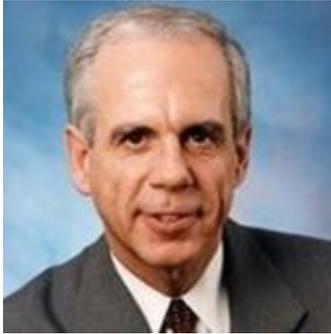


Chairman's Corner: New York's Embrace of Discriminatory Value Assessments is a Call to Action!

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The final New York budget is complete. And now we know for sure that states feel empowered by this administration to discriminate in their Medicaid programs. I had hoped that we were past these tactics to discriminate when, in 1992, HHS denied a state Medicaid waiver using quality-adjusted-life-years (QALYs) to determine its coverage because of its implications for violating the Americans with Disabilities Act (ADA) and when, in 2010, Congress banned use of QALYs in Medicare. But it looks like we are fighting this kind of discrimination state-by-state now.

I have spent my life working to amplify the voices of patients and people with disabilities under the mantra of “nothing about us without us.” I am disappointed that New York chose to move forward without us, but I am proud that advocates in New York raised awareness for our cause.

To recap the activity in New York, [a letter was circulated by CancerCare](#) with 45 signatures showing widespread opposition to the use of third party value assessments, especially those relying on quality-adjusted-life-years (QALYs) and similar metrics, as the basis for denying or restricting access to care in the State of New York. The letter made it clear that patients and people with disabilities oppose one-size-fits-all definitions of value being used to create arbitrary thresholds in state healthcare systems, especially when they rely on discriminatory methods, such as the quality-adjusted-life-year (QALY). The New York Executive and Assembly bills included language codifying authority to use QALY-based value assessments by third parties such as the Institute for Clinical Economic Review (ICER). The New York Senate included more favorable language banning use of biased discriminatory assessments that are not transparent.

I am very disappointed the final merged budget did not bar the use of discriminatory, biased assessments that are not transparent. It included language calling for third party value assessments to disclose their funding and be transparent “if reasonably possible”

in their methods. But no state should find language barring discrimination to be a bridge too far. Doing so should be commonsense if indeed their goal is to value our health.

Going forward, the Partnership to Improve Patient Care (PIPC) will work harder to amplify the voices of advocates calling on policymakers to value our health. It will take your leadership, your guidance and your time to fight back against emerging threats at the state and federal level to restrict access to care based on discriminatory value assessments from groups like ICER. We have to ask, "Value to whom?" Because when value assessments based on averages are applied to coverage decisions, we get caught in the middle without access to care. We know different people respond differently to the same treatments. We know one size does not fit all. And we are going to fight back against anyone that tries to say that value is a one-size-fits-all proposition.

I hope you will join PIPC in this fight by sharing your experiences with us and letting us know how we can support *your* work to convince policymakers to value our health.