

February 8, 2021

Honorable Greg McCortney
Oklahoma State Senate
Chair, Committee on Health and Human Services
2300 N. Lincoln Blvd., Rm. 534 Oklahoma City, OK 73105

Dear Chairman McCortney:

As organizations representing people with disabilities, we are writing with regard to our concerns about legislation, S.B. 734, being considered in the State of Oklahoma that would import discriminatory pricing policies from Canada to the State of Oklahoma. The American Association of People with Disabilities (AAPD) is a national cross-disability rights organization, advocating for full civil rights for the over 56 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 is a coalition at the forefront of applying principles of patient-centeredness to the nation's health care system, including the translation of evidence into patient care in a manner that achieves value to the patient.

Last year, we applauded Oklahoma being the first state to enact legislation that barred quality-adjusted life years (QALYs) and similar metrics that devalue the lives and quality of life improvements for people living with disabilities.¹ The Nondiscrimination in Health Care Coverage Act prohibited the 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, including age or chronic illness, as a threshold to establish what type of health care is cost-effective or recommended." It also prohibited "utilizing such adjusted life year, or similar measure, as a threshold to determine coverage, reimbursement, incentive programs or utilization management decisions, whether it comes from within the agency or from any third party."

The legislation currently under consideration would reference rates for prescription drugs from a third party in Canada, where the Patented Medicine Prices Review Board explicitly establishes prices based on a cost-utility analysis model in which health outcomes are expressed as QALYs.² While we share the state's concerns about health care affordability, we are surprised that the state Senate is considering legislation that is so inconsistent with its recent strong stand against referencing third parties that use QALYs and similar metrics. It is our hope that the state will reconsider this direction.

¹ See <https://www.aapd.com/wp-content/uploads/2020/05/Oklahoma-QALY-Ban-Support-Statement-1.pdf>

² <https://www.canada.ca/en/patented-medicine-prices-review/services/legislation/about-guidelines/guidelines.html>

The independent federal agency, the National Council on Disability, has made strong recommendations to policymakers against referencing QALYs, including a recommendation not to reference prices established in other countries. The NCD stated in its 2019 report on QALYs, “Several of these countries utilize QALYs to make benefits and coverage decisions. The coverage denials and loss of access to care faced by people with disabilities in these countries illustrate what might happen if the United States made a similar choice.” Most recently, the NCD sent a letter to the Centers for Medicare and Medicaid Services on January 19, 2021, opposing an Interim Final Rule that would have referenced international prices in Medicare, stating, “Concerns about the discriminatory impact of the QALY on patients overseas led to its prohibition in the United States.”³ The Affordable Care Act of 2010 (ACA) prohibits the Secretary of HHS from using the QALY, or similar measure, to determine coverage, reimbursement, or incentive programs under the Medicare program.⁴ In addition, HHS’ regulation implementing Section 504 of the Rehabilitation Act prohibits discrimination on the basis of disability in all programs or activities conducted by HHS.⁵ Simply put, CMS cannot adopt foreign countries’ drug prices that are determined by reliance on the QALY for the Medicare program.” Similarly, NCD pointed out in its 2019 report that Section 504 and Section 1557 also apply to Medicaid programs because they receive federal financial assistance, calling for guidance on how these authorities apply to benefits and reimbursement decisions, and stating that payment decisions should not rely on cost-effectiveness research or reports that are developed using QALYs.⁶

Therefore, we hope that the Oklahoma Senate Committee on Health and Human Services will not allow this legislation to advance, and instead work closely with stakeholders from the disability community on solutions that value disabled lives. We applaud your work to protect people with disabilities and chronic conditions from policies that would otherwise devalue their lives, especially during the pandemic.

Sincerely,

Maria Town, American Association of People with Disabilities (mtown@aapd.org)
Rylin Rodgers, Association of University Centers on Disabilities (rrodgers@aucd.org)
Tony Coelho, Partnership to Improve Patient Care (tony@pipccpatients.org)

³ See <https://ncd.gov/publications/2021/ncd-letter-cms-most-favored-nation-rule>

⁴ Patient Protection and Affordable Care Act, Pub. L. 111–148, title VI, § 6301(c), Mar. 23, 2010 (codified at 42 U.S.C. 1320e-1)(e).

⁵ Enforcement of Nondiscrimination on the Basis of Handicap in Programs or Activities Conducted by the Department of Health and Human Services, 45 C.F.R. Part 85 (1988).

⁶ See https://ncd.gov/sites/default/files/NCD_Quality_Adjusted_Life_Report_508.pdf (page 15)