

Template Letter

State-Based Advocates to Governors, State Medicaid Directors, Legislators and/or Policy Boards/Commissions

[DATE]

[ADDRESS BLOCK]

Dear XX,

[If legislation or regulations under consideration, add reference to it]

We understand that the rising cost of healthcare is a concerning issue that requires real solutions. As organizations representing patients and people with disabilities, the affordability of health care is a significant priority and we look forward to working with state policymakers 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 the state to avoid policies that would potentially violate federal laws against discrimination, including new regulations governing Section 504 of the Rehabilitation Act, by relying 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 state policymakers are aware that referencing discriminatory metrics such as QALYs, whether related to QALY-based decisions from foreign governments or to value assessments conducted by the Institute for Clinical and Economic Review (ICER), is both discriminatory and likely a violation of existing civil rights laws. 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. We encourage you to review the report from the National Council on Disability, an independent federal agency, recommending that policymakers avoid referencing or importing the QALY from other countries (such as Canada), clarifying that its use in public programs would be contrary to United States civil rights and disability policy.¹

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. In 1973, Congress passed Section 504 of the Rehabilitation Act to ensure that people with

¹ 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.

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.² Title II of the Americans with Disabilities Act (ADA) extended this protection to programs and services offered by state and local governments.³ In 2024, final regulations governing Section 504 explicitly barred use of “any measure, assessment, or tool that discounts the value of life extension on the basis of disability to deny or afford an unequal opportunity to qualified individuals with disabilities with respect to the eligibility or referral for, or provision or withdrawal of any aid, benefit, or service, including the terms or conditions under which they are made available.”⁴

Also, 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 base coverage decisions on cost effectiveness measures that give a lower value to people with disabilities.⁵ In 2020, 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 purchasing arrangements.⁶

In 2010, the Affordable Care Act (ACA) directly stated that the Secretary of Health and Human Services (HHS) 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 would attribute a lower value to extending the lives of older adults, people with disabilities or people with a terminal illness.⁷ Additionally, the ACA specifically prohibits QALYs and similar metrics from being used by HHS as a threshold to establish what type of health care is cost effective or recommended, as well as prohibiting their use as a threshold in Medicare to determine what is covered, reimbursed or incentivized.⁸

Alternatively, we urge policymakers to meaningfully engage patients and people with disabilities in decisions related to healthcare reimbursement, coverage and utilization management decisions. While patient representatives are now included in Exchange Plan P&T committees,⁹ patients and people with disabilities are not represented on other state boards and committees, nor are opportunities for patient input meaningful in their decisions. It is well recognized that patient perspectives are needed to understand the value of healthcare and its

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

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

⁴ 89 FR 40066, § 84.57

⁵ Sullivan, Louis. (September 1, 1992). Oregon Health Plan is Unfair to the Disabled. *The New York Times*.

⁶ <https://www.federalregister.gov/d/2020-12970>

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

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

⁹ 89 FR 26218

impact on outcomes that matter to them, both from individual patients and their representative organizations with expertise in the life cycle of a disease or condition.

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 and urge you to advance robust opportunities for engaging patients and people with disabilities. We stand ready to work with you on appropriate policies that do not discriminate or limit access to needed care and treatment. Please reach out to **CONTACT** at **PHONE/EMAIL** if you would like to discuss in more depth.

Sincerely,