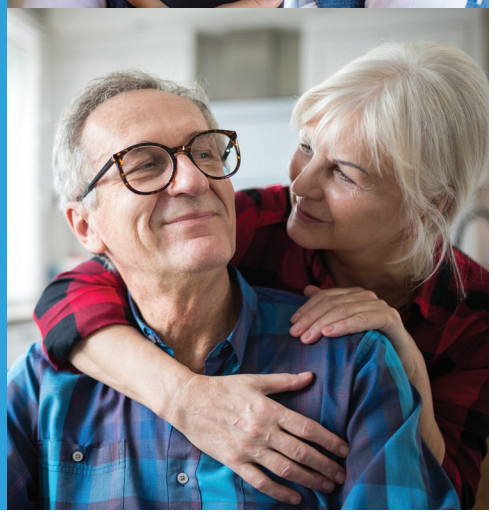
May 2019

Consumers First:
The Alliance to Make the Health Care System Work for Everyone

Our Call to Action



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CONSUMERS F1RST
The Alliance to Make the Health Care System Work for Everyone

FAMILIESUSA
THE VOICE FOR HEALTH CARE CONSUMERS

AMERICAN ACADEMY OF FAMILY PHYSICIANS
STRONG MEDICINE FOR AMERICA

AMERICAN BENEFITS COUNCIL

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Families USA dedicates this work to the families across our nation.

Consumers First: The Alliance to Make
the Health Care System Work for Everyone

Our Call to Action

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CONSUMERS F1RST

The Alliance to Make the Health Care System Work for Everyone

For 40 years, Families USA has been dedicated to the achievement of high-quality, affordable health care and improved health for all. Families USA has called together the American Academy of Family Physicians; the American Benefits Council; the American Federation of State, County and Municipal Employees; the American Federation of Teachers; First Focus; and the Pacific Business Group on Health to launch a new coalition, Consumers First: The Alliance to Make the Health Care System Work for Everyone.

Consumers First will be operated by a steering committee comprised of leading national health policy organizations that are working to ensure that the U.S. health care system provides affordable, high-quality care for America's families, children, seniors, and adults.

Steering Committee

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Advisory Committee

The Consumers First Advisory Committee was established in September 2018 and consists of former senior federal policymakers, academics, industry leaders, medical providers, and philanthropic thought leaders with deep expertise in the development, implementation, and oversight of the policies and programs that make up the U.S. health care system. The advisory committee is not tasked with officially endorsing Consumers First but will continue to provide expertise to Consumers First and the development of its policy agenda.

MEMBERS

Shawn Bishop, Former Vice President, Controlling Health Care Costs and Advancing Medicare, The Commonwealth Fund

Shannon Brownlee, Senior Vice President, Lown Institute

Gary Claxton, Vice President, the Director of the Health Care Marketplace Project, Co-Executive Director of the Program for the Study of Health Reform and Private Insurance, Henry J. Kaiser Family Foundation

Carol Cronin, Executive Director, Informed Patient Institute

Rushika Fernandopulle, Co-Founder and CEO, Iora Health

Patricia A. Gabow, Professor Emerita, University of Colorado School of Medicine; Former CEO, Denver Health

Norbert Goldfield, Founder and CEO, Ask Nurses & Doctors

Merrill Goozner, Editor Emeritus, Modern Healthcare

Lauren LeRoy, Strategic Advisor, LeRoy Strategies

Chas Roades, Co-Founder and CEO, Gist Healthcare

Jay Want, Executive Director, Peterson Center on Healthcare

Andrew Webber, Senior Adviser, Discern Health

Executive Summary

Over the past several decades, policymakers, health care providers, employers, insurers and other payers, academics, and other stakeholders have worked to improve U.S. health care payment and delivery systems. Yet, despite various reform efforts, our nation's health care system is the most expensive of any country, and it continues to lag behind peer countries in quality of care, access, patient outcomes, population health status, and administrative efficiency.

Within our nation, providers, insurers, and other financially interested actors respond to incentives that are driven by a fundamentally distorted market. Therefore, it is unsurprising that our health care system continues to fail to meet the needs of America's families. What is missing from efforts to reform U.S. health care is a unified and unbiased voice that articulates the interests of our nation's seniors, families, adults, and children in the policies and programs that govern our health care system.

This paper is our call to action for our nation: It is time for the vibrant network of consumer health care organizations, employers, labor unions, health care professionals, and leaders across the nation to join in efforts to uproot the fundamental distortions in the nation's health care system to ensure that the best health and health care are accessible and affordable for every person across the country.

Historically, consumer and patient organizations have generally — and with significant success — focused on improving health care access and coverage. But because these groups often are not deeply involved in the conversations around delivery system and payment reforms, a strong consumer voice is mostly absent. As the nation struggles to expand access to affordable, high-quality coverage and to address escalating health care costs, it is increasingly urgent to engage consumer health leaders in the value discussion. In fact, many experts believe the greatest threat to affordable, high-quality health insurance and the financial protections that such coverage provides is the rapidly escalating cost of health care across the nation.[1]

In partnership with the American Academy of Family Physicians; the American Benefits Council; the American Federation of State, County and Municipal Employees; the American Federation of Teachers; First Focus; and the Pacific Business Group on Health, Families USA

It is time for the vibrant network of consumer health care organizations, employers, labor unions, health care professionals, and leaders across the nation to join in efforts to uproot the fundamental distortions in the nation's health care system to ensure that the best health and health care are accessible and affordable for every person across the country.

We Offer This Effort in Solidarity with Health Care Professionals

This paper is a call to action to our nation's consumer leaders, families, businesses, and policymakers to address the corrosive economic incentives that underlie our health care system. In seeking to activate our nation, it is critical to understand that this effort is offered in close collaboration and solidarity with the millions of women and men who work in health care delivery. In almost all instances, these individuals work hard to provide high-quality care despite the way the U.S. organizes, staffs, pays for, and measures care. Those who have worked behind the scenes of the health care industry can tell countless stories of health care professionals who are fed up with the fragmented and inefficient system that all too often has devastating financial impacts on families. These professionals want to provide care to the people of this nation — not navigate the economic distortions that plague the health care delivery system. We intend to lend our voices to their deep frustration, and together we will create a powerful national movement focused on transforming the economics of health care. In the end, this movement will help each family to live the healthiest life possible and will enable health care professionals to provide high-quality and high-value care.

is launching Consumers First: The Alliance to Make the Health Care System Work for Everyone, which will organize consumer health care organizations, employers, labor unions, health care professionals, and allies to counterbalance entrenched interests in the health care sector. A steering committee comprised of national health policy experts will guide Consumers First's efforts.

In collaboration with leading national health policy experts, Families USA identified six major distortions in the health care system as the most urgent issues for immediate action under this new initiative:

- High and rising health care prices
- Distortions created by provider payment systems, including Medicare
- Increased health care industry consolidation
- Federal tax policy for nonprofit health care institutions and insurance plans
- Flawed workforce policy
- Inadequate access to data and lack of transparency

In the next several months, Consumers First will finalize a focused congressional and administrative policy agenda and invite other groups to join this effort.

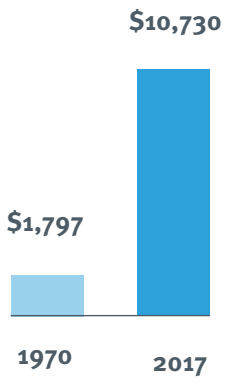
Together we will work to educate Congress, the federal government, and state policymakers about key changes that are needed in health care policy to ensure the best health and health care are available to all of our nation's families.

America's Families Are Hurting from High-Cost, Low-Quality Care

For decades, America's families have been in need of lower cost and higher quality health care. The cost of American health care is a profound economic and public health problem: 44 percent of the public report not seeing a doctor when they need to because the costs are too high; 30 percent say the cost of medical care interferes with basic needs like food, housing, and heat; and nearly two-thirds believe that, as a country, we do not get good value from the U.S. health care system.[2] As a nation, we can do better for America's families, and it's well past time for the health care system to change.

Over the last 40 years, health care spending in the United States has increased sixfold, from $1,797 per person in 1970 to $10,739 in 2017 (using constant 2017 dollars) (Figure 1).[3,4] During that same period of time, the U.S. more than doubled the percentage of its gross domestic product (GDP) on total health care spending from 6.9 percent of its GDP in 1970 to spending nearly 18 percent of its GDP on health care in 2017.[5]

Figure 1: Change in U.S. Health Care Spending Per Person (in constant 2017 U.S. $)



Source: Rabah Kamal and Cynthia Cox, "How Has U.S. Spending on Healthcare Changed Over Time?," Peterson-Kaiser Health System Tracker, December 10, 2018, https://www.healthsystemtracker.org/chart-collection/u-s-spending-healthcare-changed-time/#item-health-spending-growth-has-outpaced-growth-of-the-u-s-economy_2017.

This increase in national health care spending has outpaced the growth of the U.S. economy, with per capita national health expenditures growing faster than inflation from 1980 to 2008 and again from 2014 to 2015.[6] And, U.S. health care costs are high not only by historical standards, but also compared to other industrialized nations. Among industrialized countries, the United States ranks highest for the amount spent on health care but lowest on fundamental health outcome indicators. For example, a recent study in The Journal of the American Medical Association found that, although U.S. per capita spending on medical care is nearly twice that of 10 of the highest-income countries (Figure 2), the United States has the lowest life expectancy and the highest infant mortality and maternal mortality rates (Figure 3).[7] The United States also ranks near the bottom of the list of wealthy nations in terms of access, equity, outcomes, and administrative efficiency.[8]

High and rising health care costs are a critical problem for national and state governments, and affect the economic vitality of middle- and lower-income families. Over the last 40 years, these families have experienced stagnating wages and income. From 1973 to 2013, hourly wages rose 9 percent in real terms, while workers' productivity increased 74 percent. In comparison, from 1948 to 1973, wage growth

Although U.S. per capita spending on medical care is nearly twice that of 10 of the highest-income countries, the United States has the lowest life expectancy and the highest infant mortality and maternal mortality rates.

Figure 2: Total Spending on Health Care, Percentage of Total National GDP

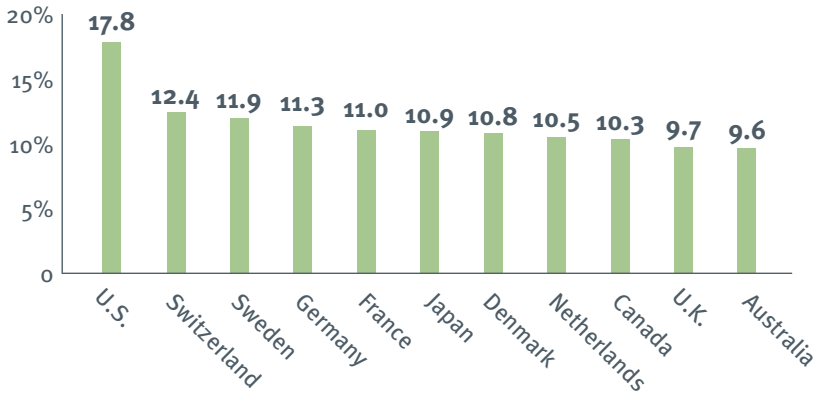
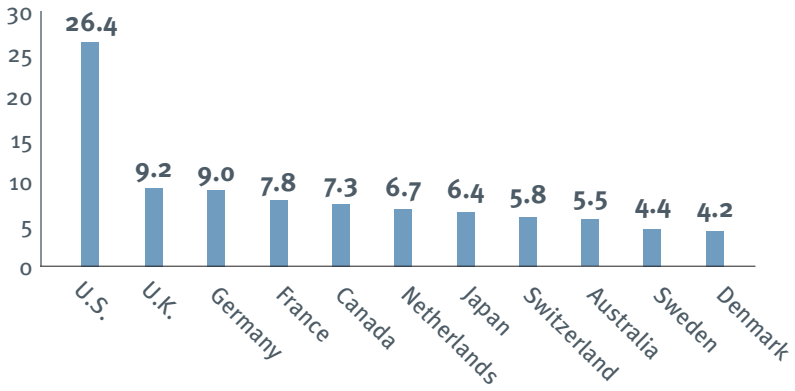


Figure 3: Maternal Mortality, Deaths Per 100,000 Live Births



Source (Figures 2 and 3): Adapted data from Irene Papanicolas, Liana R. Woskie, and Ashish K. Jha, "Health Care Spending in the United States and Other High-Income Countries," JAMA 319, no. 10 (2018): 1024, https://jamanetwork.com/journals/jama/article-abstract/2674671.

Figure 4: Worker Productivity Compared to Worker Compensation, 1948–2013

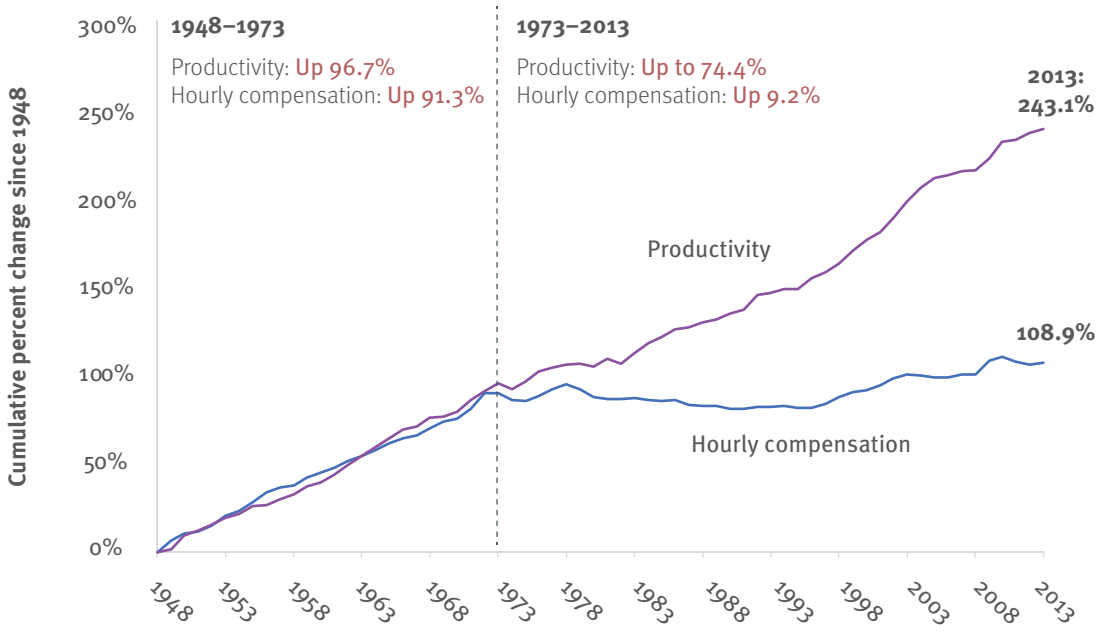
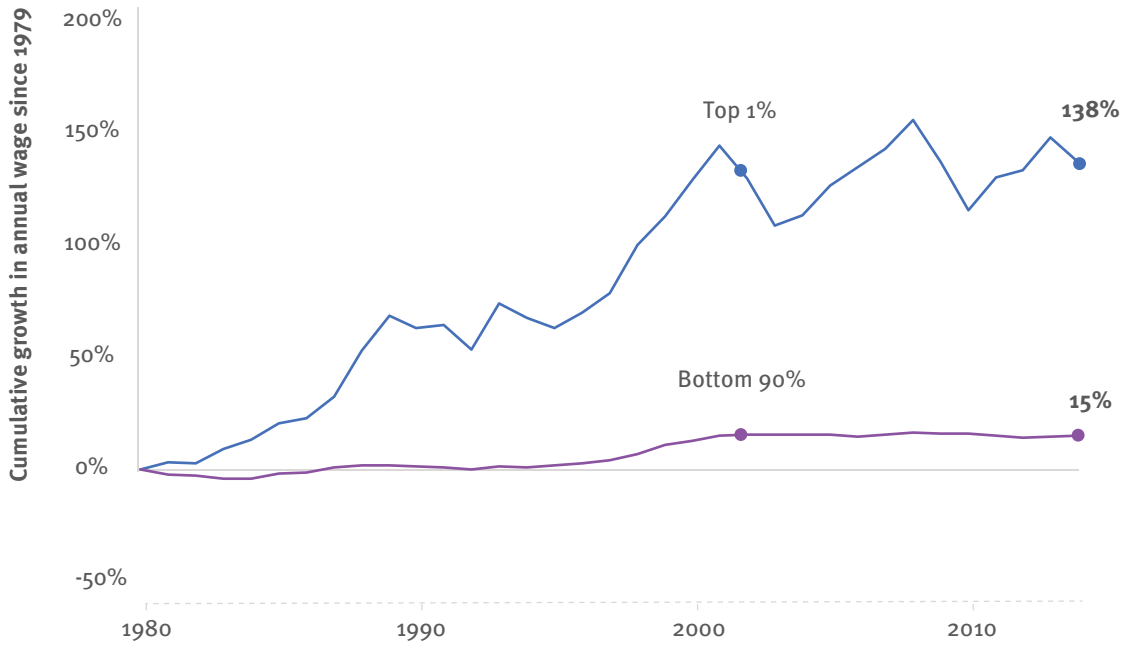


Figure 5: Cumulative Change in Real Annual Wages, by Wage Group, 1979–2013

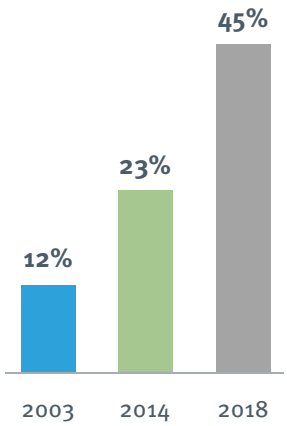


Source (Figures 4 and 5): Lawrence Mishel, Elise Gould, and Josh Bivens, "Wage Stagnation in Nine Charts," Economic Policy Institute, January 6, 2015, https://www.epi.org/publication/charting-wage-stagnation/.

kept pace with workers' productivity: Wages and productivity increased 91 percent and 96 percent, respectively (Figure 4, page 8).[9] Stagnation in wage growth is particularly evident in trends in annual pay increases for middle- and lower-income Americans. Since 1979, annual increases for the top 1 percent of America's earners increased by a startling 138 percent, while the bottom 90 percent saw their wages increase by only 15 percent (Figure 5, page 8).[10] While there are many contributors to this half-centurylong trend of lower wages, there is evidence that the rapid growth in U.S. health care costs has created sustained downward pressure on wages and incomes.[11, 12, 13, 14]

Between 1999 and 2016, the total cost of a family employer-sponsored health insurance plan rose from $5,791 to $18,142 in real 2016 dollars (Figure 7, page 10).[15, 16] And between 2016 and 2017, average employee premium contributions rose by 6.8 percent for a single-person plan and by 5.3 percent for a family plan.[17] This represents a startling increase in total employer/employee contributions for health insurance — from 26 percent to 52 percent for 90 percent of the workforce during that period.[18] Thus, the high cost of health care also is a critical problem for employers. Many employers have a vested interest in securing the health and well-being of their workers, and recognize that helping employees thrive has a measurable impact on virtually every aspect of their business. As wages remain relatively flat and health care costs increase, a growing number of families struggle to afford health insurance deductibles and cost sharing. These people are commonly referred to as being "underinsured." As of late 2018, 45 percent of U.S. adults were underinsured — an estimated 87 million people. Distressingly, this is more than triple the rate of underinsurance in 2003 and is up significantly from 23 percent (31 million people) in 2014 (Figure 6).[19]

Figure 6: Percentage of Underinsured Adults Ages 19-64



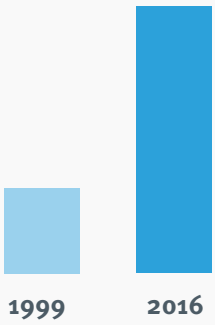
Source: Sara R. Collins, Herman K. Bhupal, and Michelle M. Doty, "Health Insurance Coverage Eight Years After the ACA," The Commonwealth Fund, February 7, 2019, https://www.commonwealthfund.org/publications/issue-briefs/2019/feb/health-insurance-coverage-eight-years-after-aca.

Figure 7:
Wage Stagnation and High Health Care Costs

The American dream tells us that if you wake up, go to work, work hard, and put in your time, you can live a decent and respectable life and care for you family. But high and rising health care costs are pushing the American dream out of reach for America's families. Stagnant wages and exorbitant health care costs mean that Americans can't afford to feed their family, keep a roof over their heads, or pay for heat in the winter.

30% of Americans say the cost of medical care interferes with their ability to pay for basic needs, like food, housing, and heat.

Between 1999 and 2016, the total cost of a family employer-sponsored health insurance plan rose from $5,791 to $18,142.



44% of the public report not seeing a doctor when they need to because the costs are too high.

Sources: see endnotes 2, 15, and 16.

Wage stagnation is correlated with many significant social problems in our nation. These include increased levels of depression and economic anxiety among middle- and lower-income individuals and families, pessimistic views of the future, increased political instability, and greater economic inequality[20, 21, 22] — all of which negatively affect the health of a population. Families across the country who face high and rising health care costs often are forced to make untenable decisions: pay a medical bill or buy groceries to feed the family; pay the electric bill to keep the heat on or buy a child's asthma medication; seek treatment for a substance use disorder or postpone treatment because an employer doesn't offer health insurance. These trade-offs have a direct impact on individuals' and families' ability to set their own course and live healthy lives (Figure 7).

It is time for our nation to stop penalizing families when they need health care. The health care system should work for families to ensure the best health possible without threatening their economic independence and vitality.

Candace, New York

> The crushing costs are not something we will be able to maintain, and they hang over my entire family's heads.

In early 2014, Candace was hospitalized with an illness that took three years to diagnose. During that time, she saw countless doctors and specialists, underwent multiple tests, and took many medications. She says, "For every doctor, hospital, medication, and test, there was a cost and a big fat bill."

Candace receives insurance coverage through her husband's employer, but she estimates that the couple spends around $3,000 a month for premiums, medications, copays, and special treatments. She left her job in June 2017, when she was no longer able to work. Now, while she awaits a disability determination, the couple's income has decreased substantially, and they are unsure how they can afford to stay in their apartment or pay their bills.

"The crushing costs are not something we will be able to maintain, and they hang over my entire family's heads. We are drowning in costs — we have thousands of dollars of medical debt, and there are times that I go without the treatment I need just so we can pay bills, keep the lights and heat on, or give our daughter the basic things she needs.

"My husband and I are in our thirties, we have worked since we were teenagers, but we have no savings, we own nothing, and have nothing to show for all of the hard work we have put in over the years. And with the way things are now, I don't see how we ever will."

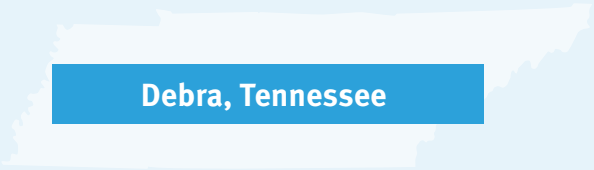
Families USA would like to thank Candace for the courage to share her story through the Families USA storytelling program.

It is time for our nation to stop penalizing families when they need health care. The health care system should work for families to ensure the best health possible without threatening their economic independence and vitality.

Health Care Value Efforts Moving Too Slowly

For too long, health care business interests have not been accountable to consumers' interests. Simply put, this is because the underlying economic incentives that form the basic structure of care delivery and payment are broken.[23, 24] The problem is particularly evident in the laws, regulations, policies, and programs that govern the health care system's costs and quality.[25] The last 10 years of value-based payment reform efforts suggest that performance measures and alternative payment models are difficult to operationalize and may actually contribute to higher spending, with only a modest impact on improving quality.[26, 27]

Most value-based payment programs have relied on small, incremental approaches that have not inherently driven the fundamental organizational and behavioral change needed to disrupt the status quo.[28] Some employers have pursued innovative strategies to lower health care costs and improve quality. For example, a large employer in California implemented a second opinion program that has corrected misdiagnosis 16 percent of the time, corrected treatment plans 62 percent of the time, and prevented 10 deaths and 161 disabilities to date.[29] However, employers' innovative efforts have been hampered by an underlying health care payment system — largely based on Medicare — that continues to misalign incentives and reward providers that pursue high volumes of services rather than high-value care. Larger-scale efforts, such as migrating providers to risk-based payments focused on outcomes and population health, have moved slowly and generally have not yet produced meaningful improvements in value.[30] Those efforts often force providers into the difficult position of attempting to transform the health care enterprise in anticipation of new, risk-based incentives while most of their margin is anchored in fee-for-service economics.[31]



Debra, Tennessee

> I had about $2 million in surgery, plus a bunch of other expenses. … I planned my life 20 years ago, and I didn't expect this to happen. It hit me so hard, and it took everything. I worked for over 30 years, and this isn't what I thought would happen to me.

For many years, Debra had a successful career as a microbiologist for the state of Tennessee. A hip replacement in 2012 kicked off a multiyear cycle of infection and illness that resulted in her leaving her job and losing almost everything she had worked for. Following the surgery, an infection spread from Debra's hips to her vertebrae and disks, and, by 2016, she was at risk of a full spinal collapse. She's had 10 back surgeries and, at times, has been in a drug-induced coma. Today, Debra is bedridden.

Since her first surgery, Debra has cycled from employer-sponsored coverage to COBRA, a plan through the Tennessee marketplace, and Medicare. Paying for her care has taken all her savings. "I had about $2 million in surgery, plus a bunch of other expenses" — including an intravenous antibiotic that cost about $850 per day. "Before this, I had a brand-new house. I had a new car. The car was repossessed, and I almost went into foreclosure," Debra says. She was in the hospital "when the repo papers came. I planned my life 20 years ago, and I didn't expect this to happen. It hit me so hard, and it took everything. I worked for over 30 years, and this isn't what I thought would happen to me."

Families USA would like to thank Debra for the courage to share her story through the Families USA storytelling program.

It is time to address fee-for-service payment issues on their own terms rather than waiting for risk-based payment to sweep away fee-for-service distortions.

Ultimately, our nation continues to struggle with a health care delivery system that is built to provide high-volume, specialty care and lacks a comprehensive, integrated framework that provides good health and high-value health care.[32]

It is time to address fee-for-service payment issues on their own terms rather than waiting for risk-based payment to sweep away fee for service distortions. Consumers have a strong interest in fundamentally changing the economic incentives of fee-for-service payments. Reforming fee-for-service will create greater momentum behind payment reform efforts.

The Missing Ingredient: An Organized and Focused Consumer Movement

A recent public policy survey found that 60 percent of Americans believe the government should be responsible for ensuring that all Americans have health care coverage.[33] Furthermore, almost 80 percent of Americans believe the government should help to ensure that everyone has access to affordable, quality health care.[34]

Despite the public's overwhelming support for universal and affordable access to health care, the interest of families and health care consumers is often absent in the decisions made by policymakers, particularly with respect to complicated and detailed health care payment and delivery system policies. Public policy research has found that well-organized groups representing specific business interests have substantial influence on U.S. policy, while consumers have little or no independent influence.[35] And, within this dynamic, the health care industry often has the unique ability to command the attention of policymakers,[36] and even assumes the consumer voice, in some instances, by speaking as a proxy for patients and families.

Consider, for example, the market failures and lack of competition that fuels "surprise" medical bills from out-of-network providers and ever-rising drug prices. Or, examine the way in which health care prices are established in the Medicare Physician Fee Schedule — the model for how most physician services are reimbursed by the Medicare program and most typically used to set prices in Medicaid and even in commercial insurance. Prices are determined by physician specialty societies that have a vested interest in maximizing prices to generate their income rather than what is in the best interests of their patients. Meanwhile, primary care physicians who are on the front lines in providing cost-effective, patient-centered, community-based health care have much less influence on the Medicare Physician Fee Schedule. They are paid among the lowest prices compared to other physicians (Figure 9, page 21).

Other anti-consumer distortions permeate much further into our health care system. For example, the system fails to address the fundamental needs of consumers when patients and health care providers lack access to timely, effective, and interoperable health care data. These data are the foundation for consumers to make informed decisions about their care. Data are critical for society to understand who provides high-quality and high-value care, for policymakers to establish evidence-based legislative and regulatory initiatives, and for innovators to be rewarded for improving the nation's health and health care systems.

Gwendolyn, Mississippi

> I sought help through coupon programs or would buy medications for 15 days at a time. Forget about trying to pay for dental and vision, there was no way I could ever afford those.

Gwendolyn worked for an automobile manufacturer for over 30 years. When the company filed for bankruptcy, she took early retirement to save her "brother's and sister's" jobs. She found that the benefits package offered in the buyout differed substantially from what regular full-time employees received. Gwendolyn says, "Our health care changed after we retired. I went from paying nothing to paying a small fee."

At first, Gwendolyn and her husband didn't mind the change. But two years after retirement, around the time she was diagnosed with diabetes, the cost sharing in the plan began to change: "I went from paying $3 or $5 a month to as much as $600 a month for my prescriptions. My office visits went from $20 to $400."

Prior to the change in benefits, Gwendolyn ran a health care cost-sharing ministry to help people without insurance pay their bills; now she faced the same challenges as those she was helping. In her own case, once the cost-sharing changes went into effect, Gwendolyn says, "I sought help through coupon programs or would buy medications for 15 days at a time. Forget about trying to pay for dental and vision, there was no way I could ever afford those."

Gwendolyn struggled to manage the consequences of rising health care costs through private coverage until she qualified for Medicare in 2018.

Families USA would like to thank Gwendolyn for the courage to share her story through the Families USA storytelling program.


Fixing the foundation of
our health care system is
needed to increase access
to affordable, high-quality
health care for everyone.

Our Call to Action: America's Families Are Paying Too Much, and It's Time for Consumer Interests to Be the Top Priority

Escalating health care costs and high prices are driven in large part by increased consolidation of physician groups, hospitals, and insurance companies, and by escalating prices for prescription drugs and medical devices. The impact of consolidation on health care prices is partly driven by the political clout that some actors within the health care sector have over law and regulatory policy. Over the last decade, the health care industry, reacting to reimbursement cuts, shifting demographics, and new payment models, has aggregated market power, strengthening its ability to increase unit prices. As economic power concentrates, so too does the ability to influence policy decisions that overlook the impact on consumers.[37, 38] The result is further entrenched policies that perpetuate the underlying distortions in our health care system, reducing consumers' purchasing power in the health care market, and shifting the burden of rising health care costs to families and employers across the country.[39]

There are remarkable organizations that have worked for decades to reshape and generate value from the health care sector. It is time for them to be joined by the vibrant network of sophisticated consumer health care organizations and leaders across the nation. Our common efforts must provide a counterbalance to the aggregated special interests that dominate health care policymaking and uproot the underlying distortions in the health care system that drive higher costs and often lower quality care.

Fixing the Foundation of Our Health Care System Is Needed to Increase Access to Affordable, High-Quality Health Care for Everyone

The efforts of Consumers First: The Alliance to Make the Health Care System Work for Everyone will focus on addressing the root causes of high and rising health care costs and low-quality care in the U.S. health care system. Solving these problems is critical for *any* system of health care coverage to work for the nation. Public policy discourse has focused significant attention on "Medicare for All" and other systems of coverage. The work of Consumers First is separate and distinct from this debate. Regardless of the path our nation takes to ensure access to affordable, high-quality health care, our goal, through Consumers First, is to ensure that we address the economic distortions in health care that often lead to poor outcomes, increased costs, and destabilized coverage and financial security.

Families USA Expert Roundtable

In autumn 2018, Families USA convened an expert roundtable of leading national health policy experts. Participants included former senior federal policymakers, academics, industry leaders, medical providers, and philanthropic thought leaders with deep expertise in the development, implementation, and oversight of the policies and programs that make up the U.S. health care system.

The panel focused on identifying the most pressing issues that threaten the U.S. health care system's ability to achieve high-value health care. They paid particular attention to issues that would benefit most from a sophisticated consumer movement focused on action in Congress and the federal government. Among the pressing issues that are ripe for a consumer movement, participants identified the underlying distortions within the health care system listed on the following page:

Underlying Distortions Within the U.S. Health Care Sytem

ECONOMIC MARKET DRIVERS

- **Industry Consolidation:** Aggregated market power resulting from the merging of hospitals, physicians, insurers, pharmaceutical companies, and other powerful health care stakeholders
- **Health Care Tax Law:** Distortions created by the tax-exempt status of nonprofit hospitals and other taxing policy
- **Market Failure:** Correcting fundamental market failures that have led to some health care industry stakeholders to pursue anti-competitive contracting and the increasing role of private equity investment in health care services

PAYMENT DRIVERS

- **Prices:** How health care prices are negotiated and established among the health care industry
- **Fee for Service:** Payment for services based on the number of services provided and ordered
- **Perverse Payment Incentives:** Incentives in the payment and coverage system that reward downstream specialty and institutional illness care at the expense of needed investments in upstream preventive and social services

SYSTEM DRIVERS

- **Insufficient Accountability:** Lack of an effective accountability system that uproots the delivery of poor-quality care and resultant paltry health outcomes
- **Insufficient Design of Health Care Supply:** The need to redesign the health care supply, including the workforce, to better serve the needs of consumers without being weighted toward higher reimbursements
- **Siloed and Fragmented Care:** The necessity for integrated, coordinated health care delivery generally, and for substance use, mental health, and chronic care services specifically
- **Inadequate Quality and Transparency:** Lack of a national framework that holds health care providers accountable for the quality and cost of health care in a way that is transparent to the public
- **Flawed System for Long-Term Services:** Lack of a health care system that provides humane end-of-life and long-term care for complex illnesses, ensures dignity, and meets the needs of patients and families
- **Inadequate Whole-Person Care:** Lack of a public health framework that understands and provides the resources needed to address the effects of the social determinants of health on health outcomes and costs

OTHER

- **Fraud and Abuse:** Unauthorized or unnecessary use of benefits or reimbursement for services that fail to meet professionally recognized standards for health care
- **Fragmented Consumer Voice:** Lack of an organized, unified consumer-based voice to represent consumers' interests in policy decisions regarding health care transformation

Addressing Health Care Prices: Focus Areas for a New Consumer Movement

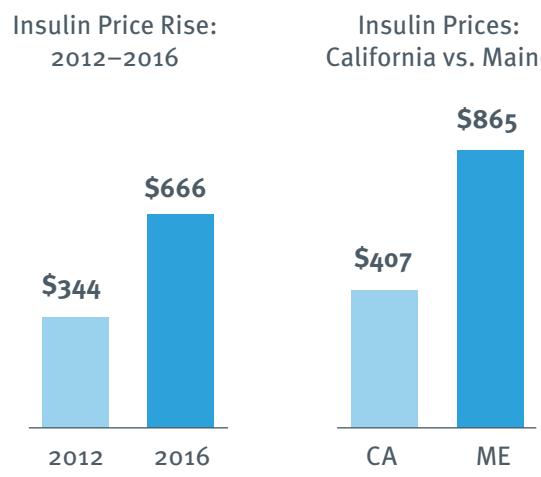
Among this expansive list of complex policy areas, expert roundtable participants were asked to identify the most pressing issues that may be ripe for immediate action on the part of a consumer movement on the national level. The panel of experts identified health care pricing as the central underlying problem driving low-value care in the health care system, and highlighted the following focus areas of change:

Distortions in Prescription Drug Pricing

In 2015, the United States spent $457 billion on prescription drugs — which accounted for nearly 17 percent of overall personal health care services.[40] The benefits of pharmaceutical drug therapies are substantial, but these benefits often come with significant financial costs to patients and to payers. For example, between 2012 and 2016, people with diabetes saw the price of insulin — the life-saving treatment that enables diabetics to manage their blood glucose levels — double from $344 to $666 per prescription. In addition to the dramatic rise in prescription drug prices, there is considerable variation in prices across different states. For example, a person in California paid $407 per insulin prescription in 2016 while a person in Maine paid $865 — the highest price in the country — for the same prescription (Figure 8).[41]

While most other federal reimbursement for health care is based on a set of standards, the government has no ability to mitigate high and rising drug costs for drugs in the Medicare program for which there is no competition. For drugs without sufficient competition, it is clear that some prices are disassociated from production costs, efficacy, and necessity.[42]

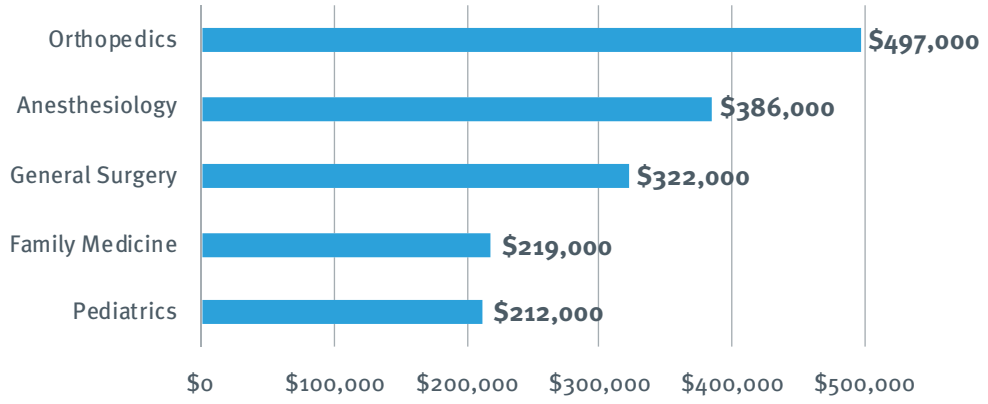
Figure 8: Variation of Prescription Drug Prices



Source: Amanda Frost and John Hargraves, "Price of Insulin Prescription Doubled Between 2012 and 2016," #HealthyBytes (blog), Health Care Cost Institute, November 29, 2017, https://www.healthcostinstitute.org/blog/entry/price-of-insulin-prescription-doubled-between-2012-and-2016.

Consumer leaders must work to better align pharmaceutical reimbursements and value for our nation's families. Consumer groups must also help develop and support new policy approaches that improve the nation's medical innovation ecosystem without putting family or payer finances at risk.

Figure 9: Average Annual Physician Compensation by Specialty, 2018



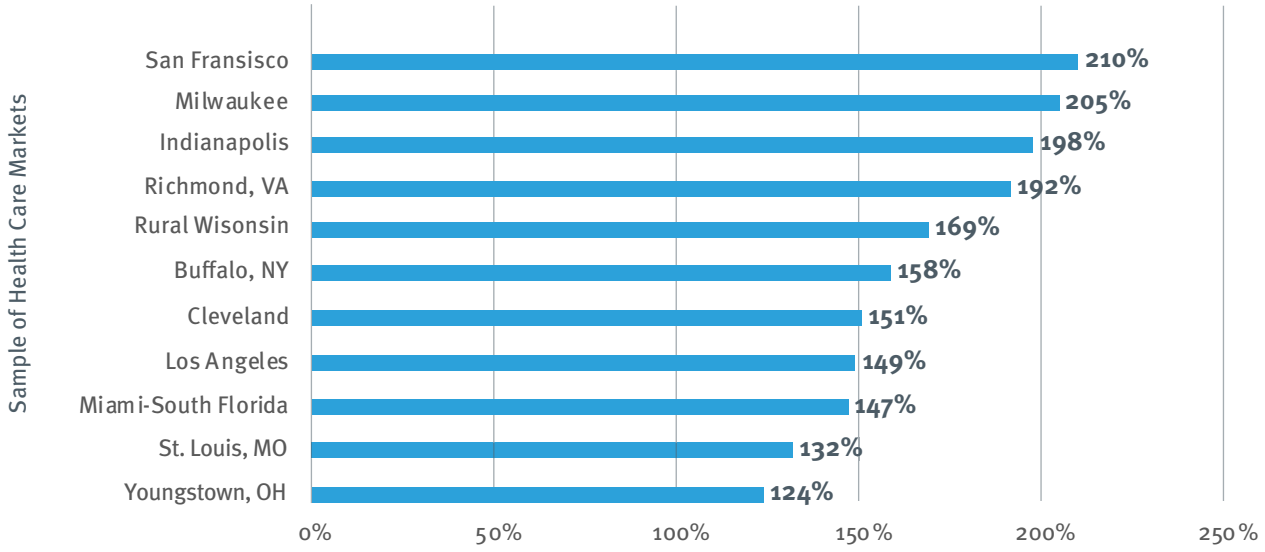
Source: Adapted data from Leslie Kane, "Medscape Physician Compensation Report 2018," Medscape, April 11, 2018, https://www.medscape.com/slideshow/2018-compensation-overview-6009667.

Distortions Created by Provider Payment Systems, Including Medicare

A similar difference exists between what private payers and public payers, such as Medicare and Medicaid, pay for health care services. Physician payment is largely based on the Medicare Physician Fee Schedule, which is the model for most health care payers' fee schedules. In most instances, Medicare determines the prices the health care system pays for physician services. Those prices are then amplified by insurers and hospitals through Medicaid, insurer policies, and employer-sponsored insurance. For example, Medicaid payments negotiated by managed care organizations often receive discounted payment rates (e.g., 20 percent discount) resulting in a reduced percentage of Medicare payments. In other words, payment rates in Medicaid are far lower than payment rates in Medicare or private insurance. But, payment rates in private insurance are often substantially more than what Medicare pays for the same services. For example, in 2012, private insurers paid 75 percent more than what Medicare paid for inpatient hospital stays. This marks a significant increase from 1996–2001, when private insurers paid 10 percent more than Medicare for inpatient hospital stays.[43] This cost shifting for employer-sponsored insurance means higher costs for working families.

In addition to different payment rates among private and public payers, there is also considerable variation in payment rates across geographic areas and within health care markets. For example, research of major

Figure 10: Average Inpatient Payment Rate as a Percentage of Medicare



Source: Adapted data from Paul B. Ginsburg, "Wide Variation in Hospital and Physician Payment Rates Evidence of Provider Market Power," Washington, DC: Center for Studying Health System Change, Research Brief no. 16 (November 2010): 1–11, http://www.hschange.org/CONTENT/1162/1162.pdf; Chapin White, Amelia M. Bond, and James D. Reschovsky, "High and Varying Prices for Privately Insured Patients Underscore Hospital Market Power," Washington, DC: Center for Studying Health System Change, Research Brief no. 27 (September 2013): 1–10, http://www.hschange.org/CONTENT/1375/.

health insurers found that average inpatient payment rates across various major health care markets ranged from 124 percent of Medicare in Youngstown, Ohio, to 210 percent in San Francisco (Figure 10).[44, 45] The same survey found that in some cases hospitals negotiated payment rates with insurers of almost 500 percent of Medicare rates for inpatient care and 700 percent for outpatient care. In addition, the variation in payment rates within health care markets is also stark. For example, in the Los Angeles market, a hospital with prices at the 25th percentile received 84 percent of Medicare payment rates for inpatient care compared to one with prices at the 75th percentile, which received 184 percent of Medicare rates (Figure 11).[46]

Furthermore, the nation's health care system relies on a fee-for-service payment model, which overemphasizes specialty care and incentivizes the generation of a high volume of tests, procedures, and

The nation's health care system relies on a fee-for-service payment model, which overemphasizes specialty care and incentivizes the generation of a high volume of tests, procedures, and inpatient and outpatient visits regardless of whether those services improve quality.

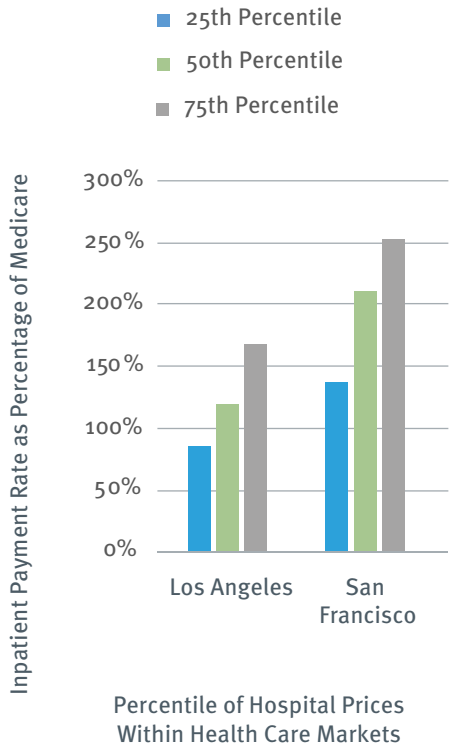
inpatient and outpatient visits regardless of whether those services improve quality.[47] Fee-for-service promotes silos between the recipients of fee-for-service — health care providers — which leads to fragmented care delivery.[48] Even newer payment models that purport to pay for value by improving quality and lowering costs are often built on fee-for-service infrastructure, continuing to incentivize increased volume.[49]

Increased Health Care, Industry Consolidation

For decades, lawmakers, academics, policymakers, and advocates have worked to uncover the root causes of high and variable health care prices among hospitals and cities. A 2010 landmark report by then-Attorney General of Massachusetts Martha Coakley correlated the underlying driver of high and variable prices in Massachusetts to market power and leverage over the negotiations among insurers, hospitals, and physician groups.[50] A similar report by the New York State Health Foundation found a correlation between increased market share and high prices.[51] The dynamics of the Massachusetts and New York health care markets described in those reports are also seen in health care markets across the nation.[52] Importantly, these studies also show that, in many instances, higher prices were not correlated or even inversely correlated to the quality of care that the institutions provided.[53, 54]

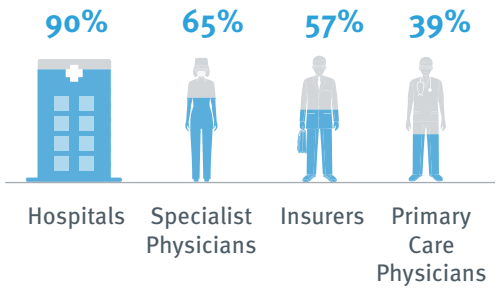
Consolidation of health care markets in the late 1990s, and again over the last decade, led to the highly concentrated market power that is pervasive today. Fully 90 percent of metropolitan statistical areas have highly concentrated hospital markets, 65 percent of those areas have highly concentrated specialist physician markets, 39 percent have highly concentrated primary care physician markets, and 57 percent have highly concentrated insurer markets (Figure 12).[55]

Figure 11: Variation of Average Inpatient Payment Rate Within Health Care Markets



Source: Adapted data from Paul B. Ginsburg, "Wide Variation in Hospital and Physician Payment Rates Evidence of Provider Market Power," Washington, DC: Center for Studying Health System Change, Research Brief no. 16 (November 2010): 1–11, http://www.hschange.org/CONTENT/1162/1162.pdf.

Figure 12: Percentages of Highly Concentrated Health Care Markets for Hospitals, Physician Organizations, and Insurers, 2016



Note: Percentages are based on metropolitan statistical areas whose Herfindahl-Hirschman Index was above 2,500. Source: Brent D. Fulton, "Health Care Market Concentration Trends in the United States: Evidence and Policy Responses," Health Affairs 36, no. 9 (September 2017): 1530–38, https://www.healthaffairs.org/doi/10.1377/hlthaff.2017.0556.

Federal Tax Policy for Nonprofit Health Care Institutions and Insurance Plans

Under federal tax law, nonprofit institutions are granted nonprofit status premised on the assumption that they provide a community benefit and public good.[56, 57] By definition, tax-exempt hospitals are prohibited from generating and distributing profits. In exchange, tax-exempt status protects billions of dollars in revenue for these institutions.[58] The Affordable Care Act included new requirements that tax-exempt hospitals report on community need and limit some charges and billing.[59] Despite these modest requirements, many nonprofit hospitals continue to charge exorbitant prices for their services, put families' unpaid medical bills in collection, and invest in new services and technologies that expand their revenue in lieu of meeting the needs of their communities.[60] There are no additional federal requirements that ensure these hospitals provide benefits to their communities commensurate with the benefit their tax-exempt status confers on them.[61] Consumer leaders must ensure that tax-exempt health care providers be held accountable for benefiting the communities that they ostensibly serve.

Employer plans cover more than 181 million people. The Cadillac tax imposes a 40 percent tax on high-value employer-sponsored health plans. The implementation of this excise tax is likely to encourage the shifting of costs to employees.[62] The Cadillac tax was originally slated to take effect in 2018 but has been delayed twice. It is now set to go into effect in 2022. At a time when the value of health insurance is decreasing, employers who chose to provide higher quality coverage should not be penalized with a tax.

Flawed Workforce Policy

Federal financial support to train the next generation of health care providers lacks a coherent strategy and is deeply unbalanced.[63, 64] The federal government spends billions of dollars helping to educate future physician specialists while providing comparatively paltry support for the education of nonspecialist physicians and allied health professionals who should make up the backbone of our primary care system.[65] Further, federal workforce policy devotes too little attention to ensuring access to care in underserved communities.[66] Consumer leaders must work to ensure that federal workforce policy and payments support providers working to the top of their licensure and incentivize the use of the most effective and efficient providers.

Inadequate Access to Data and Lack of Transparency

Meaningful improvements in all of the areas identified in this paper — including prescription drug prices, market consolidation, and workforce policy — all require better access to and flow of health care data. Today, health care data are often inaccessible and nearly impossible to share.[67] The flow of well-managed and protected health care data should be viewed as central to improving health care quality and driving down costs across the system. Because health care data are not considered for their impact of the public good, they have been used to drive the business interests of some companies, instead of being used to drive better value across the system.[68] For those who suffer from poor-quality care and unnecessarily high costs in our health care system, this dynamic must change. Access to interoperable and transparent data enables employers, purchasers, providers, and other actors to encourage the use of higher value care. Hence, it is vital that data be made more broadly available and interoperable across the payment and delivery system.

How We Organize to Take Action

Families USA, in partnership with the American Academy of Family Physicians; the American Benefits Council; the American Federation of State, County and Municipal Employees; the American Federation of Teachers; First Focus; and the Pacific Business Group on Health, is launching Consumers First: The Alliance to Make the Health Care System Work for Everyone. Consumers First will organize consumer health care organizations, employers, labor unions, health care professionals, and allies to counterbalance entrenched interests in the health care sector. These efforts will be guided by national health policy experts through the Consumers First Steering Committee.

Over the next several months, Consumers First will finalize a focused congressional and administrative policy agenda, and invite other groups to join this effort. The policy agenda will aim to uproot fundamental distortions in the health care system that drive high and rising health care costs and suboptimal quality. This work will include technical policy writing and analysis, coalition building, bipartisan stakeholder engagement with federal agency leadership and congressional champions, and disseminating and amplifying the work of Consumers First through national media partnerships. Families USA and Consumers First will also seek opportunities to integrate this work at the state level. Through this effort, Consumers First will work to ensure that the nation's health care system finally fulfills its obligation to the people it serves by providing affordable, high-quality, cost-effective care to everyone.

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FAMILIESUSA
THE VOICE FOR HEALTH CARE CONSUMERS

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