On behalf of organizations representing health care stakeholders, we would like to express concern with SB 5020, as it relies directly on reports conducted by the Institute for Clinical and Economic Review (ICER), an entity that embraces the quality-adjusted life year (QALY) as the gold standard for value assessment. The affordability of health care is a significant priority to our constituents and should be addressed through policies that are centered on the needs of people living with disabilities and chronic conditions. We are concerned that relying on ICER will further entrench discrimination against people with disabilities and chronic conditions by endorsing the use of discriminatory metrics that experience shows to lead to restricted access care, ultimately doing more harm than good for patients.

ICER conducts QALY-based cost-effectiveness analyses despite the significant input from impacted patient and disability stakeholders seeking to convince ICER to shift to a methodology that is less harmful to those living with the conditions being studied. QALY-based assessments assign a financial value to health improvements and outcomes. When applied to health care decision-making, the results can mean that people with disabilities and chronic illnesses, particularly older adults and subpopulations that already experience significant inequities in health care, are deemed not worth the cost to treat.[1]

We understand that this bill is designed to improve the affordability of health care, a shared goal for people who use health care the most. Yet, we cannot support reliance on an entity that deems the QALY the gold standard for value assessment. The United States has a thirty-year, bipartisan track record of opposing the use of the QALY and other discriminatory metrics and has established safeguards to mitigate its use.

As background, federal policymakers recognize that discriminatory value assessments are subject to civil rights laws.[2] Section 504 of the Rehabilitation Act does not allow for people with disabilities to be "excluded from participation in, be denied the benefits of, or otherwise be subjected to discrimination," under any program offered by any Executive Agency, including Medicare.[3] PIPC Chairman Tony Coelho was the original author of the Americans with Disabilities Act (ADA) which was passed in 1990 and extended this protection to programs and services offered by state and local governments.[4] As a result, in 1992, the George H.W. Bush Administration established that it would be a violation of the ADA for state Medicaid programs to rely on cost-effectiveness standards, as this could lead to discrimination against people with disabilities.[5]

In 2010, the Affordable Care Act legislated that the Secretary of Health and Human Services has no authority to deny coverage of items or services "solely on the basis of comparative effectiveness research" nor to use such research "in a manner that treats extending the life of an elderly, disabled, or terminally ill individual as of lower value than extending the life of an individual who is younger, nondisabled, or not terminally ill."[6] Additionally, the ACA specifically prohibits the development or use of a "dollars-per-quality adjusted life year (or similar measure that discounts the value of a life because of an individual's disability) as a threshold to establish what type of health care is cost effective or recommended." The ACA also states, "The Secretary shall not utilize such an adjusted life year (or such a

[1] http://www.pipcpatients.org/uploads/1/2/9/0/12902828/pipc_disparities_whitepaper[2].pdf
[2] https://www.federalregister.gov/d/2020-12970
[3] 29 USC Sec 794, 2017. Accessed November 30, 2020.
[4] 42 USC Sec 12131, 2017. Accessed November 30, 2020.
[5] Sullivan, Louis. (September 1, 1992). Oregon Health Plan is Unfair to the Disabled. *The New York Times*.
[6] 42 USC Sec 1320e, 2017. Accessed November 30, 2020.

similar measure) as a threshold to determine coverage, reimbursement, or incentive programs under title XVIII" (Medicare)."[7]

Since then, ICER has garnered significant financial support from Arnold Ventures with strong support from private insurers and pharmacy benefit managers to forge ahead in their work to conduct QALY-based cost effectiveness analyses. Organizations representing the individuals and families facing the consequences of those studies, often in the form of coverage barriers, have encouraged ICER to amend its methodologies to center on how people value care in real world settings. Unfortunately, ICER still references QALYs as the gold standard.

Most recently, in 2019, the National Council on Disability, an independent federal agency, concluded that the QALY was subject to Section 504, the ADA and Section 1557 of the ACA, stating that its use in public programs would be contrary to United States civil rights and disability policy.[8] Their sentiments are shared by federal policymakers on both sides of the aisle that have made statements against the use of QALYs in federal health programs such as Medicaid,[9] including the DNC Platform,[10] President-elect Biden[11] and Republicans that supported the bar on use of QALYs in Medicare.

We urge Washington state policymakers to engage with stakeholders representing patients and people with disabilities to create and advance policies that will improve health care affordability and access to care.

[7] 42 USC Sec 1320e, 2017. Accessed November 30, 2020.
[8] National Council on Disability. (November 16, 2019). Quality-Adjusted Life Years and the Devaluation of Life with Disability. https://ncd.gov/sites/default/files/NCD_Quality_Adjusted_Life_Report_508.pdf.
[9] https://www.congress.gov/congressional-record/2009/02/06/senate-section/article/S1774-5
[10] https://www.demconvention.com/wp-content/uploads/2020/08/2020-07-31-Democratic-Party-Platform-For-Distribution.pdf
[11] https://www.aapd.com/wp-content/uploads/2020/03/Vice-President-Biden_AAPD-and-NCIL-Presidential-Questionnaire.pdf