

**Oregon House Committee on Behavioral Health and Health Care**  
**Testimony from Tony Coelho**  
**SB 1508**  
**February 21, 2024**

Thank you for this opportunity to testify on SB 1508.

My name is Tony Coelho and I was an original author and sponsor of the Americans with Disabilities Act which passed Congress in 1990. I am also a person with epilepsy. So, as you can imagine, for me, this is personal.

Due to my seizures, I have experienced the stigma that so many people with disabilities experience routinely. The resulting barriers to care that come from assumptions that people with disabilities have a low quality of life and are not worthy of treatment are well documented. It is what drives me and so many in the disability community to advocate against the use of measures like quality-adjusted life years (QALYs) to determine how health care will be reimbursed and covered.

The bill you are discussing today represents over 30 years of advocacy from the disability community. By banning generic measures of quality of life, the most well-known being QALYs, Oregon will be a leader in advancing disability rights. These measures are known to devalue disabled lives by failing to represent how people with disabilities experience quality of life and what they most need to optimize their health.

As you may be aware, HHS denied Oregon's original Medicaid waiver in 1992 because its use of these measures to prioritize the list of covered health care services was discriminatory. I applaud recent efforts in Oregon to end their ongoing use. But the need to do so underscores why legislation is required - to make it a law that discrimination has no place in Oregon's health system. Over time, these measures came back into Oregon's decision-making process, and it will take legislation to make sure that does not happen again.

Oregon would not be the first health program to bar the use of QALYs and similar measures. In the Affordable Care Act, Congress banned the use of discriminatory measures in Medicare decisions related to coverage and reimbursement. The

Inflation Reduction Act also barred the use of discriminatory evidence in considerations related to the Medicare Drug Negotiation Program.

In response to recommendations from the National Council on Disability, an independent federal agency advising Congress and the administration on disability policy, the Congressional House of Representatives recently passed legislation extending the Medicare protections in current law for people with disabilities to other programs like Medicaid. Also, the Biden administration has openly supported current law Medicare protections and has recognized the need to extend those protections. Both sides of the aisle acknowledge the problem and want to address it. The policy you are considering today is not and should not be partisan.

As members of the committee, you have a great opportunity to advance this bill to final passage. In doing so, Oregon would be leading the nation to address this discrimination in the state's health system and demonstrate to other states and the nation it can be done.

I am grateful to the committee and to the disability advocates here in Oregon that have worked so hard on this.

Thank you for the opportunity to testify.

*Tony Coelho is a former California Congressman, an original author of the Americans with Disabilities Act, a life-long disability advocate and Chair of the Partnership to Improve Patient Care.*