

January 13, 2023

Chairwoman Judy Lee
1822 Brentwood Court
West Fargo, ND 58078

Dear Chairwoman Lee,

I am reaching out on behalf of the Partnership to Improve Patient Care (PIPC), a coalition of patient and disability organizations with a goal of advancing principles of patient-centeredness in our evolving health care system. We understand that the rising cost of healthcare is a concerning issue that requires real solutions. We look forward to working with you and your fellow elected officials to manage health costs in a manner centered on meeting the health care needs of people with disabilities and chronic conditions. In doing so, we urge you to avoid policies, like those included in SB 2031, that rely on discriminatory metrics such as the Quality-Adjusted Life Year (QALY) that have detrimental implications for access to needed care and treatment.

We want to be sure that you are aware 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. 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. Due to these discriminatory implications, Republicans in the House of Representatives [introduced a bill](#) in 2022 that would ban the use of the QALY in all state and federal programs; and Representatives McMorris Rodgers and Brady recently sent a [letter](#) to Secretary Becerra explicitly asking for confirmation that QALYs (either directly or by referencing foreign pricing structures) would not be used in the implementation of the Inflation Reduction Act.

SB 2031 would reference rates of prescriptions drugs from a third party, the Canadian government, which relies on the QALY for coverage and reimbursement decisions.¹ The bill directly references the prices paid for drugs in four Canadian provinces. Before applying for coverage by the provinces, all drugs must complete a Common Drug Review by CADTH, which uses QALYs. The result of this is that in Canada many individuals living with disabilities are unable to receive the treatments and care they need.²

In 2019, the National Council on Disability issued a report finding that use of the QALY would be contrary to United States civil rights and disability law. The report was direct in recommending that the United States should not reference prices established in other countries that rely on the use of the QALY.³

¹https://cadth.ca/sites/default/files/pdf/guidelines_for_the_economic_evaluation_of_health_technologies_canada_4th_ed.pdf

² <https://valueourhealth.org/wp-content/uploads/2020/04/Canada.pdf>

³ https://ncd.gov/sites/default/files/NCD_Quality_Adjusted_Life_Report_508.pdf

The United States has a thirty-year, bipartisan track record of opposing the use of the QALY and similar discriminatory metrics and establishing appropriate 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.⁴ Title II of the Americans with Disabilities Act (ADA) extended this protection to programs and services offered by state and local governments.⁵ 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.⁶ The Affordable Care Act (ACA) 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.”⁷ 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).”⁸ 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 when designing or participating in value-based payment arrangements.⁹

We hope that you will bear in mind these legal protections under existing health and civil rights laws as you work on policies to reduce the cost of care for beneficiaries. We would be happy to work with you and bring appropriate patient stakeholders to the table as you explore policies to meaningfully lower the cost of health care while maintaining patient access to needed treatments.

Sincerely,

Thayer Roberts
Deputy Director
Partnership to Improve Patient Care

cc: Senate Human Services Committee

⁴ 29 USC Sec 794, 2017. Accessed November 30, 2020.

⁵ 42 USC Sec 12131, 2017. Accessed November 30, 2020.

⁶ Sullivan, Louis. (September 1, 1992). Oregon Health Plan is Unfair to the Disabled. *The New York Times*.

⁷ 42 USC Sec 1320e, 2017. Accessed November 30, 2020.

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

⁹ <https://www.federalregister.gov/d/2020-12970>