FAMILIES USA
THE VOICE FOR HEALTH CARE CONSUMERS

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Before the House Energy and Commerce Health Subcommittee

Lives Worth Living: Addressing the Fentanyl Crisis, Protecting Critical Lifelines, and Combatting Discrimination Against Those with Disabilities

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Chairman Guthrie, Ranking Member Eshoo, members of the Committee, thank you for the opportunity to testify today at this legislative hearing focused on *the Protecting Health Care for All Patients Act*. It is an honor to be with you this morning. My name is Frederick Isasi, and I am the executive director of Families USA, a leading national, non-partisan voice for health care consumers. For more than 40 years, Families USA has been working to achieve our vision of a nation where the best health and health care are equally accessible and affordable to all. We are very proud to have always been a strong partner with, and supporter of, the disability community and their health care needs.

Every person in the United States should have high-quality, affordable health care that prevents illness, allows them to see a doctor when needed, and helps to keep their families healthy. Yet, almost half of all Americans have reported having to forgo medical care due to the cost, a third have indicated that the high cost of medical care is interfering with their ability to secure basic needs like food and housing,[1] and over 40 percent of American adults – 100 million people – face medical debt.[2] For people with disabilities these statistics are considerably worse: disabled people are 2.5 times more likely to skip or delay health care because of cost,[3] and they are significantly more likely to have unmet medical, dental, and prescription drug needs.[4] Despite spending two or even three times more on health care than other industrialized countries, the United States has some of the worst health outcomes including some of the lowest life expectancy and highest infant mortality rates.[5,6] For people with disabilities, these trends are even worse. People living with disabilities in the United States have a significantly lower life expectancy than those without disabilities.[7] Adults with disabilities are also four times more likely to report their health to be fair or poor than people with no disabilities (40.3

percent vs. 9.9 percent).[8] In nursing homes alone, more than 181,000 disabled people died from COVID in the first two years of the pandemic.[9] Having an intellectual disability was and is the strongest predictor for COVID-19 infection, and the second strongest predictor for COVID-19 death.[10]

I appreciate being part of this legislative hearing because for too long, people with disabilities have been largely left out of the public conversation about improved health care. They face ongoing disparities that are exacerbated by those in the medical community who perceive disabled people's quality of life as diminished and are less likely to treat them with proactive care.[11] Disabled people are often left out of decisions about their own health on both an individual and systemic basis, and they face very real threats of bias toward deprioritizing their needs in periods of scarce resource allocation.[12] The time is now to prioritize their health and well-being, and to ensure our healthcare system works for *everyone*.

In recent years this Committee, under the leadership of now-Ranking Member Pallone and Ranking Member Eshoo, prioritized investments in Medicaid, one of the most important sources of health coverage for people with disabilities. The committee approved legislation to expand Medicaid access in states that have refused to do so and pushed for billions of dollars in additional funding for Medicaid Home and Community Based Services (HCBS).[13] This is a good foundation to build on. I sincerely hope this work will continue under the leadership of Chairwoman McMorris Rodgers – a passionate champion for the health and financial security of disabled people – and Chairman Guthrie. For example, this Congress could work in a bipartisan way to ensure that no Medicaid beneficiary is forced to accept services from institutional or segregated settings. Congress should also better support health and quality of life by making

HCBS a mandatory Medicaid service, ending the two-year Medicare disability waiting period, developing a sustainable federal long-term care program for all in our nation, and by robustly funding the direct care workforce needed to sustain these services.

Given these critical priorities, **I believe the Committee's focus on *The Protecting Health Care for All Patients Act* is misplaced** and urge the committee to oppose this legislation for several reasons. I am concerned that the proposed legislation's prohibition on the use of Quality-Adjusted Life Years (QALY) *"or such similar measures"* in federal programs, is a solution in search of a problem. Specifically, I am concerned that the legislation is being proposed at this time to undermine the recently passed Inflation Reduction Act (IRA) and key provisions that allow the federal government to negotiate fair drug prices, and note that **the IRA already includes explicit disability (and other) safeguards.**[14]

These new IRA drug pricing negotiation authorities are critical to safeguarding the American people, including disabled people, from unaffordable or low-quality drugs. Furthermore, a blanket federal prohibition of the use of "adjusted life years or a similar measurement" would likely call into question non-discriminatory measures of health care value and exacerbate the terrible waste in other aspects of the U.S. health care system – estimated at an <u>astounding</u> $760 - $935 billion.[15] Ultimately, *the Protecting Health Care for All Patients Act*, could play a significant role in worsening the health care affordability and quality crisis faced by millions upon millions of our nation's families, including people with disabilities.

Just by examining the pricing abuses in the prescription drug industry, we know that price gouging is rampant; and the industry continues to dramatically overcharge for medications, including some that are low value.[16] In 2021 alone, drug makers cost the U.S. healthcare system an additional $805 million due to unjustified price increases.[17] It is critical to note that disabled people are particularly at risk for this price gouging, given their health needs, their reliance on Medicare and Medicaid, and their likelihood to have fewer financial resources.[18] The Medicare program is still being egregiously overcharged for prescription drugs, including for those that offer little therapeutic value to justify their pricing.[19] For example, Trulicity, the brand name drug of dulaglutide – a medication prescribed for type 2 diabetes – has a monthly list price ranging from $886 to nearly $11,000, a price that most Americans cannot afford.[20] Its drug maker, Ely Lilly, made headlines for falsely advertising the benefits of the drug for all diabetic populations despite it only being approved to treat people type 2 diabetes.[21]

As a nation, we need the capacity to assess the overall effectiveness and value of a drug like Trulicity to ensure the American people receive safe, effective, and affordable drugs. We can't continue to be at the mercy of the predatory marketing and pricing practices of the pharmaceutical industry that are simply designed to push profit at the expense of people's lives.

Moreover, had stronger federal guardrails to assess value been in place at the onset of the opioid epidemic (the subject of other legislation being considered during today's hearing) to actually scrutinize the underlying safety, efficacy and affordability of OxyContin, it is very likely that millions of lives - and billions of dollars - could have been saved. Instead, those guardrails did not exist and a very dangerous and highly addictive drug was unleashed into our society.

As federal lawmakers, you have an obligation to ensure that we carefully steward our national health care resources and taxpayer dollars. Central in that effort is assessing the value of the goods and services being provided to the American people through federally funded programs. I appreciate and share concerns about any measure of the value of prescription drugs or other health care goods and services that weights a year of life differently for a person based on their disability status. To provide high value health care and ensure improved health for all, including people with disabilities, we must ensure that any measure being used in health care decision-making is able to accurately capture the multifaceted lives of people living with disabilities, and does not inadvertently undervalue their lives or experience.

For that reason, Families USA supported Congress's guardrails on value assessments under the Affordable Care Act (ACA) and mostly recently under the IRA. Specifically, the IRA bars any discriminatory practices in setting a drug price for Medicare negotiation and lays out nine factors that the Secretary of Health and Human Services must use in developing negotiated prices, many of which can and should be themselves composed of multiple factors, and **explicitly bars any measure of comparative effectiveness that "treats extending the life of an elderly, disabled, or terminally ill individual as of lower value than extending the life of an individual who is younger, nondisabled, or not terminally ill**."[22]

This important protection would have to be met when considering how to incorporate any measure of clinical value or quality of life impact. For example, the Institute for Clinical and Economic Review has developed the Equal Value of Life Years Gained (evLYG) measure, which incorporates such safeguards, by:

> "evenly measur[ing] any gains in length of life, regardless of the treatment's ability to improve patients' quality of life. In other words, if a treatment adds a year of life to a vulnerable patient population – whether treating individuals with cancer, multiple sclerosis, diabetes, epilepsy, or a severe lifelong disability – that

> treatment will receive the same evLYG as a different treatment that adds a year of life for healthier members of the community."[23]

For these reasons, I believe that the committee should oppose enactment of *the Protecting Health Care for All Patients Act*. If federal policymakers want to live up to our collective ideals in supporting the civil rights, financial independence, and overall health of people with disabilities, we should refocus our efforts on the investments necessary to support the end of the Medicare disability waiting period, the extension of the Medicaid program in every state, fully funding Medicaid home and community-based services, and the other reforms described above. At the same time, it is critical that federal policy makers are able to engage in the informed analyses necessary to ensure a thoughtful approach to measuring health care value. The health and financial security of our nation, and every single person living in it, depends on it.

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