

July 21, 2021

The Honorable Jim Wood
California State Assembly
P.O. Box 942849
Sacramento, CA 94249-0002

RE: Office of Health Care Affordability Proposal

Dear Assemblymember Wood:

We understand that the rising cost of healthcare is a concerning issue that requires real solutions. As organizations representing patients and people with disabilities, chronic conditions, and rare diseases 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 discriminate against patients with disabilities, chronic conditions, and rare diseases by relying on inequitable metrics such as the Quality-Adjusted Life Year (QALY) that have detrimental implications for access to needed care and treatment by explicitly barring their use in health care decisions.

We are aware that your bill, AB 1130, is under consideration by the California legislature – or may advance as a budget trailer bill – to establish, within OSHPD, the Office of Health Care Affordability to analyze the health care market for cost trends and drivers of spending, develop data-informed policies for lowering health care costs for consumers, set and enforce cost targets, and create a state strategy for controlling the cost of health care and ensuring affordability for consumers and purchasers. We believe it is essential that people with disabilities chronic conditions, and rare diseases—those who would be most impacted by these policies—are able to have a robust voice in the development of this legislation and specifically on the Office of Health Care Affordability’s Advisory Board. If created, the undersigned organizations representing patients and people with disabilities, chronic conditions, and rare diseases would like to be resources to the Board as it strives to make balanced decisions and avoid unintended consequences for patient access to needed care.¹

We are writing to share information about QALYs and to advocate for provisions to be included that would bar their use by the Board in deliberations about the effectiveness of treatments and services. As you may know, entities that review the cost and benefit of health care often rely on QALYs and some even call QALYs the “gold standard.”² Yet, referencing discriminatory metrics such as QALYs can potentially violate existing civil and disability rights laws. Therefore, we propose the following amendments to AB 1130:

- Amendment 1: on page 26, after line 11, insert: “(9) Minimize impact on access to care with specific consideration of the impact on persons with disabilities, chronic illness, and rare diseases.”
- Amendment 2: on page 29, after line 38, insert: “(n) The Office or Board shall not develop or utilize, directly or indirectly through a contracted entity or other third-party, a dollars-per-

¹ <https://ncd.gov/newsroom/2021/NFO-state-use-qaly-based-cost-effectiveness-reports>

² <https://icer.org/news-insights/press-releases/icer-describes-qaly/>

quality adjusted life year or any similar measures in determining cost targets or developing policies or programs.”

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 the QALY, clarifying that its use in public programs would be contrary to United States civil rights and disability policy.³ Most recently, the National Council on Disability initiated work to review how states may be using QALYs and their implications for restricting access to care.⁴

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 discrimination,” under any program offered by any Executive Agency, including Medicare.⁵ Title II of the Americans with Disabilities Act (ADA) extended this protection to programs and services offered by state and local governments.⁶ Based on the ADA’s passage in 1990, in 1992, HHS rejected a state waiver application because its reliance on QALYs and cost effectiveness standards would have violated the ADA and lead to discrimination against people with disabilities in determining the state’s prioritized list of services.⁷

In 2010, the Affordable Care Act (ACA) 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.⁸ 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.⁹ Most recently, 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 VBP arrangements.¹⁰

Along with the organizations below, we hope that you will engage patients and people with disabilities, chronic conditions, and rare diseases in your current process and bear in mind these legal protections under health and civil rights laws as you pursue the worthwhile policies included in AB 1130. We appreciate the important work you are doing and stand ready to work with you on appropriate policies

³ 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.

⁴ <https://ncd.gov/newsroom/2021/NFO-state-use-qaly-based-cost-effectiveness-reports>

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

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

⁷ Sullivan, Louis. (September 1, 1992). Oregon Health Plan is Unfair to the Disabled. The New York Times.

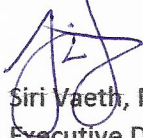
⁸ 42 USC Sec 1320e, 2017. Accessed November 30, 2020.

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

¹⁰ <https://www.federalregister.gov/d/2020-12970>

that do not discriminate or limit access to needed care and treatment. We would be happy to discuss our concerns and the experiences of patients and people with disabilities. Please reach out to Siri Vaeth or Liz Helms if you would like to discuss in more depth.

Sincerely,



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