1 Making the Case for Health Reform

> We need to focus on the uninsured and those who suffer from health care disparities that we so inadequately addressed in the past.—*Senator William H. Frist, US Senate majority leader, on his priorities for the 108th Congress*

It was Thursday, June 28, 2012, and I was rushing to the airport to catch a flight for a meeting in Washington, DC. That morning, the US Supreme Court was expected to release its decision on the landmark health reform law, and I had asked several people to contact me immediately if they heard any news. As I cleared security at the Atlanta Hartsfield International Airport I started receiving phone calls and messages, but I was running to get to my gate. My heart was racing, as I had a gut feeling these calls were to tell me the fate of the Affordable Care Act, which was hanging in the balance. I ignored them, not yet ready to hear the news. When I finally got to my gate, the airline was calling zone 1. My father had called me four times so I decided to call him back first. I will never forget his words when he answered, "They overturned the ObamaCare law! They say it's unconstitutional!"

I was stunned, in a state of disbelief and grief. Though it was unlike me to yell in an airport, I screamed, "What?! Why?!" and thought to myself this could not be happening. After ending our conversation I checked my text messages and saw more confirmation of what my father said, the Supreme Court overturned President Obama's signature health law. Text after text repeated this news and ended with condolences, as though I had just lost a loved one. The gate agents had long ago called my zone, but I would not get on the plane. I was trying to find the nearest television to see what was being reported, but no television was nearby. Finally, I had to accept that if I did not get on the plane, I would be left behind, so I hurried onto the plane, stowed my luggage, buckled my seatbelt, and was about

to turn my phone off when I got one more text: "You must be so relieved! Congratulations! Thank God."

I was perplexed. Why would I be happy with the Supreme Court holding the Affordable Care Act unconstitutional? I was even more puzzled since the message came from a fellow health reform champion. Unfortunately, I didn't have time to follow up and ask her what she meant, as the flight attendant had just ordered us to turn off our cell phones. Before this trip, I had never purchased wireless access, but as soon as I could turn my iPad on, I purchased in-flight Wi-Fi so I could find out what happened. I soon realized that there was widespread confusion about the Supreme Court's decision. Several major news networks erroneously reported that the law had been overturned. They had read the first part of the ruling, which said that the law's individual mandate could not be upheld under the Commerce Clause of the Constitution. However, they missed the crucial part of the ruling, hidden deep in the opinion, that said it could be upheld as a tax under the Taxing Clause. One on-air correspondent, in acknowledging the mistake, attributed it to the Court's "very confusing, large opinion."[1]

As I sat back to read Chief Justice Roberts's opinion myself, I could not help but agree. Even as a lawyer, I had to closely and carefully read all the way through the Court's decision to determine its impact and implications because sometimes what counts is not immediately apparent. As I read the opinion and realized that the key provisions of the Affordable Care Act had been upheld, I felt euphoric and unspeakably relieved that years of hard work had not gone to waste. To appreciate the roller coaster of emotions, you would need to have been there from the beginning—be part of the vexing journey to pass this comprehensive health care statute intended to tackle the high uninsured rates, the fragmentation in delivering care, and so many other problems inherent in our health care system. As health policy developers, we are always told never to get too attached to our bills, but this was different. Too many people from all walks of life were depending on this law—their lives, their health, and their well-being literally depended on its passage and implementation.

Consider, for example, the rabbi in Florida who made a blog post seeking a younger woman to marry him so he could get cheaper health insurance coverage. Or the former police officer in Georgia who was facing "'severe health' problems and homelessness" and robbed a bank with the intention of going to federal prison so he could finally get care and treatment. This officer who had served in his police department for fifteen years and

had been jobless for more than a year "couldn't think of any other way to get help." In a similar incident, a North Carolina man robbed a bank for one dollar with the intention of going to prison in order to gain access to health services. The man had a growth on his chest and two ruptured disks and could not afford health care. Three years prior, he had been laid off from a major company after working there for seventeen years. Since that time, he was able to secure only part-time jobs that did not provide insurance coverage.[2] These stories, of people succumbing to desperate, illegal, even life-threatening measures highlight the fundamental weaknesses of our health care system and how critically reform was needed.

Prior to the passage of the landmark health reform law, more than fifty million Americans lacked health insurance, the majority of these individuals among the ranks of the working poor. More than fifty-seven million people had been determined to have a preexisting condition, and many of these individuals were denied health insurance coverage on that basis. Before the ACA was enacted, insurers would rescind coverage to individuals who needed care the most or find any mistake in their applications to deny them coverage. And approximately forty-five thousand people in the United States were dying each year because they lacked health insurance, equating to about five individuals every hour.[3]

For consumers who had health insurance coverage and did not think reforms would positively impact them, the opposite was true—nearly 40 percent of the health care costs of the uninsured were being passed on to consumers who did have health insurance coverage, in the form of higher premiums. Moreover, the high costs of health care were directly impacting businesses and consumers, as both the family and employer shares of employer-based coverage nearly doubled from 2001 to 2010. The United States was spending far more on medical care than any other industrialized nation but ranked twenty-seventh among thirty-four Organisation for Economic Co-operation and Development countries in terms of life expectancy.[4]

Seven out of ten deaths in the United States were related to preventable diseases such as obesity, diabetes, high blood pressure, heart disease, and cancer, and 75 percent of our health care dollars were being spent treating them. However, only three cents of each dollar spent on health care (total public and private) were going toward prevention. Altogether, the five leading causes of death in the United States—heart disease, cancer, unintentional injuries, chronic lower respiratory diseases, and stroke—accounted for 63 percent of all deaths, but up to 40 percent of these annual deaths

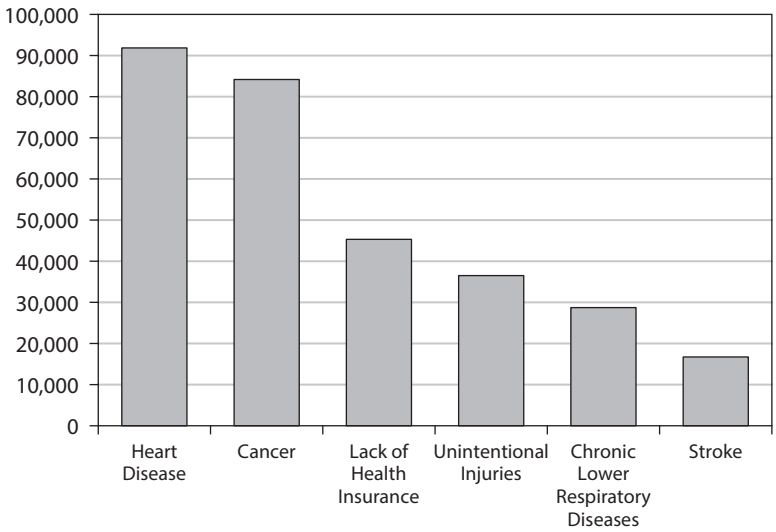

Figure 1.1. Leading causes of death in the United States. Centers for Disease Control and Prevention, "Up to 40 Percent of Annual Deaths from Each of Five Leading US Causes Are Preventable"; Wilper et al., "Health Insurance and Mortality in US Adults."

were preventable according to the Centers for Disease Control and Prevention. The total number of preventable deaths due to lack of health insurance displaces unintentional injuries as the third leading cause of preventable death.[5] This does not even include the number of preventable deaths due to medication errors, hospital acquired conditions, or other issues.

There were also considerable disparities in health status and health care among vulnerable populations. Members of underserved populations, such as racial and ethnic minorities, experience higher mortality rates and earlier onset of diseases. They also receive lower-quality health care and worse health outcomes. African American women have the highest death rates from heart disease, breast and lung cancer, stroke, and pregnancy among women of all racial and ethnic backgrounds. Hispanics have poorer quality of care than non-Hispanic whites for about 40 percent of quality measures, including not receiving screening for cancer or cardiovascular risk factors. American Indians and Alaska Natives have a suicide rate that is 50 percent higher than the national average, and Asian Americans have a high prevalence of chronic obstructive pulmonary disease, hepatitis B, tuberculosis, and liver disease.[6]

In general, people with disabilities are more likely to have difficulty or experience delays in accessing vital health services, including oral health care. Individuals with serious mental illness die on average twenty-five years earlier than the general population, at fifty-three years of age. Lesbian, gay, bisexual, and transgender individuals also experience disproportionate burden from discrimination and disease. They are approximately two and a half times more likely than heterosexuals to have a mental health disorder in their lifetime, and studies have shown that discrimination against LGBT persons has been associated with high rates of depression, substance use, and suicide.[7]

Studies have also shown that where you work, live, learn, pray, and play has a significant impact on your overall health status. Rural populations across the country have long struggled with obtaining primary care and hospital services. Depending on their geographic location, they may even endure disproportionate rates of chronic diseases or higher burden from behavioral health risks. For instance, rural communities in the South have long experienced higher rates of poverty, smoking, physical inactivity, and death due to heart disease; rural communities in the West have higher rates of alcohol abuse and suicide; and rural communities in the Northeast have higher rates of total tooth loss.[8]

The consequences of health care disparities are evident in experiences like that of a homeless woman in Missouri who sought care in a hospital emergency room. After being examined by a doctor, she was told she was healthy enough to go to jail when she refused to leave. She complained of pain in her legs, but police thought she was on drugs and arrested her for trespassing. She was carried into jail by her arms and ankles, where her body slackened and she died. An autopsy later revealed that she died from blood clots that had formed in her legs and traveled to her lungs. One HIV-positive man recounted an episode when a hospital denied him treatments and visitors and a doctor stated, "This is what he gets for going against God's will." A three-year-old girl was denied a lifesaving kidney transplant because she had a developmental disability, and a twelve-year-old boy died when his dental issue was left untreated due to lack of coverage and he succumbed to a very severe brain infection. Disproportionalities experienced by vulnerable groups lead to approximately eighty-three thousand deaths and more than $300 billion in costs to the country per year.[9]

These experiences and statistics provide only a glimpse of why we needed health reform and why it was so crucial that the Affordable Care

Act be upheld. For those of us with health insurance and access to care, it would be easy to lose sight of the individuals who struggle every day without coverage. It would be easy and unconscionable to ignore the dangerous and desperate attempts some individuals engage in to gain access to critical health services, treatments, or preventive care. It would even be easy to overlook the discriminatory and despicable treatment certain groups have experienced and continue to endure in health systems across the nation. But, as health equity advocates, we strive to attain the highest level of health for all people—to ensure that individuals and groups are not overlooked, that they have equitable access to quality, patient-centered care, as well as preventive services.[10] Stated differently, there is a public health benefit in eliminating legal and policy barriers to health equity. We know how important it is to advocate for vulnerable groups, to fight for resources for them, to ensure their voices are heard. We recognize the burden not only in lives lost but in the severe national economic impact of neglecting the health needs of underresourced communities.

Dr. Martin Luther King Jr. wrote in his "Letter from a Birmingham Jail" that "in any nonviolent campaign there are four basic steps: collection of the facts to determine whether injustices exist; negotiation; self-purification; and direct action."[11] This described his civil rights campaign, and it still rang true forty-five years later during the advocacy effort around the Affordable Care Act. Early on in the process, health equity advocates set out to apply Dr. King's teachings and decided to create a working group of committed champions for health reform and health equity. We were determined to work diligently and tirelessly to ensure the issue was prioritized in health reform negotiations. For too long, health equity had been relegated to a secondary position in health policy, but we believed it was the right time to propel it to the forefront. Armed with convincing data from studies on the impact of health disparities, we set out to demonstrate that this was an issue worth addressing finally in a comprehensive manner.

To achieve any significant reform the stars have to align perfectly. As we will later see, a bill can get through Congress and be vetoed by the president, or a bill can even be enacted and then fail to be implemented by the next administration. Sometimes, a bill can be signed into law by a president and upheld by successive administrations, but then the Supreme Court or an appellate court overturns the law. Policy making and advocacy can take countless hours, days, weeks, and even years of sacrifice and hard work. Every sentence, every word, every punctuation mark has a pur-

pose and may convey a particular meaning. Of course, deciphering legislative language can be difficult and frustrating, which is why President Bill Clinton once acknowledged in a speech to college students, "I think that it's very important to understand we live in a time when, for a whole variety of reasons, policy making tends to be dimly understood, often distrusted and disconnected from the consequences of the policies being implemented."[12]

Perhaps no recent law has elicited more confusion, distrust, and disconnect than the health reform law. In fact, President Clinton went on to state that he intensely felt this was the case "in the development, the passage, and the implementation of the Affordable Care Act."[13] This was certainly my experience, and I hope this book will help demystify some of the policy making process in passing the ACA. This is the story of more than a century and a half of the resolve, patience, and drive it took to advance a health equity agenda in the United States.

NOTES

1. Fung and Mirkinson, "Supreme Court Health Care Ruling."

2. Galewitz, "For Love or Insurance?"; "Ex-Cop Admits to Robbing Bank to Get Health Benefits in Federal Prison"; Park, "Man Says He Robbed Bank to Get Health Care."

3. Wilper et al., "Health Insurance and Mortality in US Adults."

4. Organisation for Economic Co-operation and Development, *Health at a Glance 2011*.

5. Centers for Disease Control and Prevention, "Up to 40 Percent of Annual Deaths from Each of Five Leading US Causes Are Preventable"; Wilper et al., "Health Insurance and Mortality in US Adults."

6. US Department of Health and Human Services, Office of Minority Health, Minority Population Profiles, 2015.

7. US Department of Health and Human Services, *Healthy People 2020*.

8. Hartley, "Rural Health Disparities, Population Health, and Rural Culture."

9. Park, "Hospital"; Fry, "Doctors with Gay Bias Denied Meds, Man Says"; "Serious Issues in Disabled Girl Transplant Case"; Owings, "Toothache Leads to Boy's Death"; Satcher et al., "What If We Were Equal?"; LaVeist, Gaskin, and Richard, *Economic Burden of Health Inequalities in the United States*.

10. US Department of Health and Human Services, *Healthy People 2020*.

11. King, "Letter from a Birmingham Jail."

12. Walshe and Kreutz, "Bill Clinton Accuses Political Press of 'Blindness.'"

13. Ibid.

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