

March 24, 2026

Honorable Kirk Talbot
Chairman
Louisiana State Senate, Insurance committee
P.O. Box 94183
Baton Rouge, LA 70804

Dear Chairman Talbot:

I am writing on behalf of the Partnership to Improve Patient Care (PIPC) to urge the legislature to avoid policies such as proposed in SB 401 that would devalue disabled lives by referencing measures such as the Quality-Adjusted Life Year (QALY) that have detrimental implications for access to needed care and treatment. As an original author and sponsor of the Americans with Disabilities Act (ADA), I feel strongly that QALYs and similar measures devaluing disabled lives have no place in our health care system. Over 100 organizations representing patients and people with disabilities agree.¹

Since its founding in 2009, PIPC has been at the forefront of applying principles of patient-centeredness to the nation's health care system – from the generation of comparative clinical effectiveness research at the Patient-Centered Outcomes Research Institute (PCORI), to the translation of evidence into patient care in a manner that achieves value to the patient. Having driven the concepts of patient-centeredness and patient engagement in the conduct of research, PIPC looks forward to bringing the voices of patients and people with disabilities to the discussion of how to advance patient-centered principles throughout an evolving health care system.

Over the years, we have become increasingly concerned about proposed state policies that threaten to undermine existing federal law and regulation protecting people with disabilities from being devalued in health systems. SB 401 would establish a Prescription Drug Affordability Board to prepare an annual report on prescription drug prices listing prescription drugs that have a cost “excessively high,” to be determined using data on prices from other countries that value drugs based on QALYs and other research. The bill does not limit or prohibit the use of QALYs, directly or indirectly from entities such as the Institute for Clinical and Economic Review (ICER) and explicitly calls for reference to foreign countries that devalue disability. The bill provides no guidance to the Board on avoiding recommendations that may limit or restrict

¹ <https://files.constantcontact.com/e7a90be4701/2e199106-a152-4598-838b-1b08dce510c2.pdf>

access to care nor does the bill include legal safeguards against devaluing disabled lives or an engagement process for patients and people with disabilities to share their concerns, expertise and ideas.

Federal Law Bars Use of QALYs and Similar Measures

Regulations governing disability nondiscrimination protect patients and people with disabilities against being devalued in health systems and sends a strong message that we need better solutions for U.S. decision-making that don't rely on the biased, outdated standards historically used by payers. They bar health care decisions made using measures that discount gains in life expectancy, which would include QALYs and the equal value of life years gained (eVLYG). They are consistent with federal statute barring Medicare from using of QALYs and similar measures that that discount the value of a life because of an individual's disability in coverage and reimbursement decisions. The regulations also reflect the shared bipartisan perspectives that were communicated widely early in the COVID-19 pandemic, consistent with the first Trump administration taking action to enforce disability rights laws against state Crisis Standards of Care that would have put people with disabilities at the back of the line for care in a shortage.^{2,3}

QALYs and Similar Measures Used in Foreign Countries Devalue Disabled Lives

As drafted, SB 401 would reference drug prices in other countries, thereby importing their use of QALYs and similar measures to value treatments, an algorithm that devalues the patients and people with disabilities that stand to most benefit from innovation. Referencing other countries is contrary to federal laws governing disability discrimination due to their reliance on QALYs and similar measures.⁴ The bill's proposed policy would import these value standards from other countries and bring with it the same restricted access experienced in those countries.⁵ An analysis by the Office of Health Economics (OHE), the world's oldest independent health economics research organization, sheds light on this crucial issue, finding that almost 90% of OECD countries – 33 out of 38 – reference QALYs.⁶

² "We're concerned that crisis standards of care may start relying on value judgments as to the relative worth of one human being versus another, based on the presence or absence of disability," said Roger Severino, the director of the Office for Civil Rights. "We're concerned that stereotypes about what life is like living with a disability can be improperly used to exclude people from needed care." See <https://www.npr.org/2020/03/28/823254597/hhs-warns-states-not-to-put-people-with-disabilities-at-the-back-of-the-line-for>

³ <https://www.warren.senate.gov/imo/media/doc/2020.04.09%20Letter%20to%20HHS%20OCR%20re%20Rationing%20of%20Care.pdf>

⁴ https://www.pipcpatients.org/uploads/1/2/9/0/12902828/pipc_stakeholder_comment_on_importing_qalys.pdf

⁵ <https://www.pipcpatients.org/international.html>

⁶ <https://www.pipcpatients.org/news/the-data-mine-new-analysis-by-highlights-why-the-us-could-back-into-use-of-qalys-by-referencing-other-countries>

There is significant bipartisan opposition to QALYs and similar measures. Republicans have advocated strongly for new legal protections barring QALYs and similar measures across federal programs and Democrats supported the existing law barring reference to QALYs in Medicare decisions, as articulated in a recent joint opinion penned by me and the former Chair of the Energy and Commerce Committee, Cathy McMorris-Rodgers. We found common ground, stating, “The United States should not embrace health care rationing that de-prioritizes the health and wellness of people living with disabilities, or older adults or even infants.”⁷

PIPC encourages the legislature to reference the work of the National Council on Disability, an independent federal agency advising Congress and the administration on disability policy, which has consistently recommended against referencing foreign prices.⁸ Their report highlighted how QALYs lead to restricted or denied access to care for people with disabilities in other countries and warned that importing their use to the U.S. would be a threat to the disability community.⁹

In closing, we urge the Louisiana legislature to pause its consideration of this legislation and to consider alternative strategies that are focused on improving affordable access to care for people with disabilities and serious chronic conditions. Without safeguards, this PDAB could inadvertently convey that certain drugs treating disabling conditions are less valuable and impact their placement on formularies and coverage by health plans.

We appreciate your attention to our concerns.

Sincerely,



Tony Coelho
Chairman
Partnership to Improve Patient Care

cc: Senate Insurance Committee Members

⁷ <https://rollcall.com/2026/01/15/congress-should-ban-metric-that-devalues-people-with-disabilities/>

⁸ <https://www.ncd.gov/letters/2021-04-29-ncd-letter-to-house-committees-with-concerns-regarding-h-r-3/>

⁹ <https://www.ncd.gov/report/quality-adjusted-life-years-and-the-devaluation-of-life-with-a-disability/>