

**Honorable Tony Coelho**

**Testimony to the Oregon Department of Consumer and Business Services' (DCBS) Division of  
Financial Regulation (DFR)**

**December 4, 2025**

Thank you for this opportunity to provide input. As a patient with epilepsy and a disability advocate, I have experienced the consequences of payer policies that threaten my personal health. I have advocated for others trying to overcome the hurdles put in place by payers so they can access the health care prescribed to them. Ultimately, our health system should be centered on patients and people with disabilities, not payers or value assessment entities.

Having experienced discrimination in many forms, it was my priority to advance the Americans with Disabilities Act (ADA) during my time as a Member of Congress in the House of Representatives, which was finally passed in 1990. Therefore, I was very disappointed to learn that Oregon has chosen to take counsel from the Institute for Clinical and Economic Review (ICER), an entity that views the discriminatory quality-adjusted life year (QALY) as the gold standard for measuring health care value, despite Oregon's recent history banning QALYs from use statewide in health care decisions. Too often, the policy recommendations from ICER's reports provide an excuse to payers to deny coverage or advance egregious utilization management practices intended to steer patients to treatments benefiting payers, not patients. It is my hope that any policy seeking to reduce health care costs does not do so at the expense of improving clinical outcomes for patients. To be clear, any policy relying on ICER's framework is not going to be centered on patients and people with disabilities as their framework is centered on measures that devalue disabled lives.

In 2016, I shared a bit of my story in a published blog piece, from which I am sharing an excerpt below:

"Over the years, I've been on at least eight or ten different seizure medications. Some worked, some didn't, but I have diligently found a physician that I trust to guide me to an effective treatment decision.

But what happens when those decisions are undermined by forces outside the patient-physician relationship? During a recent physician visit, I was provided a prescription to renew/refill the anti-seizure medication that has worked well for me for several years now. I filled the prescription and began taking the new pills, trusting that the medication was exactly the same as ordered by my physician. Yet, I woke up feeling tired and increasingly depressed. By dinnertime, I could barely function. I called my physician, who asked if I'd recently picked up my refill. When I replied that I had, he asked me to describe the appearance of the pills and to

read him the label. He told me to stop taking the medication immediately, though in doing so I risked triggering a break-through seizure.

As it turned out, my insurance company had required the pharmacist to substitute the brand-named drug that I had been using for some time with a generic version — without notifying me, asking my permission, or warning me about the potential implications for my health and well-being. In my case, the generic version was not an identical substitute, as it caused a dramatic reaction in my mood and energy level. My physician, wanting me to avoid a break-through seizure and being experienced enough to know that my insurance company was likely to require a lengthy appeal, promptly worked around the insurer-imposed challenge by prescribing me the original brand-name drug in a different dosage form, a delayed-release capsule, for which there was no generic substitute. (It's worth noting that while generic substitutions are generally benign, in some instances they can be problematic for seizure disorders.)

In this example, my insurance company was trying to force me into a standardized box, just as they do with millions of other patients. Unfortunately, I didn't fit. Thankfully my doctor found a resolution before my health situation became more severe, but other patients like me could find themselves requiring urgent medical attention, missing work, unable to care for their families, or worse."

See my entire blog here: <https://careforyourmind.org/patients-need-to-be-involved-in-policy-making/>

Barriers to care are too often directly related to payer reliance on cost effectiveness analyses, a point made clearly in the new regulations barring disability discrimination among entities receiving federal financial assistance (Section 504 of the Rehab Act), including the use of discriminatory value assessments. Therefore, policymakers are currently debating policies to bring more transparency and accountability to pharmacy benefit managers (PBMs) and to mitigate the misuse of non-medical switching, step therapy and prior authorization. At the federal level, Congress has built on Oregon's leadership to introduce legislation that bars the use of QALYs and similar measures across federal government programs, consistent with the existing ban in Medicare, with the goal of ensuring biased views about the quality of life of people with disabilities does not lead to discriminatory policy-making and misuse of utilization management tools by payers.

It is my hope that it will be transparent at this hearing that ICER's value assessments are illegal in Oregon and therefore may not be relied upon for decision-making. I applaud Oregon's progress to rid its decision-making process from incorporating QALYs and similar measures through legislation, and the Health Evidence Review Commission's engaged process with the disability community. I also hope that ICER's invitation to this hearing does not represent a step back in Oregon's commitment to the disability community to avoid the use of QALYs and similar measures in its policies impacting reimbursement and coverage decisions, consistent with federal law and policy as well.

Sincerely,

A handwritten signature in black ink. It consists of a stylized monogram 'TC' followed by the name 'Coelho' in a cursive script.

Tony Coelho

**Tony Coelho** is a retired U.S. Congressman from California, a former House of Representatives Majority Whip, Democratic Congressional Campaign Committee Chairman and the principal author of the Americans with Disabilities Act. He worked with President Clinton to establish the Office of Disability Employment Policy at the U.S. Department of Labor and persuaded President Barack Obama to increase enforcement of Section 503 of the Rehabilitation Act requiring federal contractors to hire people with Disabilities. Most recently, Tony worked with President Joe Biden's administration to provide requirements for internet accessibility. Diagnosed with epilepsy when he was 22 years old, Tony has spent his entire adult life helping advance the lives of people with disabilities, call it his "ministry." Tony founded The Coelho Center for Disability Law, Policy and Innovation at Loyola Marymount University and serves as the Chairman of the Partnership to Improve Patient Care.