March 12, 2026

Majority Leader Scott Surovell
General Assembly Building
Room No. 1405
Senate of Virginia
P.O. Box 396
Richmond, VA 23218

Minority Leader Ryan McDougle
General Assembly Building
Room No. 1406
Senate of Virginia
P.O. Box 396
Richmond, VA 23218

Dear Majority Leader Surovell and Minority Leader McDougle:

The Partnership to Improve Patient Care (PIPC) is writing to share the concerns of patients and people with disabilities related to HB 483 and SB 271 as amended. The patient and disability communities have in the past shared concerns about the Commonwealth's efforts to establish a Prescription Drug Affordability Board, which would have allowed for reference to value assessments of new health innovations using quality-adjusted life years (QALYs) and similar measures.[1] We remain concerned with the concept of relying on Medicare's Maximum Fair Price (MFP), as it carries many of the same risks for patients and people with disabilities.

Reference to Maximum Fair Price is Not a Solution

We are concerned that Virginia is considering a policy alternative to automatically set Medicare's "maximum fair price" as the upper payment limit (UPL) for drugs purchased in Virginia which have had a price negotiated at the federal level. By doing so, the legislation removes opportunities for public input on potential access issues, raising concerns that treatment options will be limited and cost savings for beneficiaries will not be guaranteed.

By referencing Medicare drug prices, the state risks referencing the use of discriminatory measures of cost effectiveness, quality-adjusted life years (QALYs) and similar measures, on which CMS has in the past collected information to establish these "maximum fair prices."[2] . The Medicare Drug Price Negotiation Program, under which MFPs are created, may indirectly rely on QALYs due to its consideration of cost effectiveness analyses from the Institute for

[1] https://www.hca.wa.gov/assets/program/pdab-portal-slides-september-18-2024.pdf
[2] https://aesara.com/wp-content/uploads/2025/05/10-Poster-Is-the-IRA-Drug-Price.pdf

Clinical and Economic Review (ICER), international prices, or other studies using QALYs and similar measures to value health care. There is a significant lack of transparency in the explanations for establishing these prices, although the explanations do explicitly reference studies that are based on QALYs.[3]

Such a policy also raises significant concerns for the patient and disability communities that have long fought for a seat at the table in decisions related to health coverage and reimbursement policy and against health care discrimination. Virginia should have a process for considering how a reference to Medicare prices may impact patient access to care, particularly how it may lead to misuse of utilization management tools by payers. The impact of MFPs on access and utilization management has yet to be fully understood, but based on early indicators, we are concerned it will increase use of utilization management strategies that undermine access to the drug that patients and providers agree to be the most effective option, whether the negotiated drug or others in its class. Therefore, states should study and understand all the possible unintended consequences before advancing legislation.

SB 271 Fails to Meaningfully Bar the Use of QALYs and Similar Measures, which are barred by Federal Law

The Virginia bill still does not meaningfully bar the use of QALYs, which is equally important in legislation relying on MFP.

Reliance on QALYs and similar measures is barred by federal law and regulations. On May 9, 2024, the final new regulations governing Section 504 of the Rehabilitation Act were published, protecting the rights of people with disabilities in programs and activities receiving federal financial assistance.[4] The Partnership to Improve Patient Care (PIPC) and the 100 organizations and individuals that were supportive of rulemaking to bar the use of quality-adjusted life years and similar measures in decisions impacting access to care[5] were pleased to see the final rule, which represents a critical step forward in protecting patients and people with disabilities against being devalued in health systems and sends a strong message that we need better solutions for U.S. decision-making that don't rely on the biased, outdated standards historically used by payers. As described in the final rule, the new regulations would bar health care decisions made using measures that discount gains in life expectancy, which would include QALYs and the equal value of life years gained (evLYG). The agency broadly interpreted what constitutes the discriminatory use of value assessment in its description of the rule, stating, "The Department interprets recipient obligations under the current language of § 84.57 to be

[3] https://www.pipcpatients.org/uploads/1/2/9/0/12902828/pipc_ipay_2028_comment_letter.pdf
[4] https://www.govinfo.gov/content/pkg/FR-2024-05-09/pdf/2024-09237.pdf?utm_campaign=subscription+mailing+list&utm_medium=email&utm_source=federalregister.gov
[5] https://www.pipcpatients.org/uploads/1/2/9/0/12902828/pipc_504_comment_final.pdf

broader than section 1182 of the Affordable Care Act, because it prohibits practices prohibited by section 1182 (where they are used 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 an aid, benefit, or service) and prohibits other instances of discriminatory value assessment." As you may be aware, section 1182 of the ACA bars Medicare's use of QALYs and similar measures that that discount the value of a life because of an individual's disability. PIPC was pleased that the final rules governing Section 504 would be interpreted by the agency as broader than the section 1182 statute.[6] The language of the new rule reflects the shared bipartisan perspectives that led to enforcement of disability rights laws against state Crisis Standards of Care that would have put people with disabilities at the back of the line for care in a shortage.[7,8]

The final rule referenced both § 84.56 and § 84.57 as relevant to entities receiving federal financial assistance, which includes state Medicaid programs. For example, the agency stated, "Methods of utility weight generation are subject to section 504 when they are used in a way that discriminates. They are subject to § 84.57 and other provisions within the rule, such as § 84.56's prohibition of discrimination based on biases or stereotypes about a patient's disability, among others." Therefore, it will be critical for compliance with these rules that the state understand the methods for generating the utility weights in any clinical and cost effectiveness studies that it may be using to make decisions to ensure they do not devalue people with disabilities. As PIPC and others noted in comments to HHS, studies have confirmed inherent bias against people with disabilities in the general public, finding much of the public perceives that people with disabilities have a low quality of life.[9] Therefore, the potential for discrimination is significant when measures rely on public surveys, as do QALYs and the evLYG.

Meaningful Engagement of Patients and People with Disabilities is Critical

[6] 89 FR 40066, "The Department interprets recipient obligations under the current language of § 84.57 to be broader than section 1182 of the Affordable Care Act, because it prohibits practices prohibited by section 1182 (where they are used 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 an aid, benefit, or service) and prohibits other instances of discriminatory value assessment."

[7] https://www.gillibrand.senate.gov/news/press/release/gillibrand-successfully-leads-bipartisan-bicameral-call-to-protect-civil-rights-for-people-with-disabilities-amidst-covid-19-pandemic-hhs-issues-new-guidance-to-health-care-providers-to-enhance-protec/

[8] "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." See https://www.warren.senate.gov/imo/media/doc/2020.04.09%20Letter%20to%20HHS%20OCR%20re%20Rationing%20of%20Care.pdf

[9] Ne'eman et. al, "Identifying and Exploring Bias in Public Opinion on Scarce Resource Allocation During the COVID-19 Pandemic," October 2022, https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2022.00504.

Alternatively, we encourage Virginia to engage directly with patients and people with disabilities to learn about their real-world experiences, consistent with recommendations from experts in the patient and disability communities.[10] For example, a coalition of patients came together to develop a new survey instrument to understand the affordability challenges facing patients and how to address them.[11] Despite these constructive efforts, other states have struggled and too often failed to meaningfully incorporate patient and disability perspectives in debates related to drug pricing and coverage, to respond meaningfully to questions and concerns or to establish safeguards against predictable unintended consequences for patient care.[12]

Conclusion

We can all agree that affordable access to health care is a significant priority. Therefore, state policymakers must manage health costs in a manner centered on both affordability and access to meet the differing health care needs of people with disabilities and chronic conditions. In doing so, PIPC urges Virginia to avoid policies that would potentially violate federal laws against devaluing people with disabilities and older adults, including new regulations governing Section 504 of the Rehabilitation Act, by relying on discriminatory metrics such as the QALY that have detrimental implications for access to needed care and treatment. We also urge the state to consider the implications of MFP reference pricing for formulary placement, delayed or denied care, and increased out-of-pocket costs for patients choosing the care their doctors prescribe and that best meets their health needs. We do not need more policies putting payers between decisions made by doctors and patients.

I hope that this information is useful. Thank you for your consideration.

Sincerely,

Thayer Roberts
Deputy Director
Partnership to Improve Patient Care

CC: Governor Abigail Spanberger

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[10] https://www.pipcpatients.org/resources/recommendations-for-enhancing-patient-engagement-strategies
[11] https://eachpic.org/patient-experience-revisited-what-patients-say-about-prescription-drug-affordability-and-policies-to-resolve-patient-hardships/
[12] https://www.healthaffairs.org/sponsored-content/national-minority-quality-forum/state-prescription-drug-affordability-boards-when-cost-takes-precedence-over-patient-health