

**Honorable Tony Coelho, Chairman, Partnership to Improve Patient Care**  
**Written Testimony on SB 492**  
**March 22, 2023**

Thank you for this opportunity to submit written testimony. This legislation reflects decades of work to advance disability rights and to end the use of discriminatory measures of the effectiveness of health care that too often drive barriers to care for people with disabilities. In the past this may have been considered just a disability issue, but today we recognize the implications of these biased algorithms for health equity more broadly. The COVID-19 pandemic laid bare what we have always known – that the public’s biased views about the quality of life of people with disabilities is especially prevalent for Black, Indigenous, and People of Color (BIPOC). Early in the pandemic, we saw it up close in the use of “life year” metrics driving state Crisis Standards of Care that put people with disabilities at the end of the line for care in a shortage. Disability advocates filed complaints and engaged the HHS Office for Civil Rights. As the original author of the Americans with Disabilities Act (ADA) during my time in Congress, I was relieved to see the ADA and other civil rights laws used to ensure COVID-19 care standards did not discriminate.

Yet, in Texas, Michael Hickson, an African American man in a wheelchair with pre-existing brain damage, entered a hospital with COVID-19 and his doctors decided — in defiance of his wife and likely in violation of U.S. civil rights laws — that his life wasn’t worth saving. It did not matter there was no shortage. They decided he had no quality of life. Cases like this are stark reminders about the world we could live in without legal protections against discrimination.

Today, you are considering legislation that includes language with the consistent intent of the federal statute passed as part of the Affordable Care Act in 2010 barring the use of discriminatory quality-adjusted life years and similar metrics in Medicare decisions. Medicare has operated under this statutory protection for people with disabilities for over 10 years.

As background, the quality-adjusted life year, or QALY, is a metric commonly used to determine the value of a health care treatment. To calculate a QALY, you must assign a value to a person’s life. Because the value assigned to seniors, the chronically ill, or people with disabilities is lower than that of a young, healthy person, QALYs could lead policymakers and payers to conclude that treatments for seniors, patients with chronic conditions or people with disabilities are not worth covering. QALYs also rely on biased perspectives, often from public surveys, related to quality of life to determine whether a treatment improves health.

Oregon was, in fact, the first state to explicitly seek to reference this discriminatory metric known as the QALY to determine its prioritized list of services as part of a Medicaid waiver application. The Secretary of the U.S. Department of Health and Human Services (HHS) responded, “Our principal concern is that Oregon’s plan in substantial part values the life of a

person with a disability less than the life of a person without a disability. This premise is discriminatory and inconsistent with the Americans with Disabilities Act.”<sup>1</sup>

Thereafter, it was considered to be a precedent that HHS would not give states authority to use QALYs in their Medicaid programs. In fact, I often pointed to Oregon as a state that wasn’t using QALYs based on that 1992 decision. In recent years, it has come to my attention that the Health Evidence Review Commission (HERC) in fact still uses QALYs in ranking the state’s prioritized list of services. The HERC used different language to reference its use of a quality-adjusted life year, making its use largely hidden to the public. Thankfully, Oregon has some incredibly talented disability advocates that engage routinely with the HERC and were able to identify its use of QALYs. The HERC has since engaged with disability advocates in an effort to address this historic discrimination and implement better engagement strategies. I strongly support that collaborative work between the HERC and the disability community.

Nevertheless, I would remind the Committee how easy it is for policymakers to forget and to slide back into the historic way of doing things, as happened after the 1992 rejection of Oregon’s original waiver application over its use of QALYs. In order to intentionally improve health equity and bar discrimination in the provision of health care, I strongly recommend passing this law that bars policymakers from using biased judgements about quality of life based on disability or other social identity. I agree with the National Council on Disability, a federal agency advising Congress and the administration on disability policy, that the use of QALYs in health care programs that get federal funds is contrary to existing civil rights laws. I also agree with the Council that payment decisions should not be based on QALYs nor should programs rely on health preferences of the public instead of the population being treated. Yet, I also know it will require a law on the books barring reference to QALYs and similar metrics to ensure that those making decisions related to the provision of health care in Oregon avoid using metrics like QALYs for the foreseeable future.

As a person with epilepsy, I understand stigma. As a young man, my condition meant I could not get a job, the Catholic church thought I was possessed by the devil, and my parents stood by the church – not me. The ADA was enacted to counter that bias and stigma for future generations. Combined with Section 504 of the Rehab Act and Section 1557 of the Affordable Care Act barring discrimination in health care programs, there is no question that metrics like QALYs are not fit for use in our health system. I sincerely hope Oregon will lead in explicitly abandoning its use of QALYs and taking steps with affected stakeholders to advance systemic changes that are better for the health of all Oregonians, including those with disabilities.

I appreciate this opportunity to submit testimony.

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<sup>1</sup> Sullivan, Louis W. M.D. Secy. of Health and Human Services, Washington, (Aug. 13, 1992). Oregon Health Plan is Unfair to the Disabled, *New York Times* at <https://www.nytimes.com/1992/09/01/opinion/l-oregon-health-plan-is-unfair-to-the-disabled-659492.html>