

Sean O'Day, Director
Oregon Department of Consumer and Business Services
P.O. Box 14480
Salem, OR 97309

Dear Director O'Day,

We are writing to express our concern that the Institute for Clinical and Economic Review (ICER) has been invited to participate in a public hearing convened by the Oregon Department of Consumer and Business Services' (DCBS) Division of Financial Regulation (DFR). As organizations representing people with disabilities and serious chronic conditions, we strongly supported the state's law that, when signed in 2024, immediately barred the use of any formula that assesses value of treatments based on the discriminatory "quality-adjusted life year" (QALY) and the "equal value of life year gained." ICER continues to refer to the QALY as the "gold standard" for cost effectiveness analyses despite federal rule and state law that bar use of measures devaluing disabled and medically complex lives.¹ Therefore, we urge DFR to reconsider ICER's invitation to be an advisor to this work.

As background, the State of Oregon has a long history on this issue. Two years after passage of the Americans with Disabilities Act (ADA) in 1990, the state applied for a Medicaid waiver under which the prioritized list of services would be determined by reference to QALY-based measures of cost effectiveness. The Secretary of the U.S. Department of Health and Human Services denied the waiver, claiming it would be in violation of the ADA due to its reliance on discriminatory QALYs.² Later, it was determined that the Health Evidence Review Commission (HERC) continued to reference QALYs in its work, ultimately leading to a debate about the state's waiver and resulting in instructions from the federal government to end use of the prioritized list by 2027.³

At the same time, our organizations fought to advance a statewide ban on the use of a "quality of life in general measure" intended to ban reference to QALYs and similar measures that devalue people with disabilities in favor of generalized measures of cost effectiveness.⁴ Final passage of SB 1508 (2024) was intended to put to rest the longstanding debate in the state of Oregon as to whether measures devaluing people with disabilities were allowable considerations in decisions related to our health system. SB 1508 passed with broad bipartisan support—the legislature's answer was a resounding no.

¹ See <https://olis.oregonlegislature.gov/liz/2023R1/Downloads/PublicTestimonyDocument/80196>

² See <https://www.nytimes.com/1992/09/01/opinion/l-oregon-health-plan-is-unfair-to-the-disabled-659492.html>

³ See <https://www.bizjournals.com/portland/news/2021/11/19/overhaul-oregon-medicoids-prioritized-list-for.html>

⁴ See <https://www.droregon.org/advocacy/big-wins-from-the-2024-legislative-session>

With the passage of SB 1508, Oregon law now bars reference to any measure that utilizes “quality of life in general” instead of measures capturing the specific perspectives of the population under consideration.

The foundation of this legislative language and concern is the use of health utilities as inputs into QALYs and similar quality of life in general measures that are based on surveys of the general public to identify their perceptions of quality of life for people with disabilities and those living with complex medical conditions. In its report on QALYs, the National Council on Disability, a federal independent agency advising Congress and the administration on disability policy, raised serious concerns about methods using health utilities relying on EQ-5D surveys, which take an extremely limited approach to measuring “quality of life” and fail to measure the wide variety of impacts a disability or illness could have on quality of life.⁵ Our goal in passing SB 1508 was to ensure health policy decisions did not devalue disabled and/or medically complex lives by relying on measures calculated using these discriminatory methods and utilities.

We are pleased that the HERC has responded to the legislation and to our concerns⁶ complying with Oregon law by ending its use of QALYs and avoiding use of similar measures such as the evLYG. The HERC has solicited input from our community, so it is fulfilling the intention of the bill to ensure HERC’s decisions aren’t influenced by quality of life in general measures and that its practices appropriately consider the needs of people with disabilities and complex medical conditions.

Additionally, it is important to note that the federal government has also advanced updated rules implementing Section 504 of the Rehabilitation Act, a statute barring disability discrimination among entities receiving federal financial assistance, that also bar the use of QALYs and similar measures. The federal regulations bar health care decisions made using measures that discount gains in life expectancy under § 84.57, which would include QALY, as well as methods of utility weight generation used in a way that discriminates under § 84.56’s prohibition of discrimination based on biases or stereotypes about a patient’s disability, which would also include the evLYG. In fact, HHS interpreted § 84.57 to be broader than section 1182 of the Affordable Care Act which explicitly bars the use of QALYs and similar measures in Medicare coverage and reimbursement decisions.⁷

⁵ See <https://www.ncd.gov/report/quality-adjusted-life-years-and-the-devaluation-of-life-with-a-disability/>

⁶ See <https://olis.oregonlegislature.gov/liz/2023R1/Downloads/PublicTestimonyDocument/80196>

⁷ “The Department interprets recipient obligations under the current language of § 84.57 to be broader than section 1182 of the Affordable Care Act, because it prohibits practices prohibited by section 1182 (where they are used to deny or afford an unequal opportunity to qualified individuals with disabilities with respect to the eligibility or referral for, or provision or withdrawal of an aid, benefit, or service) and prohibits other instances of discriminatory value assessment.” See <https://www.federalregister.gov/documents/2024/05/09/2024-09237/nondiscrimination-on-the-basis-of-disability-in-programs-or-activities-receiving-federal-financial>

When ICER developed the evLYG, the disability community was very vocal in its opposition.⁸ We are very concerned that ICER has engaged in Oregon to bypass legal concerns about the influence of QALYs and the similar measure, evLYG, on health care decision-making. We remain concerned the evLYG is a measure that fails to appropriately value quality of life improvement while focusing value on a treatment's ability to extend life. For people with disabilities and or complex medical conditions, quality of life improvement alone is a highly valuable outcome.

In conclusion, it is highly inappropriate for ICER to be considered an advisor to the state of Oregon in matters related to our health system. State and federal policy have made it clear that QALYs and similar measures have no place here because we are a state that values people with disabilities and serious chronic conditions. Therefore, we urge reconsideration of ICER's presence at this public hearing and in future discussions convened by the Department and Consumer Business Services (DCBS).

Sincerely,

Disability Rights Oregon
Lane Independent Living Alliance (LILA)
Oregon Council on Developmental Disabilities
Partnership to Improve Patient Care (PIPC)
Our Children Oregon (OCO)
Northwest PANDAS/PANS Network (NWPPN)

CC

Senator Deb Patterson
Senator Diane Linthicum
Representative Emerson Levy
Representative Rob Nosse

⁸ See https://www.pipcpatients.org/uploads/1/2/9/0/12902828/section_504_experts_two-pager_4.pdf