



**Testimony of Frederick Isasi, JD, MPH**  
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Before the Senate Committee on Health, Education, Labor, and Pensions

June 18, 2019

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Chairman Alexander, Senator Murray, and members of the Committee on Health, Education, Labor, and Pensions. I am Frederick Isasi, Executive Director of Families USA. For nearly 40 years, we have served as one of the leading national voices for health care consumers both in Washington, D.C. and on the state level. Our mission is to allow every individual to live to their greatest potential by ensuring that the best health and health care are equally accessible and affordable to all. As a former aide to Sen. Jeff Bingaman, a long-time member of this committee, it is my honor to have the opportunity to speak with you today.

## **The Larger Context of Health Care Costs for Families**

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.<sup>1</sup> 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 six-fold, from \$1,797 per person in 1970 to \$10,739 in 2017 (using constant 2017 dollars).<sup>2</sup> 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.<sup>3</sup>

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.<sup>4</sup> 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, the United States has the lowest life expectancy and the highest infant mortality and maternal mortality rates.<sup>5</sup> Our country also ranks near the bottom of the list of wealthy nations in terms of access, equity, outcomes, and administrative efficiency.<sup>6</sup>

High and rising health care costs are a critical problem for national and state governments, and affect the economic vitality of middle-class and working 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 kept pace with workers' productivity: Wages and productivity increased 91 percent and 96 percent, respectively.<sup>7</sup> 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.<sup>8</sup> While there

are many contributors to this half-century long 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.<sup>9,10</sup>

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.<sup>11</sup> Thus, the high cost of health care also is a critical problem for employers. 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 the “underinsured.” Currently, 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.<sup>12</sup>

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 live healthy lives.

To illustrate the myriad ways our health care system is failing so many people, allow me to take a moment to tell you the story of Debra, from Tennessee, a brave woman who shared her story with Families USA’s story bank program:

*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 coverage, 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.”*

Any of us could be Debra. Any of us could be building our lives, saving, contributing to society and then, because of poor quality and out-of-control costs, all that we have worked for could be taken from us. It is time for our nation to take a long hard look at

our health care system. The system should work for families to ensure the best health possible, not threaten their economic independence and vitality.

### **The Public Across the Political Spectrum Want and Need You to Act**

A recent survey found that 60 percent of Americans believe the government should be responsible for ensuring that all Americans have health care coverage.<sup>13</sup> Furthermore, almost 80 percent of Americans believe the government should help to ensure that everyone has access to affordable, quality health care.<sup>14</sup>

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.<sup>15</sup> And, within this dynamic, the health care industry often has the unique ability to command the attention of policymakers – indeed, health care stakeholders spend more money lobbying Congress and the administration than any other industry.<sup>16</sup>

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 as the foundation by which prices are established 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 are paid among the lowest prices compared to other physicians.<sup>17</sup>

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.

It is for these reasons that just last month, Families USA launched a new national coalition called *Consumers First: The Alliance to Make the Health System Work for Everyone*. *Consumer's First* is dedicated to uprooting the fundamental economic 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.

*Consumers First* is 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. These include organizations represent consumers, employers, organized labor, primary care providers, and children.<sup>1</sup> In its Call to Action, *Consumers First* identified six policy areas ripe for immediate action to benefit consumers. Namely:

- Economic Distortions in Prescription Drug Pricing;
- Distortions created by provider payment systems, including Medicare;
- Increased Health Care Industry Consolidation;
- Federal tax policy of nonprofit health care institutions and insurance plans;
- Flawed workforce policy; and
- Inadequate access to data and lack of transparency.<sup>18</sup>

We are delighted that the HELP Committee is seeking, in bipartisan fashion, to address several of the issues identified by *Consumers First*.

### ***The Lower Health Care Costs Act***

**First, I want to state clearly: Families USA strongly supports the Lower Health Care Costs Act discussion draft circulated by this Committee.** We applaud the Committee for working in a bipartisan fashion to develop legislation that has the potential to be meaningful and enacted this year. We have a number of recommendations to improve this legislation, summarized below, and transmitted in full to the committee in our attached comment letter dated June 5, 2019, but we are very pleased that the Committee is taking real action to improve health care for millions of struggling families across the country. **We encourage you to continue to work diligently to finalize this legislation this year.**

Below, I have provided a summary of our comments on each of the five titles included in the *Lower Health Care Costs Act*. **In addition, we've attached our more detailed comment letter as an appendix.**

#### Title I: Ending Surprise Medical Bills

Surprise out-of-network bills are a clear example of how distorted economic incentives in the health care sector are overwhelming the interests of patients. They are the result of a systemic problem in our health care system that places families directly in the middle of a tug-of-war between health care providers and insurers over the price of services.<sup>19</sup>

The rate negotiated between providers and insurers for services is at the center of their business models. Larger hospital systems have significant leverage, allowing them to

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<sup>1</sup> The Steering Committee of *Consumers First* consists of: Families USA; American Academy of Family Physicians; American Benefits Council; American Federation of State, County and Municipal Employees; American Federation of Teachers; First Focus Campaign for Children; Pacific Business Group on Health.

command top dollar for in-network rates. Insurers are often forced to pay their high charges for in-network status, or insurers may simply walk away from the negotiation.<sup>20</sup> On the other hand, when hospitals are smaller, insurers hold the leverage. Those hospitals must choose between accepting lower negotiated rates than they desire, or walking away from the negotiation and providing care out-of-network.<sup>21</sup> In general, compared to in-network providers, out-of-network providers charge nearly three times as much for care.<sup>22</sup> These prices are not disclosed to patients in advance. This leaves families with balance bills that average over \$600, but can exceed \$20,000, despite the fact they are being provided within in-network facilities.<sup>23</sup> Providers and payers should not be permitted to walk-away from negotiations for services that are occurring in relation to other in-network services and simply leave families to bear the financial burden.

### *Surprise Billing Action is Needed Now*

Among the many valuable provisions included in the *Lower Health Care Costs Act*, a prohibition on surprise billing is probably the most significant and badly needed today. The statistics are staggering: One-in-five emergency department visits results in a surprise medical bill.<sup>24</sup> More than one-in-five lab claims (22.1%) incurred at in-network hospitals are billed as out-of-network.<sup>25</sup>

Behind each of these statistics, however, is the story of a real person who has been harmed by a surprise bill. Allow me to highlight the experience of Nicole, from Colorado.

*Nicole woke up in the middle of the night with intense stomach pain. After first visiting a freestanding ER, she was told she needed an emergency appendectomy, and she went to the local hospital. She did her due diligence to confirm repeatedly that the hospital and its providers accepted her insurance. However, months later, she received a surprise bill from the surgeon for \$4,727. While the hospital was in-network, the surgeon was an independent, out-of-network provider.*

*Nicole explained the situation to the insurer, but they continued to demand payment. She declined to pay the bill, and within two years, a credit agency representing the surgeon took her to court, and won the full amount, including interest. As a result, a lien was placed on her home, and the collection agency garnished her wages by 25 percent each month. This came right as she was pregnant and about to go on maternity leave.*

The disagreement over the payment rate between providers and insurers has dominated the debate on surprise billing on Capitol Hill this year. The irony is that for decades, it has been families who have been harmed by surprise bills when powerful industries cannot agree on a payment rate. Now, the same powerful industries are fighting over this legislation and families' voices are once again overshadowed.

Whatever reimbursement methodology you choose, it is critical to millions of people like Nicole across the country that you enact legislation this year. Every day that goes by, families across the country are receiving devastating surprise bills that threaten to send them to medical bankruptcy. Families USA has been fighting surprise medical bills for three decades and we have never been this close to stopping one of the most egregious business practices harming consumers. You have come this far – please do not fail your constituents now.

### *Lower Health Care Costs Act's Protections against Surprise Bills*

Your legislation, as drafted, provides strong consumer protections by ensuring no one will pay more towards their care than their in-network cost-sharing (including copayments, coinsurance, or deductibles) in a surprise billing situation regarding emergency services (regardless of the state in which the patient resides), non-emergency services at in network facilities, and out-of-network services after an enrollee has been stabilized. We support the clear indication that cost-sharing amounts count towards the in network out-of-pocket maximum and deductible. Finally, we support the clear specification that referrals for diagnostic services are included in these protections.

In addition to recommending a few clarifying changes as reflected in our attached comment letter, I would note one particular change to ensure the best possible consumer protections across the country. Namely, **we urge the Committee to clarify that federal law applies to surprise bill situation unless, in the judgement of the Secretary, state law is equally or more robust.** For state law to take precedent, it must have as robust consumer protections and payment cost-controls as the federal law. This will prevent the potential for state laws to undermine federal law on surprise billing and therefore leave consumers unprotected and vulnerable to premium increases. Additionally, even if states have their own surprise billing laws, federal law should apply to any health plans that states cannot fully regulate, such as self-insured, ERISA-regulated plans.

### *Payment Mechanism Options*

Your legislation contemplates three different options for establishing a mechanism for settling out-of-network bills between plans and providers.

Overall, we are very concerned about any out-of-network payment mechanism that would serve to further inflate costs, which would then be passed onto consumers in the form of higher insurance premiums. Due to its ability to hold down costs, and therefore protect consumers from premium inflation, and its administrative simplicity, **Families USA supports your third option – a benchmark payment rate based on median in-network contracted rates.** Conversely, we strongly oppose basing benchmark rates on billed charges due to its inflationary effects.

While we believe Option 3 is the strongest of the three alternatives you propose, we believe both an in-network guarantee (Option 1) and independent dispute resolution (IDR) (Option 2) also hold promise and represent improvements upon the status quo.

The in-network guarantee could provide a significant degree of simplicity and clarity for consumers who would know that any provider or service they access in an in-network facility (such as diagnostic imaging or laboratories) would be considered in-network. However, we recognize that the in-network guarantee model marks a dramatic shift from the health care system as it operates currently, and thus could present substantial implementation challenges.

IDR is not likely to contain costs as significantly as a benchmark mechanism and creates additional administrative burdens. However, if implemented properly, it would lower costs in surprise bill situations relative to the status quo. We are pleased that the dispute resolution entity would be an unbiased entity, tied neither to insurers nor providers, and will consider the median in-network rate. However, we recommend explicitly requiring that if pursued, an IDR entity may *not* consider billed charges in its deliberations. Billed charges are often wildly inflated above the cost of care and what the provider has agreed to in-network negotiations. As a result, considering billed charges would drive up health care costs and therefore premiums for consumers.

### *Surprise Bills for Air Ambulances*

Air ambulances are a vital link in our country's trauma care system, saving thousands of lives every year. However, Air ambulance services are particularly likely to lead to surprise medical bills. Nearly *seven out of ten* of air ambulance patient transports that people often require in life-or-death situations are out-of-network, and balance bills from these air ambulance providers are rarely below \$10,000.<sup>26</sup>

Congressional intervention is needed to address this problem, as states are preempted from fully solving this pressing issue. Whether in this bill or future legislation, federal protections should hold consumers harmless from paying more than in-network cost-sharing for air ambulance transport when they have no option for in-network airlift. Additionally, federal preemptions that prohibit state regulation of air ambulance rates and networks should be eliminated. In the meantime, greater transparency of air ambulance costs, as proposed in this draft legislation, is beneficial.

### Title II: Reducing the Prices of Prescription Drugs

In 2015, the United States spent \$457 billion on prescription drugs — which accounted for nearly 17 percent of overall personal health care services.<sup>27</sup> The benefits of pharmaceutical drug therapies are substantial, but these benefits often come with significant financial costs to patients and to payers, and their prices are not always justified. For example, between 2012 and 2016, people with diabetes saw the price of insulin— a 100 year-old drug— double from \$344 to \$666 per prescription.<sup>28</sup> It is hard to understand how a drug so old can cost so much, until one looks at the financial practices of drug companies: On average they spend less than a quarter of their revenue on innovation<sup>29</sup> and nine out of 10 of the largest drug companies spend more on marketing than creating new drugs.<sup>30</sup> What's more, drug companies spent \$172 million on lobbying in 2018 — more than any other industry.<sup>31</sup>



While most other federal reimbursement for health care is based on a set of standards, the government has no ability to establish a rational price for drugs in the Medicare program. For drugs without sufficient competition, it is clear that some prices are wildly inflated and those prices are not associated with production costs, efficacy, value, or need.<sup>32</sup>

Families USA supports the measures included in the legislation that lay a foundation of federal reforms on prescription drug costs. In particular, the bill includes several measures to bring generics to market faster, providing lower cost alternatives to costly, monopolistic brand-name drugs. In particular, we support provisions like Section 201 and 202 that will provide greater transparency on patents for biologics, including on exclusivity periods and when they expire, so that generic manufacturers have the timely and accurate information they need to bring competition to market.

We also support sections 203, 204, and 205, which include important measures to prevent gaming that can delay the availability of generics. We recommend that the Committee supplement these provisions, whether in this legislative package or elsewhere, with the CREATES Act and legislation to completely ban so-called “Pay for Delay” practices, which would also make important progress in bringing generic drugs to market faster.

The bill would also be improved by facilitating greater transparency in how prescription drug prices are set. S. 1391, the *FAIR Drug Pricing Act*, sponsored by Sen. Tammy Baldwin, would require drug manufacturers to justify price increases of more than 10 percent in a single year or 25 percent over three consecutive years. We would also support a requirement that drug companies justify launch prices over a specified amount. One option would be mandated justification on launch prices that exceed the threshold in Medicare to qualify as a specialty drug, currently \$670 per month (\$8,040 annually).

While we support the prescription drug provisions in the Lower Health Care Costs Act, they will not significantly reduce the escalating cost of drugs without overarching reforms that will directly lower list prices. Some of these provisions may fall outside of the Committee’s jurisdiction. **We urge the Committee to work with Senate leadership and ensure that policies that allow for government oversight of drug pricing be enacted this year. In particular, we urge the Senate to consider legislation to allow the federal government to directly negotiate the price it pays for prescription drugs in Medicare Part D.** S. 377, the *Medicare Negotiation and Competitive Licensing Act*, sponsored by Sen. Sherrod Brown, is one such example.

### Title III: Improving Transparency in Health Care

Meaningful improvements in all of the areas included in your legislation — including prescription drug prices, surprise billing, and improved public health — all require better access to and flow of health care data. Today, health care costs and measures of

quality and effectiveness are often inaccessible and nearly impossible to share.<sup>33</sup>

Consumers face many barriers to being informed purchasers of health care when they do not have access to price and quality information in the health care system. We also believe that it is critical to ensure that health care providers, payers, researchers and policymakers have access to underlying cost and quality data in order to make informed and effective health care payment and delivery system policies.

### *Banning Gag Clauses*

Families USA supports Section 301 of the legislation, removing barriers to obtaining accurate and complete health care price and quality information including banning gag clauses included in executed contracts between insurance plan issuers and providers or provider networks. Increasing the transparency of such information will not only enable consumers to be more informed purchasers of health care but it would also unveil fundamental information that policymakers, researchers and other stakeholders need in order to identify health care markets with the highest prices and then build policy that encourage competition.

### *National All-Payer Claims Database*

Further, we strongly support Section 302 of the bill, which would establish a national all-payer claims database (APCD) that receives and utilizes health care cost and quality information to generate reports available to the public and to researchers.

Your legislation could be meaningfully strengthened by making the following additions to the bill text:

- **Require that price and quality data be collected and accessible through the APCD in manner that allows for research and analysis.** Some in industry argue that the collection and dissemination of price data could result in increased prices because industry negotiators will drive toward the highest prices being paid. While this is a valid concern, with simple protections price information can be collected and provided to researchers and governments to study health care cost and value without unveiling prices to industry negotiators.
- Specify the categories of claims data that the APCD will utilize to include: medical and clinical, prescription drug, dental, behavioral health, and available social services data.
- Establish a mechanism in statute or direct the Secretary to establish a mechanism through rulemaking that will require health plans, hospitals, health care providers to share claims data with this new entity.
- Direct the Secretary to establish national interoperability standards to facilitate data sharing between health care industry entities and with state APCDs.

- Require that the establishment of a board of directors or other governance structure over the APCD equal representation of consumer groups in its composition.
- Require in statute that the Advisory Committee include at least 12 percent representation by consumer health care organizations and at least 12 percent representation by consumer groups whose missions are to reduce racial/ethnic health disparities.

### *Provider Directories*

Inaccurate provider directories cause consumers to struggle to obtain needed medical care and to pay high out-of-network costs for care due to no fault of their own. Studies have found that for some specialties, directory information is accurate less than half of the time.<sup>34</sup> We applaud the HELP Committee for including this issue in the *Lower Health Care Costs Act*. Our attached comment letter includes more detailed recommendations on how to ensure directory accuracy requirements are sufficient, but I would like to highlight two specific recommendations for your attention:

**First, we recommend clarifying the legislation to ensure that providers would be prohibited from balance billing consumers in instances when consumers received inaccurate information about their network status.**

Providers should be required to provide notice about their network status at least seven days before delivering care. If a patient does not provide advanced consent to receiving out-of-network care at least seven days before a service, a provider should be prohibited from balance billing.

Second, all provider directories should be required to include a prominent notice of consumers' rights to pay no more than in-network cost-sharing if they receive out-of-network care due to a provider directory inaccuracy, and how to contact the health plan if they believe they relied on inaccurate information. Without such a notice, consumers are unlikely to know of their rights as proposed in this draft legislation.

### Title IV: Improving Public Health

Families USA strongly supports the HELP Committee's attention to critical public health problems that our nation currently faces. Maintaining a robust and effective public health infrastructure is essential to ensure that America's families have access to the health and health care they deserve. From the importance of vaccinations, to addressing the high rates of maternal mortality, to addressing the impact of discrimination on health in our health care system, we support efforts that enable our public health infrastructure to respond quickly and effectively to emerging public health challenges.

Achieving health equity is central to becoming a nation where the best health and health care are equally accessible to all. Throughout our history, people of color have been

systematically denied a fair opportunity to be as healthy and productive as possible and reach their full potential. Consequently, these communities continue to struggle with deep and persistent health inequities. In addition to facing disproportionate barriers to high-quality, affordable health care, communities of color, and other underserved communities, also face significantly higher health risks, and markedly lower opportunities to improve their health. As a result, these communities are more likely to suffer from a myriad of serious health conditions, like diabetes, asthma, and many cancers, among others. This drives higher rates of poor health status and premature death, even among infants.

**In our attached comment letter, Families USA identified a number of improvements to this title to help ensure that policies to improve public health are culturally tailored, evidence informed, and address social determinants of health.** One of the central challenges in improving health care equity in the United States is the relative paucity of data that is stratified by race, ethnicity, gender, sexual orientation, and disability status. To improve data stratification, we recommend that Section 405, which would provide data system modernization grants to public health departments, include community-based organizations as grant recipients; and require that the grants include building capacity to collect and report data by race, ethnicity, gender, sexual orientation, and disability status.

#### Title V: Improving the Exchange of Health Information

Today, health care data are often inaccessible and nearly impossible to share.<sup>35</sup> 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.<sup>36</sup>

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.

Among several additional comments Families USA made in its attached comment letter (including comments on to improve patient privacy), I would like to highlight two recommended improvements to Section 501.

First, we recommend the legislation be updated to be made consistent with a recent Centers for Medicare & Medicaid Services (CMS) proposed rule regarding application programming interfaces (APIs): To be consistent with the CMS proposed rule, we recommend including language that requires payers (including dental plans) to include the following data sets price and cost data:

- Adjudicated claims (including cost);
- Encounters with capitated providers;
- Provider remittances;
- Enrollee cost-sharing;
- Clinical data, including laboratory results (where available);
- Provider directory data;
- Drug benefit data including pharmacy directory and formulary data; and
- Dental claims data.

Second, while we support requiring payers to provide data to consumers through APIs, we have serious concerns about the oversight over third-party apps to ensure that consumers' privacy is protected. With the rapid proliferation of health technology innovations over the last decade, it is critical that third-party apps and any other entities that may be involved with consumer health data are subject to the highest standards of protection and security for consumer health data.

We recommend the bill text stipulate that HIPAA be used as a framework for a comprehensive privacy structure for third party apps and any new entities that would create, store or transfer health care data.

### **More Action is Needed**

The *Reducing Lower Health Care Costs Act* is an ambitious piece of legislation – particularly so as a bipartisan bill in these most contentious of times. You deserve commendation for your leadership. That being said, with our health care system so rife with economic distortions, misaligned incentives, and bloated prices, **the bill should best be thought of as a down payment on future reforms.** Once this legislation is passed into law, we look forward to working with you on continuing to address the many ways in which the needs of children and families are not being met by our current health care system. Among the policies we believe Congress must take up are:

- Legislation to directly lower prescription drug prices, including by allowing the federal government to leverage its power to negotiate through the Medicare program.
- Legislation to establish a national health care workforce strategy, including funding for the national health workforce commission
- Changes to graduate medical education policy
- Better oversight of non-profit hospitals to ensure they are meeting the needs of their local communities
- Further efforts to improve data interoperability and transparency, including through a federally-mandated interoperability standard.

Once again, thank you for the opportunity to testify before this committee, and for your leadership on these vital issues for America's families.

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- <sup>4</sup> *ibid.*
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***APPENDIX – Families USA Comment Letter to HELP Committee on the Lower Health Care Costs Act.***

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June 5, 2019

The Honorable Lamar Alexander  
Chairman  
Committee on Health, Education,  
Labor and Pensions  
U.S. Senate  
Washington, DC 20510

The Honorable Patty Murray  
Ranking Member  
Committee on Health, Education,  
Labor and Pensions  
U.S. Senate  
Washington, DC 20510

Dear Chairman Alexander and Ranking Member Murray:

Families USA, a leading national voice for health care consumers, is dedicated to the achievement of high-quality, affordable health care and improved health for all. We write to comment on the United States Senate Health, Education, Labor and Pension (HELP) Committee’s May 23 bipartisan discussion draft, *the Lower Health Care Costs Act of 2019*.

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.<sup>36</sup> As a nation, we can do better for America’s families, and it is well past time for the health care system to change. Families USA commends the Senate HELP Committee on the release of the *Lower Health Care Costs Act*, and appreciate the Committee’s attention to rising consumer health care costs.

Below are our specific comments on the draft legislation, by title. Recommended changes to the legislation are **bolded** in the text below. Recommendations for specific legislative text are in **red**.

**Title 1: Ending Surprise Medical Bills**

Families USA strongly supports the HELP committee’s attention to the critical consumer problem of surprise medical bills. Consumers face surprise medical bills when they receive out-of-network medical care due to no fault of their own. Whether due to an emergency visit at an out-of-network facility or unexpected care from an out-of-network provider in an in-network facility, surprise bills can be hundreds or even thousands of dollars and are all too common.<sup>36</sup>

Families USA believes that a federal legislative solution is needed to address the problem of surprise medical bills. Consumers in every state experience this unfair



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problem. Even in states that have passed laws to address surprise medical bills, many consumers remain without sufficient protection, as state laws cannot fully protect consumers in self-insured plans that are regulated by the Employee Retirement Income Security Act (ERISA).<sup>36</sup>

We urge the Senate HELP Committee and the full Senate to pass legislation on surprise medical bills swiftly to protect consumers from this harmful problem while holding down health care costs overall.

Our specific comments on Title I of the legislation follow. Our comments first apply to options 1, 2, and 3 in the draft legislation overall, and we then provide comments regarding the pros and cons of the various options.

### Section 102: Protection against Surprise Bills

We strongly support that the bill clearly protects consumers from paying any more towards their care than their in-network cost-sharing (including copayments, coinsurance, or deductibles) in a surprise billing situation regarding emergency services (regardless of the state in which the patient resides), non-emergency services at in-network facilities, and out-of-network services after an enrollee has been stabilized. We also support the clear indication that cost-sharing amounts count towards the in-network out-of-pocket maximum and deductible. Finally, we support the clear specification that referrals for diagnostic services are included in these protections.

Families USA strongly supports that this draft legislation applies to self-insured, ERISA-regulated plans. **We read the draft legislation to apply to grandfathered plans, but the language appears ambiguous. We urge the Committee to clarify that the legislation does apply to grandfathered plans.**

**Regarding enrollees who are admitted to hospitals after receiving emergency services or who are in labor, we recommend the bill be strengthened as follows:**

- **Insert missing language on page 6, line 16 as follows:** Clarify that enrollees cannot be balance billed unless the “enrollee, once stable and in a condition **safe for transport...**” We believe it is critical that legislation does not put enrollees in a situation to choose between experiencing out-of-network balance billing or transit for which they are not medically ready.
- **Indicate that enrollees cannot be forced to choose between balance billing and transferring to another facility unless in-network medical transport is available, or the enrollee can safely be transported by non-medical transportation.** Consumers should not be set up to experience surprise ambulance bills under surprise bill legislation.
- In addition to requiring paper and electronic notification, **require hospitals to provide verbal notice of enrollees’ options.**

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**We recommend the bill clarify whether the Secretary or the states serve as the primary line of enforcement for the law.** If states are to enforce the law, they may require resources and training from federal agencies. If federal agencies are to enforce the law, they may require additional resources for oversight and enforcement capacity.

Regarding the maintenance of state surprise billing protections, we are concerned about the potential for state laws to undermine federal law on surprise billing and therefore leave consumers unprotected and vulnerable to premium increases. Families USA recommends permitting states to apply their own surprise bill laws, if state law is equally or more robust than federal law, in terms of both consumer protections and a payment rate between insurers and providers that holds costs down. **Specifically, we urge the Committee to clarify that federal law applies unless, in the judgement of the Secretary:**

- **State law requires insurers to pay out-of-network providers a lower amount in surprise bill situations, or**
- **State law implements a baseball style arbitration system that forbids the consideration of billed charges.**

**Even if states have their own surprise billing laws, federal law should apply to any health plans that states cannot fully regulate, such as self-insured, ERISA-regulated plans.**

#### Section 103: In-Network Guarantee (Option 1)

A guarantee that all providers delivering care in a facility are in the same insurance network as the facility itself could greatly simplify the health care system for consumers. No longer would consumers have to worry about navigating complicated provider directories or about provider directories inaccurately indicating that providers and facilities are in the same networks. Similarly, if *both* the facility and provider were in the consumer's insurance network, surprise bills would be cut down dramatically for consumers.

However, the in-network guarantee model for addressing surprise bills marks a dramatic shift from the health care system as it operates currently, meaning it could also face some implementation challenges that would need to be addressed to prevent difficulties for consumers. For example, if insurers cannot contract with a health care facility unless the facility guarantees that all practitioners are in the facility's network, will there be facilities that cannot contract with insurers at all in rural areas where hospitals face great challenges attracting providers, even under current rules?

We strongly support that in this section, laboratories and diagnostic services that are referred by the health care practitioners are included in the requirements. However, it is possible that some laboratory and diagnostic providers may contract with some, but not all, of the same insurers as a referring facility. It should be appropriate for a facility to refer a patient to such a lab or diagnostic provider as long as the provider accepts the

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particular patient's insurance. Under the bill as written, it appears that facilities may only refer to labs or diagnostic providers who accept *all* insurance plans that the facility accepts. This may result in consolidation and too much market power to insurers, so **we urge the Committee to modify the language to reflect alignment with a patient's insurance plan, not *all* insurers that a facility and providers accept.**

**Additionally, we believe an addition is required to this section to provide information on how a referring practitioner and facility obtain information regarding which laboratories and diagnostic providers are in-network for patients, as well as who is responsible if a lab or diagnostic provider to which a patient is referred does ultimately balance bill a patient.**

*We strongly support the use of the median in-network contracted rate to reimburse providers of out-of-network emergency services.*

#### Section 103: Independent Dispute Resolution (Option 2)

Although we believe that a benchmark payment rate is an ideal way to resolve payment in surprise billing situations, as if set appropriately it is most likely to deter premium increases while minimizing administrative burden, independent dispute resolution (IDR) can also present an improvement upon the status quo. We support that the proposed independent dispute resolution process will still apply a benchmark payment rate in a large share of cases. Additionally, we are glad that the dispute resolution entity will be an unbiased entity, tied to neither insurers nor providers, and will consider the median contracted rate.

However, **we recommend explicitly requiring that the IDR entity may *not* consider billed charges in its deliberations.** Billed charges are often wildly inflated above the cost of care and what the provider has agreed to in network negotiations. As a result, considering billed charges would drive up health care costs and therefore the premiums that consumers pay.

#### Section 103: Benchmark for Payment (Option 3)

Due to its ability to hold down costs, and therefore protect consumers from premium inflation, and its administrative simplicity, *a benchmark for payment is Families USA's recommended approach for resolving payment between insurers and providers in surprise billing situations.* We support setting payments based on median in-network contracted rates. Conversely, we strongly oppose basing benchmark rates on billed charges due to its inflationary effects.

#### Section 106: Air Ambulance

Surprise bills for air ambulance are typically over \$35,000. As air ambulance rides are usually out of network, consumers often have no ability to protect themselves from balance bills when in need of air lift.<sup>36</sup> Congressional intervention is needed to address this problem, as states are preempted from fully solving this pressing issue.

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Whether in this bill or future legislation, federal protections should hold consumers harmless from paying more than in-network cost-sharing for air ambulance transport when they have no option for in-network airlift. Additionally, federal preemptions that prohibit state regulation of air ambulance rates and networks should be eliminated. In the meantime, greater transparency of air ambulance costs, as proposed in this draft legislation, is beneficial.

## **Title II- Reducing the Prices of Prescription Drugs**

High and rising prices of prescription drugs impact families' access to the medicines they need and even impact their ability to afford other health services and basic necessities. Voters across the country are therefore eager for Congress to enact reforms that will rein in egregious drug costs that strain family budgets.<sup>36</sup>

Families USA supports the measures included in the legislation that lay a foundation of federal reforms on prescription drug costs. While we support the prescription drug provisions in the Lower Health Care Costs Act, we cannot significantly reduce the escalating cost of drugs without overarching reforms that will directly lower list prices. Prescription drug reforms must directly target these prices, which drive high costs throughout the drug supply chain and health care system and keep needed medicines out of reach for families.

This bill includes many measures to bring generics to market faster, providing lower cost alternatives to costly, monopolistic brand-name drugs. Specifically, we support provisions like Section 201 and 202 that will provide greater transparency on patents for biologics, including on exclusivity periods and when they are expired, so that generic manufacturers have the timely and accurate information they need to come to market. We also support sections 203, 204, and 205, which include important measures to prevent gaming that can delay the availability of generics. **We recommend that that the Committee supplement these provisions, whether in this legislative package or elsewhere, with the CREATES Act and legislation to completely ban so-called "Pay for Delay" practices, which would also make important progress in bringing generic drugs to market faster.**

**We urge the HELP Committee and Congress to advance legislation to directly lower prescription drug prices, including by allowing the federal government to leverage its power to negotiate through the Medicare program.** For more on this issue, please see [Reining in High Prescription Drug Prices: What Families Need from Congress](#), by the Coalition for Fair Drug Prices, chaired by Families USA.

## **Title III – Improving Transparency in Health Care**

Families USA strongly supports the HELP Committee's attention to the critical problem of transparency of cost and quality information in the health care system. Consumers face many barriers to being informed purchasers of health care when they do not have access to price and quality information in the health care system. We also believe that it

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is critical to ensure that health care providers, payers, researchers and policymakers have access to underlying cost and quality data in order to make informed and effective health care payment and delivery system policies. While we support efforts to increase transparency of cost and quality data across the health care system, Families USA believes that transparency alone will not meaningfully bring down the costs of health care.

#### Section 301: Increasing Transparency by Removing Gag Clauses on Price and Quality Information

Families USA supports legislation that removes barriers to obtaining accurate and complete health care price and quality information including gag clauses included in executed contracts between insurance plan issuers and providers or provider networks. We believe that increasing the transparency of such information will not only enable consumers to be more informed purchasers of health care but it would also unveil fundamental information that policymakers, researchers and other stakeholders need in order to identify health care markets with the highest prices and then build policy that encourage competition.

#### Section 303: Designation of a Nongovernmental Nonprofit Transparency Organization to Lower Americans' Health Care Costs.

Families USA supports the designation of a nonprofit, nongovernmental transparency organization to support the establishment and maintenance of a database that receives and utilizes health care cost and quality information to generate reports available to the public. **The legislation could be strengthened significantly by making the following additions to the bill text:**

- **Specify the categories of claims data that the nongovernmental nonprofit organization will utilize to include: medical and clinical, prescription drug, dental, behavioral health, and available social services data.**
- **Require that price and quality data be accessible through the nongovernmental nonprofit transparency organization.**
- **Establish a mechanism in statute or direct the Secretary to establish a mechanism through rulemaking that will require health plans, hospitals, health care providers to share claims data with this new entity.**
- **Direct the Secretary to establish national interoperability standards to facilitate data sharing between health care industry entities and with state all-payer claims databases.**
- **Require that the establishment of a board of directors or other governance structure over the entity includes equal representation of consumer groups in its composition.**

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- **Require in statute that the Advisory Committee include at least one consumer health care organization, and at least one consumer group whose mission is to reduce racial/ethnic health disparities.**

Section 304: Protecting Patients and Improving the Accuracy of Provider Directory Information

Inaccurate provider directories cause consumers to struggle to obtain needed medical care and to pay high out-of-network costs for care due to no fault of their own. Studies have found that for some specialties, directory information is accurate less than half of the time.<sup>36</sup>

Families USA believes that Congressional action is needed to guarantee that accurate, comprehensive and easily accessible information on in-network providers and facilities is available to consumers. We applaud the HELP Committee for including this issue in the Lower Health Care Costs Act. Below we outline specific recommendations for this section of the draft legislation.

Regarding the information that consumers must be able to receive on in-network providers, **we recommend consumers have the ability to obtain information over the phone at their request, in addition to online. This is important for consumers who do not have internet access or who have disabilities that may make online information challenging to receive. Additionally, we recommend that plans be required to make information on provider network status available to consumers in their preferred language.**

We strongly support that plans may not charge consumers more for services than in-network cost-sharing if enrollees can demonstrate that they relied on inaccurate information in a provider directory. To ensure this section comprehensively protects patients, **we recommend two additional requirements:**

- **Providers should be prohibited from balancing billing consumers in instances when consumers had inaccurate information about their network status. Providers should be required to provide notice about their network status at least 7 days before delivering care. If a patient does not provide advanced consent to receiving out-of-network care at least 7 days before a service, a provider should be prohibited from balance billing.**
- **All provider directories should be required to include a prominent notice of consumers' rights to pay no more than in-network cost-sharing if they receive out-of-network care due to a provider directory inaccuracy, and how to contact the health plan if they believe they relied on inaccurate information.** Without such a notice, consumers are unlikely to know of their rights as proposed in this draft legislation.

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We support requirements that plans verify and update their provider directories. However, we believe that the particular verification and update standards in the draft legislation are not strong enough to make a meaningful impact for consumers and are not in line with other common laws and regulations on provider directory accuracy. **We urge modifying this section as follows:**

- **Require health plans to verify and update their provider directories at least monthly.** This requirement was in place for Federal Marketplace plans until 2017 when CMS removed it and other related provider directory and network adequacy requirements and deferred them to states.<sup>36</sup> We strongly support Congress instituting federal requirements, as not all states have requirements in place. However, a monthly update and verification requirement or more stringent requirements are in place in states like California and Georgia, as well as the District of Columbia.<sup>36</sup>
- **Add additional specificity on steps required to verify and update a provider directory:** Most health plans already indicate they update their provider directories even more frequently than every month. Problems arise when they are only updating directories based on information they directly receive from providers, and not doing any audits of whether old information has been remaining in the directories untouched for months or even years. Provider directory updates require active processes from insurers in order to be effective. Therefore, **we recommend that the legislation require the following to ensure updates and verification are meaningful:**
  - **Require each health plan to place a prominent link and phone number on the directory where consumers can report inaccurate information. Require each health plan to investigate reports, and if applicable, remove inaccurate information within one month.**
  - **Replace the requirement that plans remove providers from the online directory if providers have not verified information within 6 months with a requirement that plans proactively contact any providers who have not filed claims within the past 2 months to verify their network status. If network status cannot be verified, plans should remove the providers from the directory within one month of the attempt to contact the provider.**
  - **Require an annual audit of the plan directory: At least annually, health plans should be required to do a comprehensive audit of their provider directories, contacting all providers listed and verifying their network status. Any providers who do not respond in within 2 months should be removed from the directory.**

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We support states enacting their own provider directory laws, if those laws are more robust than federal law. However, **we recommend clarifying that federal law will preempt state law if state law does not provide standards that are at least as robust as those outlined in federal law.**

#### Section 305: Timely Bills for Patients

Families USA supports requiring health care facilities and practitioners to provide to patients a list of services rendered during the visit to that facility or practitioner prior to discharge, and that all bills are sent to patients within 30 business days. **We recommend adding a requirement that the list of services provided upon discharge indicate whether each service was provided in-network or out-of-network.**

#### Section 306: Health Plan Oversight of Pharmacy Benefit Manager Services

Pharmacy Benefit Manager (PBM) practices can contribute to the problem of high and rising drug costs that are ultimately due to large underlying drug prices set by manufacturers. We appreciate the HELP Committee's attention to PBM practices.

We strongly support providing plan sponsors clear and user-friendly information about covered drugs and utilization mechanisms for those drugs. **For the requirement that group plans receive this information, we recommend adding a requirement that the information be made available to plan enrollees as well, in a reader-friendly format. This requirement should apply to individual market enrollees as well.**

We support providing employers with price information about covered drugs, as well as information about the rebates that PBMs receive for those drugs. However, we are concerned about the information on employees' prescriptions that this section makes available to employers, without providing clear indications of what the information will be used for and with very limited privacy protections. We are concerned that providing employers with information about which drugs employees are prescribed, and how many employees are prescribed them, along with information as specific as prescription fills, will leave employees vulnerable to identification by their employer and potentially discrimination. **Instead of providing employee prescription information to employers, we urge the Committee to instead require insurers to provide in comprehensive rate review reporting on how much they spend on drugs and how much they receive in rebates, as well as the share of rebates that are passed on to consumers, in addition to providing price and rebate information to employers.**

Families USA strongly supports protecting enrollees from paying more for a drug than the actual price paid by the issuer to the pharmacy for the drug and from upcharges on drugs dispensed by pharmacies wholly owned by the issuer or PBM.



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Section 308: Disclosure of Direct and Indirect Compensation for Brokers and Consultants to Employer-Sponsored Health Plans and Enrollees in Plans on the Individual Market

Greater transparency about broker compensation can help consumers and employers understand the role that compensation may have in how brokers provide information about health coverage. Families USA supports providing additional information about direct and indirect compensation that brokers receive for connecting consumers and employers to health care. **We recommend that the legislation clarify that this section applies to web-based brokers and to the sale of short-term plans, association health plans, and other non-ACA complaint arrangements that may be sold by brokers.**

**Title IV – Improving Public Health**

Families USA strongly supports the HELP Committee’s attention to critical public health problems that our nation currently faces. Maintaining a robust and effective public health infrastructure is essential to ensure that America’s families have access to the health and health care they deserve. From the importance of vaccinations, to addressing the high rates of maternal mortality, to addressing the impact of discrimination on health in our health care system, we support efforts that enable our public health infrastructure to respond quickly and effectively to emerging public health challenges.

Section 401: Public Awareness Campaign on the Importance of Vaccinations

Families USA supports the development and implementation of a public awareness campaign on the importance of vaccinations. As this committee knows well, vaccinations are a foundational component of an effective public health infrastructure for any nation to keep its citizens healthy, safe and secure. The scientific and evidence-base is clear: vaccinations greatly reduce disease, disability, death and inequity around the world, and are safe. At a time when our nation is struggling to combat certain disease outbreaks directly resulting from lower vaccination rates in certain communities, the need for a robust public awareness campaign about the importance, safety and efficacy of vaccinations is critically important. In addition to the efforts detailed in this bill focused on at-risk populations, **we also recommend that public awareness campaigns include a broad national campaign to help educate the public at large about the importance of vaccinations in protecting public health and safety, and to help maintain current vaccinations rates at the population level.**

Section 403: Guide on Evidence-Based Strategies for State Health Department Obesity Prevention Programs

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The obesity epidemic is a critical public health priority and an important health equity and child health issue. We applaud efforts to develop solutions for this public health challenge. However, we have several concerns about how the legislation is currently drafted. Given the disparate impact of obesity on communities of color, and the rapid growth of obesity rates in children, we would like this legislation to strengthen its focus on these populations, understanding the need for culturally tailored strategies to maximize effectiveness. Moreover, given that there are many social determinants of health that contribute to obesity, and the role of family and community in preventing obesity, we suggest that there be more input from and coordination with representatives and experts from affected communities and expertise in community engagement.

To that end, it is vital that the guide include strategies tailored to the specific populations most at need. Given the changing demographics of the nation, ensuring that the strategies that are developed and implemented are effective in communities of color must be a high priority. No single approach will work to combat the obesity epidemic.

Further, the guide should include strategies based on evidence-informed practices, mixed method research, and community based participatory research. Evidence based medicine is the gold standard to which we all should aspire. However, we have concerns that the exclusive focus on evidence-based strategies that focus heavily on randomized control trials, while ideal, is incompatible with the current state of the evidence base in relation to addressing the health needs of women, children, and racial and ethnic minority groups. For example, Blacks and Latinos make up only 6 percent of all participants in federally funded health research even though they comprise nearly one-third of our population.

Our current evidence base does not accurately reflect which treatments work well among different racial and ethnic groups. Instead, our clinical guidelines and policies have been informed by research that only studies the average efficacy and safety of individual medications, medical devices, and treatments. While important efforts are underway to diversify participation in clinical and health systems research, the bulk of the data available is generated from non-heterogeneous studies where women, children, and racial and ethnic minorities are largely underrepresented. Therefore, in order to capture emerging evidence generated from these groups, which are badly needed given the disparate impact of obesity they face, and the need for culturally tailored strategies, we must widen the findings included in the guide to encompass evidence-informed strategies.

Finally, the strategies promoted by the guide should encompass a broader definition of interdisciplinary coordination that includes additional roles. Interdisciplinary coordination between relevant public health officials specializing in fields such as nutrition, physical activity, epidemiology, communications, and policy implementation is critical. **We recommend that the list be expanded to include community health workers, and navigators.**

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To ensure guide includes evidence-informed strategies; culturally tailored strategies based on evidence-generated from populations that are representative of those communities; and acknowledge the importance of different intervention strategies for adults and children, we recommend the following legislative language changes:

- Amend subsection a(1) A. (page 133) to read:  
“describe ~~an~~ integrated program structures for implementing interventions proven to be effective in preventing, controlling, and reducing obesity that include culturally tailored interventions for specific racial and ethnic groups that bear a disproportionate burden of obesity as well as specific to children; and that take into account community needs and challenges”
- Amend subsection a (1) B (ii) to read:  
(I) the application of evidence- based and evidence informed practices to prevent, control, and reduce obesity rates

#### Section 404: Expanding Capacity for Health Outcomes

We support the development of award grants to expand the use of technology-enabled collaborative learning and capacity building models to increase access to health care services. Health is driven predominantly by the factors that influence health such as socioeconomic status, stable housing, employment, food security, exposure to trauma and violence and other factors. These factors are referred to as the social determinants of health. As congress establishes support to use new technology innovations to increase access to health care services, it is critical to include specific reference to those services not typically defined under the medical system, which are predominantly responsible for driving health outcomes. Those services include a wide range of social and human services including but not limited to housing support, nutritional assistance programs, employment services, community-based programs, child care services. **In addition to the health care services outlined in Sec.404(6)(b)(18-23), we recommend that the bill text specifically include reference to social services and the social determinants of health.**

#### Section 405: Public Health Data System Modernization Grants

Families USA strongly supports efforts to help public health departments to modernize public health data systems including enhancing interoperability of current public health data systems incorporating certified health information technology. The ability to safely and security collect, store and transfer public health data is critical to ensure the health care system is meeting the needs of the 21<sup>st</sup> century. Local health departments often lack the resources needed to invest in new technology to support a robust public health data system. Similarly, community-based organizations which are often the bedrock of the health care system and infrastructure at the community level often lack the capitol needed to make investments into health information technology and data systems.

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We also believe it is critical to collect and disseminate data that is disaggregated to clearly identify variations in treatment responses that are often overlooked when only analyzing aggregated data. Disaggregating data will enable improved tailored treatment interventions that promote high-quality health care for all.

**We recommend that the HELP Committee make the following changes to the bill text:**

- **Include community-based organizations as grant recipients to modernize their health care data systems.**
- **Require in statute or mandate the Secretary to establish national interoperability standards that include public health data systems and the data systems for community-based organizations to ensure these various data systems can effectively communicate with the broader health care system.**
- **Require in statute that the public health data modernization grants include building the capacity to collect and report data by race, ethnicity, gender, sexual orientation, and disability status.**

#### Section 406: Innovation for Maternal Health

We support the efforts to address the high rates of maternal mortality in the United States and to improve maternal health. The wealthiest nation in the world can do better to ensure the health and well-being of our mothers. Importantly, racial and ethnic minorities have significantly worse maternal and infant health outcomes even when compared to their white counterparts of the same socioeconomic status. Black women are twice as likely to suffer from severe maternal morbidity or experience infant mortality when compared to non-Hispanic whites. **We recommend adding language to prioritize activity that is culturally-tailored to the racial and ethnic groups that are disproportionately affected by poor maternal and infant health outcomes.**

Additionally, we want to ensure that new programs to improve maternal health outcomes address the importance of oral health. Oral health coverage and oral health care are critical to supporting a woman's overall health and the health of her pregnancy. Untreated oral disease has been shown to be linked with various pregnancy complications, like preeclampsia, preterm birth, and low birth weight infants. Research has also established that a woman's oral health status during pregnancy is a good predictor of her future child's risk for developing oral disease. **We recommend specifically including oral health in the establishment of best practices or implementation of programs to improve maternal health outcomes both during pregnancy and postpartum.**

#### Section 408: Study on Training to Reduce and Prevent Discrimination

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We applaud the efforts to conduct a study on training to reduce and prevent discrimination in the health care system. Establishing training that reduces and prevents discrimination and mitigates implicit bias is a key strategy for reducing health inequities. This type of training should be implemented throughout the provision of all health care services since racial discrimination is at the root cause of health inequities. **We recommend including this type of training throughout the provision of all health care services.** It is critical that everyone who is involved with delivering health care services takes part in these trainings since care coordination is a necessity in delivering equitable care. **We also recommend including a clear definition of health professional training programs.**

### **Title V – Improving the Exchange of Health Information**

Families USA strongly supports the HELP Committee’s attention to improving the exchange of health information. We believe that to ensure good health and high-quality health care, consumers, providers, policymakers, insurers and payers must be equipped with the tools to address the factors that influence health. Those factors extend beyond the medical system, where we know that only 10 percent of a person’s health is influenced by clinical care. While 60 percent of factors that influence health are based on social and environmental factors. The health care data system should be equipped to be interoperable across the factors that influence health. Families USA believes that we must modernize our health care data system to meet the needs of consumers, health care providers, payers, researchers and policymakers in the 21st century and beyond. As the health care data system is modernized, Families USA believes that it is critical to ensure that the privacy of consumers is protected and preserved, and that public trust and confidence in health information technology and health information exchanges is held to the highest standard.

#### **Section 501: Requirement to Provide Health Claims, network and Cost Information**

We support efforts to require payers to share certain data with patients through application programming interfaces (API). A robust data system incorporating APIs will enable consumers to access health care data from multiple health care providers including hospitals, providing them with a comprehensive view of their health and health care. Historical claims, provider encounter and payment data for each enrollee is an important step. A recent Centers for Medicare & Medicaid Services (CMS) proposed rule, if finalized in its current form, would require payers to make the following data sets available through APIs:

- Adjudicated claims (including cost);
- Encounters with capitated providers;
- Provider remittances;
- Enrollee cost-sharing;
- Clinical data, including laboratory results (where available);
- Provider directory data;
- Drug benefit data including pharmacy directory and formulary data.

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While this list of data sets are comprehensive, it does not include specific cost and pricing information. Congress is keenly aware of the high and rising costs of health care in the United States. These uncontrolled costs threaten the affordability of care for families, seniors and children, and create unsustainable budget pressures on the federal government and state governments. As the largest single payer, Medicare rates are often used as a standard upon which private payers and providers negotiate prices *without* transparency and oversight by the public. Payment rates in private insurance are often substantially more than what Medicare pays for services. Further, we know that payment rates not only vary by payer but also that there is considerable variation in payment rates across geographic areas and within health care markets.

There are several actions Congress could take to address price distortions which fall outside the scope of this bill. Within the scope of this bill, however, Congress could mandate substantially improved price transparency. Requiring payers to include price and cost data through APIs would be a groundbreaking development that would not only enable consumers to be more informed purchasers of health care but would also unveil critical information that policymakers, researchers and other stakeholders need to inform better payment policies. **To be consistent with the CMS proposed rule, we recommend including language that requires payers (including dental plans) to include the following data sets price and cost data:**

- **Adjudicated claims (including cost);**
- **Encounters with capitated providers;**
- **Provider remittances;**
- **Enrollee cost-sharing;**
- **Clinical data, including laboratory results (where available);**
- **Provider directory data;**
- **Drug benefit data including pharmacy directory and formulary data**
- **Dental claims data**

While we support requiring payers to provide data to consumers through APIs, we have serious concerns about the oversight over third-party apps to ensure that consumers privacy is protected and preserved, and that public trust and confidence in health information technology and health information exchanges are not eroded. Third-party apps are notorious for their lackluster effectiveness in protecting and securing consumer data. With the rapid proliferation of health technology innovations over the last decade, it is critical that third-party apps and any other entities that may be involved with consumer health data are subject to the highest standards of protection and security for consumer health data. **We recommend the bill text stipulate that HIPAA be used as a framework for a comprehensive privacy structure for third party apps and any new entities that would create, store or transfer health care data.**

Strengthening the regulatory framework for the health technology innovations of today, and the future, must clearly define who governs and controls health data; who has access to it; which entities are responsible for protecting and securing the data; and the

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extent to which these data and data systems will be interoperable with the health data systems within the health care system. Federal laws and regulations have not kept pace with rapid innovations in health technology. The existing health data regulatory infrastructure already contains significant gaps in the privacy and protection of patient-generated and personally identifiable data. Decisions about whether or not these data are subject to HIPAA's privacy and security protections is dependent on the role of a covered entity in creating or storing the data for a particular patient. The emergence of new health technology innovations will continue to challenge the existing regulatory framework. **We recommend including language mandating the Secretary be responsible for strengthening the regulatory framework and infrastructure needed to operate an efficient, effective, interoperable health care data system that protects and secures consumers health data and maintains the highest level of public trust in health care data systems and information exchanges for the 21<sup>st</sup> century and beyond.**

**We further recommend mandating the Secretary to develop national interoperability standards for which all payers are required to participate.**

### Conclusion

Thank you for the opportunity to comment on this discussion draft of the Lower Health Care Costs Act of 2019. We greatly appreciate the Committee's efforts to increase access to affordable, high-quality health care for everyone. We commend you for your leadership, and we look forward to working with the Committee again on this important issue.

Should you wish to discuss our comments, please contact me at 202-626-3030 or [sgremminger@familiesusa.org](mailto:sgremminger@familiesusa.org).

Sincerely,

/s/

Shawn Gremminger  
Senior Director of Federal Relations