



March 16, 2023

Dear Members of the Senate Health & Human Services Committee,

We understand that the rising cost of healthcare is a concerning issue that requires real solutions. ALS is a quickly progressing condition that requires complex care, so the affordability of health care is a significant priority. 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 have the potential to discriminate against our patient population 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 are concerned that SF 168 would do just that and cannot support it in its current form.

At this point we have seen many states enact policies that create drug pricing review boards or commissions. In other states, like New York and Massachusetts, we have seen that, without proper patient protections, the newly formed board turns to the use of value assessments that rely on quality-adjusted life years (QALY) and similar metrics or even to directly contract with entities such as the Institute for Clinical and Economic Review (ICER) that refer to QALYs as the “gold standard.”

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 potentially in 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. 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

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.

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 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.⁴ The Affordable Care Act (ACA) passed under President Barack Obama directly states 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.⁵ 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.⁶

If you continue to consider this type of legislation, it is imperative that you include robust protections for patients and people with disabilities. These include standards for research used in decision-making, opportunities for engagement from patient and disability stakeholders, a ban on discriminatory metrics including the QALY modeled on the existing law barring the use of QALYs in the Medicare program, and a physician override mechanism to assure that such decisions do not trump the judgement of clinicians.

We hope that you will bear this in mind and not, in an attempt to help patients, pass legislation that, in reality, discriminates against them and makes accessing the care they need more challenging. Please do not hesitate to reach out to discuss.

Sincerely,



Sarah Sanchez
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The ALS Association

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

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

⁴ Sullivan, Louis. (September 1, 1992). Oregon Health Plan is Unfair to the Disabled. The New York Times.

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

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