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The Color of Pain: Blacks and the U.S. Health Care System--Can the Affordable Care Act Help to Heal a History of Injustice?, Part II

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# THE COLOR OF PAIN: BLACKS AND THE U.S. HEALTH CARE SYSTEM— CAN THE AFFORDABLE CARE ACT HELP TO HEAL A HISTORY OF INJUSTICE? PART II

Part I of this article can be found in the last issue of the *National Lawyers Guild Review*. See Jennifer M. Smith, *The Color of Pain: Blacks and the U.S. Health Care System Can the Affordable Care Act Help to Heal a History of Injustice? Part I*, 72 NLG REV. 238 (2015).

#### IV. The general state of health care in the United States before reform

The state of Americans' health care has been troubling, especially before health care reform. The Affordable Care Act (ACA) is often touted as universal health care, and the initial intention was for the U.S. to have universal health care. However, with all of the compromises involved in its passage, the ACA resulted in comprehensive health insurance reform, significantly increasing the accessibility, affordability, and quality of health care for most, but not all, Americans. The ACA is a substantial step toward universal health care—a near-universal mandate—that may soon provide coverage to all Americans, and even include undocumented immigrants. 146

Americans can find excellent health care—if they can afford it. The key is health insurance. For those without health insurance, inadequate health care has been determined to be a chief cause of death, putting it statistically ahead of HIV/AIDS and diabetes.<sup>147</sup> Uninsured adults often forego needed medical care or preventive care, and are twice as likely to have poor health as their privately insured counterparts.<sup>148</sup> Furthermore, uninsured Americans with chronic conditions, such as diabetes, cancer, or heart disease, have difficulty managing their ailments precisely because they have no insurance.<sup>149</sup>

Lack of health insurance has been linked to "developmental and educational deficits for children, reductions in workforce productivity, and significant familial and community stresses." By the time uninsured adults reach the age of sixty-five and are able to qualify for Medicare, they generally require

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more care than their insured counterparts.<sup>151</sup> Uninsured patients are three times more likely to die during their hospital stays than insured patients, and they are 25 percent more likely to die prematurely than those with insurance.<sup>152</sup>

In addition, uninsured citizens use the emergency room as their primary source of care, placing a huge burden on medical facilities. Indeed, uninsured persons receive billions of dollars in care from emergency room services, for which they do not pay.<sup>153</sup> Finally, uninsured individuals receive about \$100 billion in health care services annually for diseases that could have been treated more cheaply and efficiently had they been diagnosed earlier, and that would have been more likely to occur if they had insurance and utilized preventative health care services.<sup>154</sup>

The number of uninsured Americans has soared due to rising "health insurance premiums, a changing labor market, and underfunded health care safety net programs" such as Medicaid and the Children's Health Insurance Program ("CHIP"). <sup>155</sup> In the mid-2000s, America's uninsured population swelled to nearly 47 million, representing about 16 percent of the population. <sup>156</sup> There were an additional 16 million Americans who were underinsured. <sup>157</sup> Incomes of many uninsured individuals are below \$25,000. <sup>158</sup> While all racial and ethnic groups are impacted, <sup>159</sup> these problems disproportionately affect African Americans and Hispanics, <sup>160</sup> who have significantly greater uninsured rates than whites. <sup>161</sup>

America's health care crisis is a societal concern, because Americans collectively shoulder the health care costs of its uninsured and underinsured citizens. <sup>162</sup> Faced with the possibility of creating a permanent "health and health care underclass" consisting of African Americans, Hispanics, and the working poor, <sup>163</sup> Americans needed a solution—a national health care system for its citizens.

## V. Patient Protection and Affordable Care Act ("ACA")

In the first few weeks of his administration, President Obama, who firmly believes that "health care is a right for every American," <sup>164</sup> called for an overhaul of the United States health care system. <sup>165</sup> Days before the historic vote on the Affordable Care Act in the United States, President Obama declared:

And in just a few days, a century-long struggle will culminate in a historic vote. We've had historic votes before We had a historic vote to put Social Security in place to make sure that our elderly did not live out their golden years in poverty. We had a historic vote in civil rights to make sure that everybody was equal under the law. As messy as this process is, as frustrating as this process is, as ugly as this process can be, when we have faced such decisions in our past, this nation, time and time again, has chosen to extend its promise to more of its people. 166

President Obama's "century-long struggle" referred to then-presidential candidate Theodore Roosevelt's call for national health insurance in 1912. Indeed, since 1912, there have been periodic discussions about providing

universal health care in the United States. Prior to the passage of the Hill-Burton Act in 1946, liberals were pressing for universal health care, and the charity care provisions of the Hill-Burton Act were the compromise provided by the conservatives to placate the liberals.<sup>168</sup>

On March 23, 2010, President Obama signed into law the Patient Protection and Affordable Care Act ("ACA"). On March 30, 2010, he signed into law the Health Care and Education Reconciliation Act ("HCERA"), which amended various provisions of the ACA. 169 These two pieces of groundbreaking legislation comprise America's new health care system

As previously noted, universal health care in the United States has been a highly controversial topic for a century, and the passage of the ACA was fraught with disputation. Nonetheless, the ACA has survived contentious and heavily funded attacks spearheaded largely by conservatives.<sup>170</sup> Indeed, the ACA was passed by congress without a single Republican vote.<sup>171</sup> Contrary to its decades-long opposition to a national health program,<sup>172</sup> the American Medical Association (AMA) championed comprehensive health care reform and supported ACA.<sup>173</sup> Because of the reputation and influence the AMA has over the medical community, its support was critical. Similarly, the National Medical Association (NMA), which for decades had championed a national health care program, also played a key role in shifting the national consensus.

Subsequent to the enactment of the ACA, several states' attorneys general filed state and federal lawsuits challenging its constitutionality.<sup>174</sup> The individual mandate of the ACA, requiring Americans to purchase insurance or pay a penalty, was the most challenged provision. The U.S. Supreme Court accepted certiorari and decided the matter in 2012.

Prior to the Court's decision, President Obama stated:

Ultimately I am confident that the Supreme Court will not take what would be an unprecedented, extraordinary step of overturning a law that was passed by a strong majority of a democratically elected Congress. And I just remind conservative commentators that for years what we have heard is that the biggest problem on the bench was judicial activism or a lack of judicial restraint; that an unelected group of people would somehow overturn a duly constituted and passed law. Well, this is a good example. And I'm pretty confident that this court will recognize that and not take that step.<sup>175</sup>

Obama's prescience was affirmed by the Court. The Court upheld the constitutionality of ACA with a 5–4 vote, finding the individual mandate within Congress's power under the Taxing Clause. The justices broke along partisan lines, save for the conservative Chief Justice Roberts, who sided with the liberal justices to garner a majority to uphold the constitutionality of the Act, albeit on narrow and unexpected grounds.<sup>176</sup>

The ACA was unsuccessfully challenged once again. On June 25, 2015, the U.S. Supreme Court held that federal subsidies for health insurance

premiums could be used in the 34 states which did not set up their own insurance exchanges.<sup>177</sup>

However, in in a 2016 federal district court opinion, *U.S. House of Representatives v. Burwell*, Judge Rosemary Collyer found that part of the ACA is unconstitutional in that it provides for subsidies which the ACA did not provide for as an appropriation. Specifically, Judge Collyer, a George W. Bush appointee, found that Section 1402, which reduces deductibles, copays, and other means of "cost sharing" by insurers, needed its own direct appropriation from Congress before it can be funded: "Paying out Section 1402 reimbursements without an appropriation thus violates the Constitution. Congress authorized reduced cost sharing but did not appropriate monies for it, in the FY 2014 budget or since. Congress is the only source for such an appropriation, and no public money can be spent without one." However, the Obama administration believed that it could fund Section 1402 (Offset Program payments) from the same account as Section 1401 (Refundable Tax Credit Program payments).

The impact of Judge Collyer's ruling, if it is not reversed, is far-reaching. The ACA provides cost-sharing subsidies intended to reduce consumers' out-of-pocket medical bills. If these are witheld, as the Republicans are seeking to do, then low-income individuals covered under the ACA would likely experience higher co-payments, deductibles and other costs at hospitals and doctors' offices, thus making the ACA not so affordable for those who most need assistance in obtaining health care.

The Obama administration has spent significant time in the last several years contending against more than sixty attempts to repeal all or part of the ACA<sup>179</sup>These attacks against the ACA have sometimes even been bipartisan. Time spent defending the ACA "could have been better spent working to improve our healthcare and economy." <sup>181</sup>

## VI. The ACA and minority inclusion

As set forth earlier, health statistics confirm that even after fifty years of progress, the vestiges of racism in health care remain. Neither desegregation, litigation, legislation, the passage of time, nor the election of America's first African American president has eradicated racism in health care and other aspects of society. Racism still thrives and the health of blacks and other people of color has been compromised.<sup>182</sup>

The ACA is one of the most important pieces of legislation in American history. President Obama ensured a great legacy through his leadership in passing comprehensive health care reform that past American presidents had been unable to achieve. Health care reform carries a promise that America's health, and thus wealth, will only improve and increase now that America has

joined other industrialized nations in securing greater and more affordable access to health care for most citizens.

The ACA is long and complex. The Act is 906 pages and HCERA is 55 pages long (also including educational reforms)—a total of 381,517 words. Moreover, the Obama administration has published an additional 11,588,500 words of final ACA regulations, making the regulations 30 times longer than the statute <sup>183</sup>

As evidenced by its length and complexity, the ACA is one of the most sophisticated and strategic reform laws, and it extends well beyond health care. It not only seeks to ensure health access for all Americans, but it also seeks to right many wrongs that have existed within the health care system. It has built in cost-saving and cost-fairness mechanisms to prevent overreaching by insurance companies and to aid citizens in obtaining health care by prohibiting denial of coverage due to preexisting conditions. It regulates discriminatory pricing. It prohibits annual and lifetime coverage limits, but requires annual out-of-pocket limits for covered services. It also institutes cost-sharing controls with minor financial assistance.<sup>184</sup> The Act seeks to improve health care by emphasizing preventative care. It expands community health centers, where people of color and the poor so often end up. It obtains national statistics for health care enforcement. It invests in the National Health Services Corps, which provides financial assistance for those committing to work in rural and urban communities, investing in research and a Public Health Trust Fund to encouraging community initiatives. It extends nonprofit hospitals' community benefit obligations. 185 The Act requires policies to be explainable and summarized for policy holders and protects policy holders against plan rescissions except for fraud or intentional misrepresentation. 186 Just as Medicare played a key role in desegregating hospitals and the medical care system in general, 187 the ACA will do the same and much more. Many individuals do not realize the sheer breadth of the Act—it is a complete overhaul of the current health care structure.

The ACA—now fondly called "Obamacare," although "Obamacare" began as a derogatory attack on the Act—was rejected wholesale by most Republicans. Yet some Republicans (many personal beneficiaries of the Act) are now admitting and even celebrating the benefits of Obamacare. New Hampshire Republican state representative, Herb Richardson, praised Obamacare for restoring his health and wealth:

Richardson was injured on the job and was forced to live on his workers' comp payments for an extended period of time, which ultimately cost the couple their house on Williams Street. The couple had to pay \$1,100 a month if they wanted to maintain their health insurance coverage under the federal COBRA law. Richardson said he only received some \$2,000 a month in workers' comp payments, however, leaving little for them to live on. "Thank God for Obamacare!" his wife

exclaimed. Now, thanks to the subsidy for which they qualify, the Richardsons only pay \$136 a month for health insurance that covers them both. 188

The slow start of ACA was partly due to Republican leaders convincing their consituents to oppose President Obama and his agenda, even at the expense of their own health interests. "[T]hrough inadequate funding, opposition to routine technical corrections, excessive oversight, and relentless litigation, Republicans undermined ACA implementation efforts." Consequently, many citizens rejected "Obamacare," but supported "the Affordable Care Act," not understanding they were the same. Though the ACA has some flaws, few in America want to return to the days when insurance companies denied coverage for those with preexisting health conditions. 190 President Obama's race and popularity as the most admired man in the world for seven years have skewed conservative voters' concept and appreciation for the ACA.<sup>191</sup> Hatred, born out of jealousy and racism, has driven Republicans to oppose the most President Obama and his bills. 192 In addition, the Act merges health insurance and taxes—two areas most consumers find complex, thus spawning various opportunities for fraud. 193 Notwithstanding staunch conservative opposition and complicated provisions, the ACA has survived.

While studies reveal that Republican constituents who have used Obamacare are satisfied with their plans, in those states where primarily Republican governors declined the ACA's Medicaid expansion plan, the poor remain uninsured. 194 Two-thirds of impoverished blacks and single mothers and over half of uninsured low wage workers will be left out of the national effort to provide health care to millions of citizens. 195 Other than Arkansas, every state in the Deep South rejected the Medicaid expansion, and these states are home to nearly 70 percent of the poor, uninsured African Americans and single mothers—that is "435,000 cashiers, 341,000 cooks, and 253,000 nurses' aides." 196 Thus, the states with the largest populations of poor and uninsured people are the very states that are rejecting the Medicaid expansion—rejecting the opportunity to help those most in need of health care. 197 These are individuals with significant health care needs, and who will therefore have a significant impact on the health care system.<sup>198</sup> Expanding Medicaid was intended to provide coverage for the poorest citizens, those who are too poor to participate in the subsidies and new health exchanges for low and middle-income earners.<sup>199</sup> (By contrast, about half of Latinos who are poor and uninsured reside in states expanding Medicaid, except for Texas.<sup>200</sup>) Universal Medicaid expansion would have saved thousands of lives. It could have prevented nearly 20,000 unnecessary deaths if it had been expanded in every state. 201

Enrollment under the ACA has exceeded initial expectations. Nearly 11.4 million citizens signed up for coverage for 2015.<sup>202</sup> This total includes automatic re-enrollees and first time users.<sup>203</sup> Meanwhile, the uninsured rate has dropped from 17.1 percent to 12.9 percent since 2014, when the ACA

took effect.<sup>204</sup> Even more recent numbers indicate an historic low of 9.1 percent—nearly 7.4 million uninsured less since 2014.<sup>205</sup> In addition, there is some evidence that the uninsured rate went down the greatest among blacks and other lower-income Americans.<sup>206</sup> Nevertheless, racial and ethnic minorities remain overrepresented among those uninsured, even after the 2014 initial enrollment.<sup>207</sup> Individuals below the poverty line are the most likely to be uninsured.<sup>208</sup> Much of that has to do with the cost of health insurance. Although people of color comprise 40 percent of the population, they account for over half of the uninsured.<sup>209</sup> People of color have significantly higher rates of being uninsured than whites: Latinos, 25.6 percent, blacks, 17.3 percent and whites 11.7 percent.<sup>210</sup>

ACA opens a door to health care for nearly all citizens. Medicaid and Medicare were significant for health care access as well, but they covered certain populations—the poor and the elderly, respectively—whereas ACA seeks to provide coverage for all categories of Americans. Instead of discarding all of the country's health care programs, the ACA seeks to use the foundational building blocks (other legal reforms) already in place, such as Medicare, Medicaid, EMTALA, the Children's Health Insurance Program, health insurance through a private or public employer (including military employment), and the individual coverage market. The ACA builds on all of these health care laws, with its most generous reforms toward the individual and small group markets and Medicaid. Even so, America has a somewhat fragmented health insurance system that remains burdened by high costs significantly greater than those of other nations

America is still a "color conscious" society, notwithstanding our first African American president. Discrimination persists. Even the president, our highest political office holder, is consistently subjected to consistent racist jokes and comments. <sup>211</sup> Thus, it is to be expected, with the Act's inclusion under Title VI of the Civil Rights Act of 1964 for remedial action, that discriminatory practices that people of color have historically experienced will continue. Sadly, Title VI has not offered much assistance in ending health care discrimination against minorities. <sup>212</sup> Its failure was largely because relevant health care statistics demonstrating disparate treatment sufficient to meet the legal standard were unavailable.

To remedy this, the ACA mandates collecting and reporting race statistics in health care treatment, but that has thus far been stymied by political and implementation hurdles. <sup>213</sup> Yet there must be more than mere remedial action pursuant to Title VI. The ACA reproduces the anti-discrimination obligations imposed by the civil rights laws, but it must give those obligations teeth. Health insurers may continue to thwart the anti-discriminatory obligations of the ACA. For example, they may avoid provider networks that cater to minorities, such as community health centers and hospitals serving

underserved communities. Studies have shown, however, that in 2014, racial minorities, low-income workers, and immigrants have benefitted the most from the ACA.<sup>214</sup>

Civil rights leaders have acknowledged that, while race has not been mentioned in the state-level debates on the Medicaid expansion, the disproportionate impact on blacks perpetuates the historic pattern of exclusion of blacks from the American health care system. The Republican governors and Republican-controlled states retort that health care is a purely economic issue, additionally noting that Medicaid is already burdening their states. But the sordid history of blacks in America's health care system leaves little doubt that racism, and not merely economics, is influencing outcomes. The U.S. needs real, practical remedies to move forward with the advent of universal health care—for the poor generally, and people of color particularly. The availability of health insurance, by itself, will not cure the separate problem of accessing that system.

#### VII. Recommendations

Studies consistently reveal that people of color—African Americans in particular—continue to receive substandard care compared to that of white Americans, even if the black patients are enrolled in health plans comparable to their whites counterparts.<sup>217</sup> It is also estimated that by 2043, people of color will constitute more than half of the population of the United States.<sup>218</sup> It is therefore imperative that we immediately undertake to find real, practical solutions for all Americans to benefit from the ACA.

There is no doubt that the ACA has allowed more people to obtain medical care. Physicians are reporting that they are seeing more patients and receiving compensation for services that previously went unpaid. Meanwhile, patients are relieved that they can obtain early detection of various illnesses that blacks and other people of color consistently die from.

## A. Co-pays and deductibles

Since the deductibles and co-pays of the plans offered under the ACA remain high, many of the newly insured still cannot afford to use the insurance they have. <sup>219</sup> The insurance is available to the patient, but high co-pays preclude its use. Only the insurance companies benefit under this scenario. In addition, some have taken out policies to avoid the fine, but have not maintained the policy by paying their premiums. In such circumstances, a health care service provider may furnish some services (such as early detection tests), but the claim is denied when submitted for reimbursement because of the unpaid premium. Federal and state governments must continue to work with physicians and insurance companies to reduce deductible and co-pay costs as well as other ways to reduce costs for the poor. This is not a new issue. It endures

under the ACA. The avarice of insurance companies and other ACA partners must be reined in to ensure that the insurance sold can also be used as needed.

In addition, the recent federal district court case, *Burwell*, holding that paying out Section 1402 reimbursements without an appropriation is unconstitutional, places another hurdle to overcome with co-pays and deductibles. *Burwell* is a potentially severe blow to the ACA if it is upheld. As a result, insurers who, by law, were guaranteed reimbursements for offering reduced rates for co-pays and deductibles will not receive their reimbursements until a valid appropriation is in place. The biggest losers will be the millions of low-income Americans who have been benefitting from the cost-sharing subsidies that assist them with out-of-pocket costs.

Even before the *Burwell* decision, there were grumblings from insurance companies as a result of their alleged losses from participating in the ACA. Some companies are threatening to withdraw from the ACA in the next few years. <sup>220</sup> Insurance companies are claiming that the ACA is not sustainable, <sup>221</sup> although some of them simply made errors in pricing their health care plans—15 percent lower than the Congressional Budget Office predicted. <sup>221</sup> But the additional possibility of disappearing reimbursements may increase the threats of the insurance companies.

Under the threat of insurance companies' unwillingness to participate, the time may be ripe to renew a transparent discussion on a single-payer system. While there are various versions of what a single-payer system means, generally it is a federally-funded health care system. Physicians for a National Health Program describes one:

Single-payer national health insurance is a system in which a single public or quasi-public agency organizes health financing, but delivery of care remains largely private. Under a single-payer system, all Americans would be covered for all medically necessary services, including: doctor, hospital, preventive, long-term care, mental health, reproductive health care, dental, vision, prescription drug and medical supply costs. Patients would regain free choice of doctor and hospital, and doctors would regain autonomy over patient care. <sup>222</sup>

Democratic presidential candidate Bernie Sanders indicated in 2016 that the only way to truly provide universal health care is a "Medicare for all single-payer system," which would do away with deductibles and co-pays.<sup>223</sup> But at what cost? Sanders has estimated \$14 trillion.<sup>224</sup> Other countries have single-payer systems, but they have smaller populations than the U.S. Furthermore, millions in the insurance industry would become displaced workers if America moved to a single-payer system.<sup>225</sup> Democratic presidential candidate Hillary Clinton has spoken about potentially expanding Medicare to 50 year old citizens.<sup>226</sup>In addition, because more medical providers are telling Obamacare customers that their Obamacare insurance is not accepted by the medical providers, there is a renewed interest in a public option that would

supplement current offerings.<sup>227</sup> Colorado is gearing up to vote in November 2016 to abandon the ACA and create a taxpayer-financed public-health system—universal health care for Coloradans.<sup>228</sup> And, based on his experience with the ACA, President Obama concluded, "I think Congress should revisit a public plan to compete alonside private insurers in parts of the country where competition is limited."<sup>229</sup>

A proposal for a single-payer system was bandied about before the ACA was passed, but failed to generate enough support among lawmakers. That proposed system could have eliminated co-pays and deductibles. The ACA is really a compromise bill among key stakeholders. As of now, however, co-pays and deductibles are pricing out those the ACA is designed to embrace. Like the ACA, the *Burell* decision is political, and discontinuing the reimbursements to the insurers will close access to health care for millions of low income individuals. Even without a single-payer system, the ACA should not become unaffordable or health care become inaccessible because of out-of-pocket costs. Health plans must be restructured to meet the end goal of the ACA—health care services for America's citizens, not simply insurance put to no use.

#### B. "Fear or fine"

The Individual Shared Responsibility Provision of the ACA requires that individuals either have basic, minimum health insurance for each month or pay a fine when paying federal income tax (assuming no exemption applies to the individual). This "fear or fine" provision is ineffective if the individual simply cannot afford the insurance or the fine. In addition, as noted above, there are some individuals who are opting for basic, minimum health insurance so as to avoid the tax penalty, but the insurance is unusable because the co-pays and deductibles are too high. This tax on the poor is putting money either in the pocket of the insurance companies or the federal government while medical services are not being provided. While there may need to offer an incentive for obtaining health insurance, a penalty will likely be ineffective. There is a tax credit to help those who purchase insurance in the marketplace, but that is a supplement, and not an incentive.

Again, there must be more than just punishment to incentivize maintaining health insurance. This problem may be partially due to a lack of information and positive experience, as well as truly affordable access to health care or affordable insurance plans. While it may be the case that maintaining one's health through regular check-ups is a security against greater medical needs and costs later, far too many individuals distrust or dislike doctors. These individuals must be persuaded, through experience, that they can receive quality medical care, which will reduce the high rate of early deaths among people of color and the poor.

#### C. "Pay-for-performance"

The "pay-for-performance" provision of the ACA is an umbrella term for improvement programs targeted to ensure the efficiency, quality, and overall value of health care. In return, these programs may generate financial incentives to health care providers (hospitals and physicians) who meet the predetermined goals. However, since many blacks and other people of color have higher noncompliance rates of treatment than whites, <sup>230</sup> often due to economics, what avenues will providers take to give medical care to those most non-compliant in order to meet the quality goals? For example, amputation is already several times more likely for blacks than nonblacks. <sup>231</sup> If doctors suspect that a patient is not likely to fully comply with the therapy, the doctor may choose amputation instead, to prevent the patient's noncompliance from interfering with the quality goals and appurtenant financial incentives. To end this cycle, "quality of care" must be re-defined to ensure that all patients can both access comparable services and receive similar treatment from providers.

Kidney transplants are illustrative of this circularity problem. Immunosuppressive drug therapy is the most significant health care expense after the three year post-transplant.<sup>232</sup> But, due to the cost of immunosuppressive medications, many individuals fail to comply with their post-transplant medical regimen.<sup>233</sup> Thus, the therapy has swiftly developed "as a major health care issue with implications for chronic rejection and graft loss."234 Chronic rejection is known as "any form of nonspecific late graft dysfunction[]"235 and is "the leading cause of late graft failure in renal transplant recipients."236 Furthermore, noncompliance with immunosuppressive drug therapy for kidney transplants is the third leading cause of graft loss. 237 Put simply, patients who are noncompliant with their immunosuppressive drug therapy lose their transplants or die at rates much higher than patients who comply. <sup>238</sup> Thus, medical compliance after a kidney transplant is critical to the maintenance of the transplanted kidney and the patient's life. "The inability to afford immunosuppressive agents is thought to underlie as many as half of all [noncompliance] cases."239 If noncompliance is going to be an issue, again largely with blacks, doctors may opt to not seek a transplant for the patient but continue dialysis, with a lesser quality of life than a transplant. And, despite this decision, the doctor would still satisfy the quality of care goals, even though it is apparent that better options are available.

Medical schools, medical educators, medical associations, hospitals and the like must advance remedying medical racism as a topic of education and basic orientation to the medical profession. This will save lives and improve medical care.

#### D. Litigating health care access

The civil rights movement spawned various legislation, resulting in notable and influential litigation and advocacy to reduce health disparities

due to race.<sup>240</sup> At the time, these class-action lawsuits were a substitute for true access to health care in that they were used to open doors in health care that were closed due to discrimination. Unlike the employment and housing contexts, however, there was no independent federal statutory framework governing civil rights enforcement in health care access, other than Title VI of the Civil Rights Act of 1964,241 which extended to public accommodations (e.g. hotels, restaurants, but not health care), employment, and federally funded programs, such as Medicare. This resulted in intermittent involvement by the major civil rights advocates, such as the NAACP Legal Defense & Educational Fund ("LDF").242 Even though the legislative history of Title VI reveals the federal lawmakers' intent to include health care when they enacted it, organized medicine was able to effect a carve out for physicians in private practice. Organized medicine opposed the idea that receipt of federal funds (e.g. Medicare) would expose them to anti-discrimination laws, thus forbidding physicians from continuing to select their patients as they chose. 243 Thus, the Johnson administration orally pledged not to enforce Title VI against physicians in private practice.<sup>244</sup> However, it required every hospital that intended to participate in the Medicare program to sign a Title VI pledge that it would not discriminate.245

The Nixon administration dismantled much of the gains made through the Johnson administration by disconnecting federal spending laws from federal spending programs and stripping away the authority of federal civil rights officials from meaningfully enforcing Title VI, and thus, by the mid 1990s, active government enforcement of Title VI had all but ended.<sup>246</sup>

The ACA relies upon the same enforcement laws that have been in existence for decades to eradicate discrimination in health care, Title VI of the Civil Rights Act of 1964. Thus, it follows the same course of failure in ensuring that African Americans and other people of color will not be able to fully participate in America's health care system due to race discrimination. Section 1557 of the ACA prohibits discrimination in health care programs on the basis of race, color, national origin, sex, sex stereotypes, gender identity, age, or disability. The pertinent section of the text is as follows:

Except as otherwise provided for in this title (or an amendment made by this title), an individual shall not, on the 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. <sup>247</sup>

Section 1557 provides that a person shall not be excluded from participation in, be denied the benefits of, or be subjected to discrimination on the grounds prohibited under, among other laws, Title VI of the Civil Rights Act of 1964, under any health program or activity, any part of which is receiving federal financial assistance, or under any program or activity that is administered by an Executive Agency or any entity established under Title I of the Affordable Care Act or its amendments. Pursuant to Section 1557, the Office of Civil Rights ("OCR") is responsible for enforcing Section 1557, just as it is for Title VI. The law became effective when ACA was enacted, and OCR has been receiving and investigating complaints under Section 1557. But extending Title VI provisions to the ACA is unlikely to result in racial equality within the health care system, since Title VI has historically been unable to create health care access for blacks.

At the time of the enactment of Title VI:

Discrimination against Negro hospital patients was flagrant and widespread. They were housed in segregated wings or floors and forced to use separate waiting rooms, nurseries, cafeterias and clinics. In many cases Negroes were entirely excluded from hospital facilities. Negro physicians were refused staff privileges at any but all-Negro on inner-city hospitals. Most nursing homes were restricted to whites, although over ninety percent had patients supported by federally assisted public welfare agencies. Even state-owned or operated health facilities, such as mental health institutions, tuberculosis sanitariums and charity hospitals were in many cases segregated by law.<sup>249</sup>

Title VI of the Civil Rights Act prohibited racial discrimination in federally-assisted programs and activities.<sup>250</sup> It provides:

No person in the United States shall, on account of race, color, or national origin, be excluded from participating in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.<sup>251</sup>

Title VI applies to all states and providers receiving federal assistance in various medical facilities or programs, such as hospitals, nursing homes, mental health centers, Medicaid and Medicare, and public assistance programs. <sup>252</sup> Title VI was enacted to protect against unlawful race, color and national origin discrimination in access to health care and social services. <sup>253</sup>

The Office of Civil Rights is the federal government agency that is responsible for enforcing Title VI and ensuring "that people have equal access to and an opportunity to receive services from all HHS-funded programs and services."<sup>254</sup>

Notwithstanding that federal funds accounted for nearly half of hospital care, a third of nursing home care, and nearly a third of physician fees in

the 1990s, Title VI claims have not been frequently utilized in health care matters.<sup>255</sup> Thus, federal dollars continued to support racial discrimination, in spite of Title VI. And, although Title VI authorized federal agencies to withold funding from facilities that discriminate on the basis of race, the federal government has done little to enforce the provisions of Title VI in the health care arena.<sup>256</sup> Thus, a year after the passage of Title VI, the United States Commission on Civil Rights found health care discrimination to be widespread, and litigation to be of little help.<sup>257</sup>

Overall, the application of Title VI to health care has proven insurmountable primarily because of the strict legal standards and the complex organization of the health care system. Because hospitals pledged not to discriminate to receive federal funding, the legal challenges were largely centered on discriminatory impact, rather than intentional discrimination. However, discriminatory impact cases require significant amounts of relevant statistical data, which neither Title VI or Medicare/Medicaid standards required to be collected. Thus proof of racial disparity was virtually impossible to find.

ACA Section 4302, however, requires the collection of data on "race, ethnicity, sex, primary language, and disability status for applicants, recipients and participants" and that this data be reported in a form accessible to researchers and the public. 258 The data collection can aid in the reduction of race disparities in health care by identifying and measuring disparities, designing and implementing programs and interventions to address race disparities, monitoring progress in reducing disparities, and tweaking programs and interventions to achieve greater equality on health care. Although there are some barriers to the effective collection of data, such as the concerns and perceptions of the members providing the data, limitations of resources, and inefficient information systems for data gathering, collecting data from health plans, purchasers, and health care providers would provide information to improve medical care, as well as provide evidence of racial disparity. Depending upon how this data is used, it can potentially reveal and begin to repair the discrimination that persists in medical treatment on a large scale.

#### E. Early detection versus prevention

The ACA requires that most health plans cover preventive care without cost-sharing, which is quite beneficial to patients. In fact, over 71 million Americans directly benefitted from this provision of the ACA.<sup>259</sup> However, the ACA views preventive care as early detection care, which is not necessarily coextensive with true preventive care. For example, early detection of cancer is based upon patient education and screenings,<sup>260</sup> while preventive care is a bit different. For example, vitamin D and not smoking may help to prevent cancer; and exercise and protecting your eyes may help to prevent glaucoma.<sup>261</sup> Therefore, there needs to be more emphasis on prevention as well

as early detection, such as screenings and mammograms. Prevention requires education—education in diet, nutrition, exercise and health. Prevention also puts the ball back in the hands of the patient, allowing the individual to take control of his or her health. This could be accomplished with the assistance of community health workers, who could help individuals manage their health plans, unexpected co-pays and deductibles, compliance with treatment plans, and prevention of disease. Community health care workers could also assist patients with multiple chronic conditions—often affecting people of color—who commonly lack access to timely, high-quality care due to poverty and homelessness, lack of transportation, and racism.

#### VIII. Conclusion

Racism has had a significant negative impact on the health care of blacks and other people of color in the United States. The ACA is truly the first time that African Americans have collectively had significant access to health care. It is noteworthy that America's first African American president is chiefly responsible for this access. The ACA is an aggressive and strategic effort to cure many of the ills affecting blacks and other people of color in health care.

President Obama believes that the ACA is working. His assessment is based on statistics that reveal reductions in hospital admission rates, numerous lives being saved, tens of millions of insured Americans who had not previously had insurance, and a slowdown in the growth of health care spending. <sup>265</sup> In addition, the repeated failure of the Republicans to repeal the law is a victory, even with the recent set back from *Burwell*. As President Obama stated:

The bottom line is this for the American people: the Affordable Care Act, this law, is saving money for families and for businesses. This law is also saving lives," the president said. "It's working, despite countless attempts to repeal, undermine, defund and defame this law...it's not the fiscal disaster critics warned about for five years.<sup>266</sup>

The ACA is working, and even for the most vulnerable among us. Racial minorities, low-income workers, and immigrants are the greatest beneficiaries of the ACA, and because of the ACA, the number of lower-income children getting health coverage continues to rise.

Many will not recognize the ACA's successes for political reasons. When the historic findings were released revealing the record lows for the uninsured in the eight year history of the poll, even the mainstream news media largely ignored it. <sup>267</sup> And Obamacare has even been good for the U.S. economy. <sup>268</sup>

Before the ACA the uninsured population was steadily rising and so were health care costs. For the first time in America's history, health care is, at least theoretically, accessible to nearly all people. The ACA is a great accomplishment, albeit an imperfect one. It is enormous, complex, and ambitious. It is a model of progress, not perfection. However, if Americans continue to support

the ACA and it continues to evolve to meet their needs, it will accomplish its lofty goal: accessible, affordable, quality health care for all.

NOTES

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- 148. See Sara R. Collins et al., Gaps In Health Insurance: An All American Problem, THE COMMONWEALTH FUND 11 (Apr. 1, 2006), http://www.commonwealthfund.org/usr\_doc/Collins\_gapshltins\_920.pdf ("For many people with comprehensive insurance coverage, preventive care tests and screens like mammograms, colonoscopies, pap spears, and blood workups for cholesterol are part of their health care routine, performed annually or once every few years and requiring little out-of-pocket expense.").
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- 155. FAMILIES USA, *supra* note 147, at 11, 14.
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- 157. See Mehlman, supra note 149, at 2-3; see also Timothy Stoltzfus Jost, Access to Health Care: Is Self-Help the Answer?, 29 J. LEGAL MED. 23, 25 (2008) (defining "underinsurance" as "having to spend more than 10 percent of household income on health care costs").
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- 159. FAMILIES USA, supra note 147, at 9.
- 160. W. MICHAEL BYRD & LINDA A. CLAYTON, AN AMERICAN HEALTH DILEMMA, RACE, MEDICINE, AND HEALTH CARE IN THE UNITED STATES, 1900-2000 587 (2002).

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- 239. Willoughby et al., *supra* note 232, at 127 (noting also that this noncompliance may be partly a result of loss of or lack of health insurance coverage).
- 240. Marianne Engelman Lado, Unfinished Agenda: The Need for Civil Rights Litigation to Address Race Discrimination and Inequalities in Health Care Delivery, 6 TEX. F. ON C.L. & C.R. 1, 26 (2001) (citing Simkins, Eaton v. Grubb, 329 F.2d 710 (4th Cir. 1964), Hawkins v. North Carolina Dental Society, 355 F.2d 718 (4th Cir. 1966), Cypress v. Newport News General and Nonsectarian Hospital, 375 F.2d 648 (4th Cir. 1967), which aided in disassembling the sanctioned discrimination in health facilities; and Cook v. Oschner Foundation Hospital, 61 F.R.D. 354 (E.D. La. 1972), aff'd, 559 F.2d 968 (5th Cir. 1977), which aided in increasing access for blacks and reduce the flight of health facilities from urban communities); see also The Greenwood Encyclopedia of African American Civil Rights: From Emancipation to the Twenty-First Century 461 (Charles D. Lowery & John F. Marszalek eds., 2d ed. 2003) [hereinafter The Greenwood Encyclopedia].
- 241. Lado, *supra* note 240, at 5.
- 242. Id. at 25-26.
- 243. See DAVID BARTON SMITH, HEALTH CARE DIVIDED: RACE AND HEALING A NATION 96-142 (1999).
- 244. See id.
- 245. See id. at 146-96.
- 246. See id.
- 247. Patient Protection and Affordable Care Act § 1557, 42 U.S.C. § 18116 (2012) (emphasis added).
- 248. See Section 1557 of the Patient Protection and Affordable Care Act, HHS.GOV, http://www.hhs.gov/ocr/civilrights/understanding/section1557/ (last visited on Apr. 13, 2016).
- 249. Linda R. Singer et al., Comment: Title VI of the Civil Rights Act of 1964 Implementation and Impact, 36 GEO. WASH. L. REV. 824, 980 (1968) (citations omitted).

- 250. THE GREENWOOD ENCYCLOPEDIA, supra note 240, at 461.
- 251. Title VI of the Civil Rights Act of 1964, 42 U.S.C. § 2000d.
- 252. Your Rights Under Title VI of the Civil Rights Act of 1964, HHS.GOV, http://www.hhs.gov/ocr/civilrights/resources/factsheets/yourrightsundertitleviofthecivilrightsact.pdf (last visited on Apr. 13, 2016).
- 253. Discrimination on the Basis of Race, Color, or National Origin (Including LEP), HHS. GOV, http://www.hhs.gov/ocr/civilrights/understanding/race/index.html (last visited on Apr. 13, 2016).
- 254. Id.
- 255. See Jane Perkins, Race Discrimination in America's Health Care System, 27 CLEARING-HOUSE 371, 380 (1993); Stan Dorn et al., Anti-Discrimination Provisions and Health Care Access: New Slants on Old Approaches, 20 CLEARINGHOUSE 439, 439 (1986).
- 256. See Lado, supra note 240, at 21; VERN L. BULLOUGH & BONNIE BULLOUGH, HEALTH CARE FOR THE OTHER AMERICANS 193 (1982) ("In spite of Title VI, most hospitals that had discriminated in the past (including those previously built with Hill-Burton funds) continued to do so, since reimbursements for patients usually came third-hand, from local welfare agencies, and since the state agencies that managed the federal funds were reluctant to enforce the prohibitions against discrimination.").
- 257. See BULLOUGH & BULLOUGH, supra note 256, at 193 ("Blacks were housed in segregated wings or floors, forced to use separate waiting rooms, nurseries, cafeterias, and clinics, and in many cases, blacks were entirely excluded from the medical facilities. Black physicians were refused staff privileges at any but all-black or inner-city hospitals."); Watson, supra note 212 at 942. ("Title VI litigation has so far proved to be of little assistance in ending health care discrimination caused by these facially neutral policies with a disproportionate impact on minorities.").
- 258. Affordable Care Act Section 4302.
- See Affordable Care Act Rules on Expanding Access to Preventive Services for Women, HHS.GOV, http://www.hhs.gov/healthcare/facts/factsheets/2011/08/womensprevention08012011a.html (last visited on Apr. 13, 2016).
- 260. See Early Detection of Cancer, WORLD HEALTH ORGANIZATION, http://www.who.int/cancer/detection/en/ (last visited on Apr. 13, 2016).
- 261. See Vitamin D May Play Key Role in Preventing Macular Degeneration, SCIENCEDAILY (Aug. 31, 2015), https://www.sciencedaily.com/releases/2015/08/150831112621.htm; What Can I Do to Prevent Glaucoma?, GLAUCOMA RESEARCH FOUNDATION, http://www.glaucoma.org/gleams/what-can-i-do-to-prevent-glaucoma.php (last visited on Apr. 13, 2016).
- 262. See Reforming the Way Health Care Is Delivered Can Reduce Health Care Disparities, FAMILIESUSA (May 2014), http://familiesusa.org/sites/default/files/product\_documents/ HSI percent20Health percent20Equity percent20Delivery percent20Reform percent-20Brief final web.pdf.
- 263, See id.
- 264. See id.
- 265. See Rebecca Kaplan, Five Years In, Obama Taunts GOP Over Obamacare's Success, CBS NEWS (Mar. 25, 2015, 12:44 PM), http://www.cbsnews.com/news/five-years-in-obama-taunts-gop-obamcare-success/.
- 266 Id
- 267. See Alex Morash & Craig Harrington, TV News Ignores Historic Findings That Uninsured Rate Drops To "Record Low," MEDIA MATTERS FOR AMERICA (Apr. 15, 2016, 3:55 PM), http://mediamatters.org/research/2016/04/15/tv-news-ignores-historic-findings-uninsured-rate-drops-record-low/209941.
- Bob Bryan, Obamacare Has Been Good For the Economy, Business Insider, (May 13, 2016, 8:22 AM), http://www.businessinsider.com/obamacare-has-been-good-for-the-economy-2016-5.

