PIPC Partnership to Improve Patient Care

March 22, 2021

Dear Members of the Committee:

My name is Thayer Roberts, registered lobbyist for Partnership to Improve Patient Care (PIPC), and I would like to present PIPC's chairman, The Honorable Tony Coelho, to provide written testimony:

Dear Members of the Committee:

We understand that the rising cost of healthcare is a concerning issue that requires real solutions. While we agree health care affordability is a significant priority, we oppose policies, like SB 2170, that rely on discriminatory metrics such as the Quality-Adjusted Life Year (QALY) that are known to devalue disabled lives and lead to restricted access to needed care and treatment in countries like Canada.

As background, the American Association of People with Disabilities (AAPD) is a national cross-disability rights organization, advocating for full civil rights for the over 61 million Americans with disabilities by promoting equal opportunity, economic power, independent living, and political participation. The Association of University Centers on Disabilities (AUCD) is a membership organization that supports and promotes a national network of university-based interdisciplinary programs. The Partnership to Improve Patient Care (PIPC) is a coalition effort to apply principles of patient-centeredness to the nation's health care system. We encourage policymakers to manage health costs in a manner centered on meeting the health care needs of people with disabilities and chronic conditions. We are all joined in opposition to the use of the QALY, including the importation of the QALY through SB 2170.

Experts agree that referencing discriminatory metrics such as QALYs, whether in reference to QALY-based decisions from foreign governments or to value assessments conducted by the Institute for Clinical and Economic Review (ICER), is discriminatory and risks depriving North Dakotans of needed medical treatments.[1] QALY-based assessments assign a financial value to health improvements provided by a treatment that do not account for outcomes that matter to people living with the relevant health condition and that attribute a lower value to life lived with a disability. When applied to health care decision-making, the results can mean that people with disabilities and chronic illnesses, including older adults, are deemed not worth the cost to treat. In 2019, experts at the National Council on Disability (NCD), an independent federal agency advising Congress and the administration on disability issues, published a report finding that use of the QALY would be contrary to United States civil rights and disability law and recommended that the United States avoid referencing prices from other countries that rely on the QALY in order to avoid the access challenges experienced in those countries.[2]

[1] https://f2i.811.myftpupload.com/wp-content/uploads/2019/12/IPI-One-pager-.pdf
[2] https://ncd.gov/sites/default/files/NCD_Quality_Adjusted_Life_Report_508.pdf

SB 2170 would reference rates of prescriptions drugs from a third party, the Canadian government, which relies on the QALY for coverage and reimbursement decisions.[3] The bill directly references the prices paid for drugs in five Canadian provinces. Before applying for coverage by the provinces, all drugs must complete a Common Drug Review by CADTH, which references QALYs. In Canada, the outcome is that many individuals living with disabilities are unable to receive the treatments and care they need.[4]

Yet, the United States has a thirty-year, bipartisan track record of opposing the use of the QALY and similar discriminatory metrics and has established legal safeguards to mitigate their use:

- Section 504 of the Rehabilitation Act ensures that people with disabilities will not 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.[5]
- Title II of the Americans with Disabilities Act (ADA) extended this protection to programs and services offered by state and local governments.[6] Based on the ADA's passage in 1990, 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.[7]
- The Affordable Care Act (ACA) passed under President Barack Obama directly states 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."[8] 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 similar measure) as a threshold to determine coverage, reimbursement, or incentive programs under title XVIII" (Medicare)."[9]
- Most recently, the U.S. Department of Health and Human Services (HHS) reiterated in a final rule that it is a violation of section 504 of the Rehabilitation Act, the ADA, the Age Discrimination Act, and section 1557 of the ACA for state Medicaid agencies to use measures that would unlawfully discriminate on the basis of disability or age.[10]

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[3] https://cadth.ca/sites/default/files/pdf/guidelines_for_the_economic_evaluation_of_health_technologies_canada_4th_ed.pdf

[4] https://valueourhealth.org/wp-content/uploads/2020/04/Canada.pdf

[5] 29 USC Sec 794, 2017. Accessed November 30, 2020.

[6] 42 USC Sec 12131, 2017. Accessed November 30, 2020.

[7] Sullivan, Louis. (September 1, 1992). Oregon Health Plan is Unfair to the Disabled. *The New York Times*.

[8] 42 USC Sec 1320e, 2017. Accessed November 30, 2020.

[9] 42 USC Sec 1320e, 2017. Accessed November 30, 2020.

[10] https://www.federalregister.gov/d/2020-12970

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We hope that you will consider these legal protections under existing health and civil rights laws as you work on policies to reduce the cost of care for beneficiaries. We urge you to reject SB 2170 and stand ready to work with you on appropriate policies that do not devalue disabled lives.

Sincerely,

Tony Coelho
Chairman
Partnership to Improve Patient Care