

PATIENTS AND PEOPLE WITH DISABILITIES CALL FOR REPRESENTATION AND PATIENT PROTECTIONS IN DRUG REVIEW BOARDS AND COMMISSIONS

State Drug Review Boards: Many states have or are considering adoption of a drug review board or commission. These boards have differing names from state to state but their goal is to allow the state to review and evaluate the reimbursement rate and/or coverage for pharmaceuticals. Most have fairly broad parameters of how they can assess a drug's value, and specifically permit the state to rely on third-party research or contract directly with a third-party for the purpose of fulfilling its duties. As has happened in other states such as New York and Massachusetts, without patient protections, these bills allow the new state board or commission to reference 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."

The Quality-Adjusted Life Year is a Discriminatory Metric: The quality-adjusted life year, or QALY, is a metric commonly used to determine the value of a health care treatment. To calculate a QALY, the formula assigns a value to a person's life and to the incremental improvement in quality of life with treatment. The value assigned to seniors, the chronically ill, or people with disabilities is lower than that of a young, healthy person and does not capture how people living with a condition value quality of life improvements. Therefore, QALYs often lead policymakers and payers to conclude that treatments for seniors, patients with chronic conditions or people with disabilities are not worth it.

Protect Patients and People with Disabilities from Discrimination: As states consider legislation that would establish a drug review board or commission, it is important to include patient protections. 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. Value Our Health has developed template legislation for consideration in states to achieve these goals.

Representation of Patients and People with Disabilities: Nothing about us without us has long been the ethos of the disability community. As decisions are being made about coverage and access to treatments that will largely impact patients and people with disabilities, it is essential that they have a seat at the table. Any state forming a board or commission should ensure that it has seats specifically dedicated to patients and people with disabilities.