



To: House Committee on Health Care
From: Meghan Moyer, Public Policy Director of DRO
RE: HB 4035 and the use of QALYs

Chair Prusak, Vice Chairs Hayden and Salinas, and members of the House Health Care Committee,

You may be asking yourself, why would Disability Rights Oregon (DRO) have concerns with HB 4035? All this bill does is direct OHA to find ways to save money on Health Care and make recommendation to the Legislature. To understand DRO's concerns it is helpful to understand the history of the Oregon Health Plan and Oregon's use of the Quality Adjusted Life Year (QALY) metric in establishing our prioritized list. DRO has submitted two reports. The first is from the National Council on Disability with an in-depth explanation of how QALYs discriminates against people with disabilities. And the second is a 1992 letter from Health and Human Services rejecting Oregonians 1115 Medicaid Waiver Application because of our use of QALY to determine what conditions we will or won't cover on OPH.

National Council on Disability Report:

"QALYs place a lower value on treatments which extend the lives of people with chronic illnesses and disabilities. In this report, NCD found sufficient evidence of the discriminatory effects of QALYs to warrant concern, including concerns raised by bioethicists, patient rights groups, and disability rights advocates about the limited access to lifesaving medications for chronic illnesses in countries where QALYs are frequently used. In addition, QALY-based programs have been found to violate the Americans with Disabilities Act."

DRO represents a diverse community of people with disabilities who strenuously oppose the use of quality-adjusted-life-years (QALYs) to determine care. QALYs attempt to measure the value of health outcome to help a health care provider determine the cost-effectiveness of any treatment. In the guise of cutting healthcare costs, QALY scores are inherently discriminatory, placing an arbitrary value on the lives of people with disabilities, patients, older adults and people of color because of existing disparities in healthcare. The measure of "quality of life" used as a multiplier in the QALY is not based in science but rather complete based on the bias perceptions of medical professionals. QALY scores have no place in deciding what conditions will be covered or not covered in Oregon's Medicaid Program.

The National Council on Disability, an independent federal agency charged with making recommendations to the President and U.S. Congress, [found QALYs](#) place a lower value on the lives of people with chronic illnesses and disabilities. This approach leads to a devaluation of the lives of Americans and perpetuates unequal access to healthcare.

According to NCD, “One of the most prominent attempts to utilize QALYs in a state-run health insurance program was found to violate the Americans with Disabilities Act (ADA). Starting in 1989 and continuing into the early 1990s, the state of Oregon attempted to reform its Medicaid program by ranking treatments in terms of their cost-effectiveness..... The Bush administration ultimately rejected Oregon’s Medicaid plan, as it was found to violate the Americans with Disabilities Act.” But that didn’t stop Oregon from using QALY as it assigned scores to medical conditions and treatment used to establish to prioritized list for OHP.

The Oregon Health Authority (OHA) now says they stopped rely on QALY scores in 2017 and only uses QALY scores for background information. Yet, OHA would not provide DRO with the scoring formula they are now using. OHA would also not commit to prohibiting the use of QALY in Health Evidence Review Committee (HERC) scoring conversations. Due to the lack of transparency regarding such a critical topic, we are left to assume that Oregon still relies on a discriminatory scoring process to determine who gets healthcare. OHA also confirmed to DRO that the prioritized list has not been rescored without the use of QALY.

DRO opposes any policies that use QALYs or other discriminatory health assessment tools. People with disabilities, older adults and people of color already face discrimination in their lives, we don’t need healthcare policies implemented in a global pandemic to systemically deprioritize resources from protected classes. Such policies would move our state backwards rather than forward and exacerbate existing disparities.

While the disability community has been told our lives don't have as much value as other Oregonians, we refuse to accept this discrimination. What we need from policymakers is to make clear the lives of all Oregonians are equally valued and that discrimination against any protected class will not be tolerated. We need affordable, equitable, and safe medical treatments and technology. For this reason, we urge you to reject any discriminatory framework that values the lives of some people over others.

Suggested amendment language:

SECTION 1. (1) The Oregon Health Authority shall conduct a study and recommend potential options to improve access to or lower the cost of health care in this state. Based on the findings of the study, the authority shall implement the recommendations to the extent consistent with the agency’s existing statutory authority.

(2) The authority shall not develop or utilize, directly or indirectly, in whole or in part, through a contracted entity or other third-party, a dollars-per- quality-adjusted life

year or any similar measures or research in conducting the study or developing the recommendations under subsection (1) of this section.

(3) No later than September 15, 2023, the authority shall report to the interim committees of the Legislative Assembly related to health any legislative changes necessary to fully implement the recommendations under subsection (1) of this section.

SECTION 2. Section 1 of this 2022 Act is repealed on January 2, 2024.

About Disability Rights Oregon

Since 1977 Disability Rights Oregon has been the State's Protection and Advocacy System.¹ We are authorized by Congress to protect, advocate, and enforce the rights of people with disabilities under the U.S. Constitution and Federal and State laws, investigate abuse and neglect of people with disabilities, and "pursue administrative, legal, and other appropriate remedies".² We are also mandated to "educate policymakers" on matters related to people with disabilities.³

IF you have any questions regarding DRO's position please call Meghan Moyer at 503-432-5777 or mmoyer@droregon.org

¹ See ORS 192.517.

² See 42 U.S.C. § 15041 et seq; 42 U.S.C. § 10801 et seq.

³ See 42 U.S. Code § 15043(a)(2)(L).