

**Responses to Questions for the Record for Frederick Isasi, Executive Director, Families USA**

U.S. House of Representatives Committee on Energy and Commerce Health Subcommittee

Wednesday, February 1, 2023

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

**Questions from the Honorable Gus Bilirakis**

*Mr. Isasi, the U.S. health care system is one that fosters pharmaceutical innovation and development that is leaps and bounds beyond any other global entity. The cures that come out of America benefit patients the world over. That being noted the use of QALYs has created ethical questions in nations like the UK.*

- *Do you believe it is ethical to ration treatments for patients based on subjective methodologies like the QALY?*

**Response:**

Nobody should be denied access to a treatment or coverage for health care due to their age, health, or disability status, and we should never assign more value to one life over another in making health care decisions.

But the proposed legislation under discussion, H.R. 485, *The Protecting Health Care for All Patients Act*, would do nothing to prevent rationing of care. The vague and broad federal prohibition of the use of “adjusted life years or a similar measurement” included in this legislation 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 astounding \$760 - \$935 billion.<sup>1</sup> For example, the proposed legislation likely would create a very serious legal “loophole” that the pharmaceutical industry will use to argue against any efforts to determine the real value of a prescription drug and negotiate a fair price for our nation’s families, under new drug negotiation authorities authorized through the *Inflation Reduction Act of 2022 (IRA)*.<sup>2</sup> For this reason, the legislation could play a significant role in worsening the health care affordability and quality crisis faced by millions upon millions of our nation’s families, often most acutely by people with disabilities, and could lead to the *actual* rationing of health care services and treatments due to people being unable to afford the care they need.<sup>3</sup>

- *Is it reasonable to utilize an elongated QALY based review processes, like the Institute of Clinical and Economic Review (ICER) model or the National institute for Health and Care*

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<sup>1</sup> Shrank WH, Rogstad TL, Parekh N. Waste in the US Health Care System: Estimated Costs and Potential for Savings. JAMA. 2019;322(15):1501–1509. doi:10.1001/jama.2019.13978

<sup>2</sup> Public Law No: 117-169.

<sup>3</sup> As recently as late last year, CDC estimated that more than a million Americans with diabetes rationed their insulin annually due to the high costs of the life-saving drug, and that Medicare beneficiaries were disproportionately impacted. For more information, see [Insulin: 1.3 million Americans with diabetes rationed their supply in the past year, study finds | CNN](#)



***Excellence (NICE) model in the United Kingdom, which have been proven to have negative life shattering implications for patients?***

Response:

We do not support utilizing any measure in health care decision-making that discriminates on the basis of disability status, age, or severity of illness, including the quality-adjusted life year (QALY). We are proud to have supported including language in both *the Patient Protection and Affordable Care Act* (ACA)<sup>4</sup> and IRA that explicitly bars the U.S. Department of Health and Human Services from using QALYs in treatment and coverage decisions.

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<sup>4</sup> Public Law 111–148.