

Submitter: Tony Coelho
On Behalf Of:
Committee: Senate Committee On Health Care
Measure: SB1508

Thank you for this opportunity to testify on SB 1508.

My name is Tony Coelho and, as some of you may know, I was an original author and sponsor of the Americans with Disabilities Act which later 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 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 because its use of these measures to prioritize the list of covered health care services was discriminatory.

I am aware that there have been recent efforts in Oregon to address their ongoing use over the years and applaud the state for it.

But this underscores why legislation is so needed to make it a law that these measures have no place in your health system. Over time, they came back into Oregon's decision-making-process and it will take legislation to make sure that does not happen again.

And Oregon is not alone.

In the Affordable Care Act, Congress banned the use of discriminatory measures in Medicare decisions related to coverage and reimbursement, and did so again in the Inflation Reduction Act.

In response to recommendations from the independent federal agency called the National Council on Disability, today the House of Representatives passed legislation extending those Medicare protections to other programs like Medicaid.

The administration has also recognized the need to extend the ACA's protections as part of rulemaking.

Both sides of the aisle have recognized the problem and want to address it. The policy is not partisan.

But we do not know what will happen at the federal level despite bipartisan consensus.

Which is why Oregon passing this bill is so needed and so impactful. You would be leading the nation to address this discrimination in the 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.