grant a minority religion a building permit.¹⁸⁹ This Note is making a similar argument. That is, if popular discrimination is the reason for denying a Muslim organization a building permit, unless the community changes its mind, then it's more likely than not that the Muslim organization would continuously be denied a building permit, thereby preventing its members from congregating—a tenet of their religion—which infringes on their freedom of religion.

Finally, we should not repeat past mistakes. After the Japanese attack on Pearl Harbor during the Second World War, the Supreme Court of the United States abdicated its duty when it acquiesced to the illegal detention of U.S. citizens of Japanese descent in an internment camp.¹⁹⁰ The Court was called on to protect the rights of the Japanese minorities in *Korematsu v. United States*, but the Court failed to do its duty.¹⁹¹ Instead of siding with the U.S. citizen of Japanese descent that challenged the military's policy, the Supreme Court reasoned that national security concerns afforded deference to executive decisions. That decision was palatable then because the majority of the U.S. population was in support of the government's action. They saw Japanese Americans as potential allies of the enemy.¹⁹²

The events of 9/11, the war on terror, and the animosity towards Muslims in the United States today is arguably similar to the Japanese situation during World War II. While there is no danger of internment camps, lackluster protection of the rights of Muslims will amount to allowing the prejudices of the majority to determine the fate of the

188. *Id.*

189. *Guru Nanak Sikh Soc'y of Yuba City v. Cnty. of Sutter*, 456 F.3d 978, 992 (9th Cir. 2006).

190. *See generally* *Korematsu v. United States*, 324 U.S. 885 (1945). This was a case where the petitioner, an American of Japanese ancestry, was convicted in a district court for remaining in a military area where all people of Japanese ancestry had been excluded by order of the U.S. Army. *Id.* at 216. The Court held that while any law that restricted a racial group was inherently suspect, the imperatives of war allowed for such drastic actions. *Id.*

191. *Id.* at 223-24.

192. *See id.* at 223 (reasoning that Congress decided to hold all citizens of Japanese ancestry because Congress believed some of them were aiding the enemy).

minority. Allowing land-use decisions that were made with discriminatory intent to stand will amount to validating people's prejudice towards Muslims. Moreover, modern scholars universally condemn the Supreme Court's *Korematsu* performance. More importantly, today's Supreme Court Justices see it as a travesty. Justice Stephen Breyer, Associate Justice of the Supreme Court, singled out *Korematsu* as one of the most egregious decisions of the U.S. Supreme Court.¹⁹³ The fact that the U.S. is at war in Muslim countries, which creates an understandable fear in the population, should not be allowed to manifest itself in the suppression of our constitutional values.

CONCLUSION

RLUIPA requires the federal courts to invalidate any land-use decisions that substantially burden a person or religious organization if there is no compelling governmental interest. The federal appellate courts have not adopted a precise definition of a substantial burden; most courts use an ad-hoc approach. There are trends in the definition used by the courts, and none of these trends involves that analysis of popular discrimination as a substantial burden.

Nonetheless, 9/11 and the wars in Afghanistan and Iraq have created animosity towards Muslims in the United States. This animosity has manifested itself in serious citizen campaigns to encourage zoning boards to deny mosque permits across the country. In 2009, thirty-five mosque permit applications across the U.S. encountered severe opposition, leading to some permit denials. Because the requirement to congregate with fellow worshippers is a tenet of Islam, building permit denials are a substantial burden on the freedom of Muslims to practice their religion.

Federal courts should consider popular discrimination as a *prima facie* substantial burden by considering the following factors: (1) the record of the zoning board on the permit at issue, including public hearings; (2) the community's reaction to that specific mosque project; and (3) a causal link between the alleged discrimination and the permit denial. These factors would enable the courts to determine if the zoning board reached its decision for impermissible reasons. These

193. Interview by Linda Greenhouse with Justice Stephen Breyer, Assoc. Justice, Supreme Court of the United States, in the National Archives Building, Washington, D.C. (Sept. 13, 2010).

factors are community focused, and therefore, the potential relevance of popular discrimination would not be assumed across the board.

There are substantial legal and policy reasons that support using these factors to analyze a substantial burden. In *Church of the Lukumi*, the Supreme Court's examination of the legislative record of a city ordinance led to the conclusion that the ordinance was passed specifically to burden the religious organization.¹⁹⁴ The Ninth Circuit, in *Guru Nanak* held that the rationale proffered by the local zoning board for denying a minority religious group's applications for a building permit indicated unfairness in the board's treatment of the group.¹⁹⁵ Rightfully, the Ninth Circuit protected the religious freedom of the minority Sikhs in *Guru Nanak*.

In sum, the legislative history of RLUIPA and the judiciary's societal role require that popular discrimination be considered in the analysis of a substantial burden. The U.S. Congress passed RLUIPA to protect religious organizations from "well documented" discrimination by zoning boards. Furthermore, one of the solemn duties of the judiciary in a democracy—majority rule—is protection of minority rights. To fulfill this solemn duty, courts must consider the majority's attitude towards the right of Muslims to practice their religion freely.

194. See discussion *supra* Part IV.B.

195. See discussion *supra* Part III.B.

