

February 6th, 2019

Executive Office of Health and Human Services
1 Ashburton Place, Boston, MA 02108

Dear Governor Baker, Secretary Sudders and Assistant Secretary Tsai,

We, the undersigned organizations representing Massachusetts' disability, aging, and healthcare advocacy community, write in response to the proposal to control prescription drug costs that was included in the Governor's budget proposal. We would firstly like to express our gratitude to state officials for listening to the concerns of our communities regarding access to vital medications. We are enthusiastic to see the state proceeding with a strategy that does not rely on closing the Medicaid drug formulary or on imposing excessive utilization management. Such measures would have undermined MassHealth's longstanding commitment to low-income Massachusetts residents and been profoundly harmful to people with disabilities and chronic illnesses, subjecting them to burdensome bureaucracy at best and severe or even life-threatening health issues at worst.

Instead, Massachusetts has decided on other approaches, ones meant to emphasize transparency and public accountability as tools to bring down prices, ones that will hopefully set a national standard. We have high hopes that transparency and accountability will help to control medication costs. We also believe the Commonwealth could take further actions to reduce drug prices without harming consumers, such as through reining in Prescription Benefit Managers (PBMs) and requiring them to pass along a greater share of rebates to consumers, importing drugs from Canada, or joining with other states to pursue intellectual property reform for drugs. As a community, we hope to be a part of holding drug manufacturers to account and keeping medication affordable.

However, we remain concerned about the metrics that will be used to set the proposed value of drugs as described in Section 48. In particular, we wish to express our opposition to any use of Quality Adjusted Life Years (QALYs) to determine the value of prescription drugs. QALYs are described as an objective measure that captures the total value of individuals' lives, accounting for both the number of years they live and the quality of those years. Unfortunately, QALYs measure the quality of life by the presence or absence of disabilities. QALYs grossly underestimate the quality of life of people with disabilities.

QALYs measure the value of the lives of people with disabilities as a percentage of the value of the lives of people without disabilities, thus utterly misrepresenting the lived experiences of people with disabilities. This misrepresentation has potentially harmful consequences for both disease mitigation and life-extension. While recent proposals to modify QALYs to address concerns regarding the value of extending the lives of persons with disabilities are a positive development, QALYs still depend on a discriminatory and arbitrary approach to the measurement of quality of life, often relying upon broad population surveys that query how people perceive the impact of disability or chronic illness. This public perception does not reflect the value that people with disabilities or chronic illnesses place on their own lives and their ability to obtain healthcare, including needed medications.

QALYs are based on stigma, not science. Disability rights advocates have long opposed the use of QALYs as discriminatory, as has the federal government. The Affordable Care Act prohibited the use of QALYs in Medicare and within the ACA's Patient Centered Outcomes Research Institute (PCORI). In the 1990s, HHS rejected a proposal from the State of Oregon to use QALYs in their Medicaid program because it would have violated the ADA. Under a QALY-based model, individuals with cystic fibrosis, rheumatoid arthritis, spinal muscular atrophy and a wide variety of other conditions that require ongoing medication to manage symptoms would be put at a distinct disadvantage. We oppose any introduction of QALYs to the Massachusetts health-care system and any partnership with entities that rely on them. We ask the state to affirmatively adopt a policy that state entities will not use QALYs for any purpose related to healthcare analysis or decision-making

Finally, because the Governor's budget proposal significantly expands the role and authority of the Health Policy Commission, we feel it is vital that it include those who will be most affected by Commission decisions—specifically people with disabilities and complex care needs. We therefore ask that a seat be created on the Commission that is filled by a representative of an organization representing people with disabilities and complex care needs. As organizations with substantial expertise in these issues, including the lived experience of both our clients and our own staff members, we are ready and willing to advise you on how healthcare costs can be controlled in ways that do not target many of Massachusetts' most vulnerable residents. For example, the preservation and expansion of long-term services and supports (LTSS) and increasing insurer responsibility to effectively address social determinants of health, serve to promote independence and improved quality of life *and* to reduce healthcare expenditures.

Please accept our Coalition's offer to work with you to address the issues of both quality and cost of healthcare in the Commonwealth. It is imperative that we not pursue cost-cutting measures that are discriminatory and hurt those most in need of care. Doing so would be inconsistent with our state's values and the values of the disability rights movement.

Sincerely,

Disability Policy Consortium

Mental Health Legal Advisors Committee

Boston Center for Independent Living

Disability Law Center

Disability Resource Center

Center for Living and Working

AdLib Inc.

Cape Organization for Rights of the Disabled

Easter Seals of Massachusetts

Stavros

Independence Associates

Metrowest Independent Living Center