



## Disability Rights Organizations Oppose Washington State SB 5020

On behalf of people with disabilities, the American Association of People with Disabilities and the American Association of University Centers on Disabilities are deeply concerned that Washington State Senate Bill SB 5020 explicitly references value assessments that are developed in reliance on the discriminatory quality-adjusted life (QALY) year metric. For 30 years, advocates in the disability community have advocated against the use of discriminatory metrics to assess the value of health care and how it will be covered and reimbursed in federal programs, including Medicaid. In 1992, we were successful in advocating against QALYs when Oregon proposed their use in a Medicaid waiver application to determine the prioritized list of services, with strong statements from the Secretary of the U.S. Department of Health and Human Services acknowledging how they violated the Americans with Disabilities Act that had just passed in 1990.<sup>1</sup> We were later successful in advocating for the Affordable Care Act to bar their use in Medicare.<sup>2</sup> At the federal level, there is bipartisan recognition that discriminatory metrics such as QALYs have no place in federal health care programs.<sup>3</sup>

Therefore, we urge the Washington State legislature to avoid policies that would reduce health spending through policies that discriminate. Instead, we would urge Washington State to pass legislation defending the equal dignity of people with disabilities by banning the use of the

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

<sup>2</sup> 42 USC Sec 1320e, 2017 and 42 USC Sec 1320e, 2017.

<sup>3</sup> Colloquy by Senators Baucus, Enzi, Conrad, Hatch, Carper and Menendez. "Comparative Effectiveness Research Funds." *Congressional Record* 155:24 (February 6, 2009) p. S. 1796.

Article submitted by Senator Blunt (OH). "Health Care Debate." *Congressional Record* 155: 101 (July, 8, 2009) p. H7829. (Of NICE and Men. *Wall Street Journal*, July 7, 2009.)

Senator Kyl (AZ). "Statements on Introduced Bills and Joint Resolutions." *Congressional Record* 155: 89 (June 15, 2009) p. S6584.

discriminatory QALY metric and requiring the state to consult with disability organizations, including self-advocacy groups, prior to making decisions on coverage, reimbursement, and utilization management. QALYs devalue the lives of people with disabilities by discounting disabled life relative to non-disabled life and failing to account for the value of outcomes that are meaningful to people living with a disabling condition. Therefore, we are deeply concerned to see states considering adoption of QALY-based analyses to slash costs by limiting access to essential medication for people with disabilities.

Please consider the positions of federal policymakers and thought leaders that have concluded that discriminatory metrics such as QALYs have no place in our federal programs, and in fact are subject to civil rights laws. Members of Congress on both sides of the aisle expressed concern with the use cost effectiveness analyses in Medicare during consideration of the Affordable Care Act. The DNC Platform states that Democrats will “ensure that people with disabilities are never denied coverage based on the use of quality-adjusted life year (QALY) indexes” and commits to ensuring non-discrimination in access to health care, building on the protections for people with disabilities enshrined in the Affordable Care Act.<sup>4</sup> Notable progressive Democratic Senators like Senator Elizabeth Warren, in a letter to the Office for Civil Rights opposing COVID-19 discrimination against people with disabilities, recognized that “traditionally, American health care policy and treatment approaches have largely been driven by the concepts of cost-effectiveness analysis (CEA) and quality-adjusted life year (QALY). But these approaches are inherently discriminatory. They devalue the life of people with disabilities and older adults.”<sup>5</sup> You may also have noted that recently, the Centers for Medicaid and Medicaid Services stated in a final rule, “In accordance with legal obligations under section 504 of the Rehabilitation Act, the Americans with Disabilities Act, the Age Discrimination Act, and section 1557 of the Affordable Care Act, manufacturers and payers, including state Medicaid agencies, may not make use of measures that would unlawfully discriminate on the basis of disability or age when designing or participating in VBP arrangements.”<sup>6</sup> Additionally, the HHS Office for Civil Rights has issued a Request for Information as they prepare guidance or rulemaking on the application of civil rights laws to the use of discriminatory metrics that underpin value assessment.<sup>7</sup> The National Council on Disability provided a comprehensive report recommending that civil rights laws be enforced against the use of QALYs and that they be avoided in federal programs, including Medicaid due to their implications for discrimination.<sup>8</sup>

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<sup>4</sup> DNC Platform at page 32. See <https://www.demconvention.com/wp-content/uploads/2020/08/2020-07-31-Democratic-Party-Platform-For-Distribution.pdf>

<sup>5</sup> See [https://www.warren.senate.gov/imo/media/doc/2020.04.09 Letter to HHS OCR re Rationing of Care.pdf](https://www.warren.senate.gov/imo/media/doc/2020.04.09%20Letter%20to%20HHS%20OCR%20re%20Rationing%20of%20Care.pdf)

<sup>6</sup> *Medicaid Program; Establishing Minimum Standards in Medicaid State Drug Utilization Review (DUR) and Supporting Value-Based Purchasing (VBP) for Drugs Covered in Medicaid, Revising Medicaid Drug Rebate and Third Party Liability (TPL) Requirements*, 85 FR 87000 (December 31, 2020) page 87013-87014.

<sup>7</sup> See <https://www.hhs.gov/sites/default/files/504-rfi.pdf>

<sup>8</sup> 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](https://ncd.gov/sites/default/files/NCD_Quality_Adjusted_Life_Report_508.pdf).

We would remind Washington State legislators that 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.<sup>9</sup> Title II of the Americans with Disabilities Act (ADA) extended this protection to programs and services offered by state and local governments.<sup>10</sup>

Therefore, we strongly urge Washington State to reconsider SB 5020 and instead work with disability advocates on solutions to reduce health spending that do not violate our civil rights, especially in the middle of a deadly pandemic.

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<sup>9</sup> 29 USC Sec 794, 2017.

<sup>10</sup> 42 USC Sec 12131, 2017.