



October 13th, 2023

Chairwoman Cindy F. Friedman
Joint Committee on Health Care Financing
24 Beacon Street
Room 313
Boston, MA 02133

Chairman John J. Lawn, Jr.
Joint Committee on Health Care Financing
24 Beacon Street
Room 236
Boston, MA 02133

**Re: H.1183/S.730, An Act Advancing Health Care Research and Decision-Making
Centered on Patients and People with Disabilities**

Dear Chairwoman Friedman and Chairman Lawn:

I am writing on behalf of the National Alliance on Mental Illness of Massachusetts (NAMI Mass) to support **H.1183/S.730, An Act Advancing Health Care Research and Decision-Making Centered on Patients and People with Disabilities**.

NAMI Mass is a grassroots nonprofit whose members, staff, and supporters are made up of individuals with mental health conditions, their families, loved ones, and caregivers. Our base is often immersed in the intricacies of our complex health care system, including biased presumptions based on Quality-Adjusted Life Year (QALY). This metric puts a lower value on treating seniors and people with disabilities and chronic conditions.

The Mental Health Foundation defines QALY as “a measure of the state of health of a person or group in which benefits, in terms of length of life, are adjusted to reflect the quality of life. One quality-adjusted life year (QALY) is equal to one year of life in perfect health.”¹ As we incorporate learnings from the pandemic into our systems, it is essential that basic protections are in place to ensure that all citizens of Massachusetts can access the care they need, not just those in “perfect” health.

Scientists and healthcare experts have underlined that using the Quality-Adjusted Life Year methodology has significant shortcomings^{2,3} when assessing the value of healthcare interventions, particularly for individuals with mental health conditions. This legislation addresses several critical issues that are paramount to ensuring equitable access to healthcare, including:

¹ McDaid, D., and Park, A. (2022). The economic case for investing in the prevention of mental health conditions in the UK. Mental Health Foundation. <https://www.mentalhealth.org.uk/sites/default/files/2022-06/MHF-Investing-in-Prevention-Full-Report.pdf>

² Pettitt, D., Raza, S., Naughton, B., Roscoe, A., Ramakrishnan, A., Ali, A., Davies, B., Dopson, S., Hollander, G., Smith, J., & Brindley, D. (2016). The limitations of QALY: a literature review. *Journal of Stem Cell Research and Therapy*, 6(4).

³ Sawhney, T. G., Dobes, A., & O'Charoen, S. (2023). QALYs: The Math Doesn't Work. *Journal of health economics and outcomes research*, 10(2), 10–13. <https://doi.org/10.36469/001c.83387>

- **Ban on QALY in Health Programs:** The most significant step proposed in this legislation is the ban on the use of QALY in Massachusetts' health programs. While the Affordable Care Act included a ban on the use of the QALY in Medicare, some Medicaid programs still used it as a cost-cutting measure. This action aligns with the concerns raised by the Biden Administration regarding the equity implications of methodologies like QALYs for individuals with disabilities and chronic conditions.
- **Patient-Centered Research:** H.1183 and S.730 mandate that Massachusetts ensures any research relied upon for decision-making meets standards of patient-centeredness. This mandate includes research that looks at patient subgroups, evaluates outcomes that matter to patients, and meets the requirement of scientific rigor. As an organization that centers the voices of individuals and families with lived experience, this is a much-needed improvement.
- **Appeals and Physician Override Mechanisms:** All policies must have an appeal and physician override mechanism to ensure that patients and their clinicians remain the ultimate decision-makers regarding their care. Physicians will additionally be protected from retaliation for using this mechanism. NAMI Mass promotes the values of agency and self-determination and thus believes this to be an essential aspect of the bill.

Thanks to these measures, NAMI Mass endorses **H.1183/S.730** as a vital step toward a more equitable and inclusive healthcare system for individuals living with mental health conditions in Massachusetts. This legislation aligns with the evolving understanding of healthcare evaluation and ensures that the diverse needs and experiences of individuals living with disabilities-including serious mental illness- are acknowledged and respected.

Thank you for considering our testimony and for your commitment to improving mental healthcare access for all residents of Massachusetts. We urge the committee to support and advance this critical legislation.

Sincerely,

A handwritten signature in black ink, appearing to read 'Myisha R. Rodrigues', with a stylized flourish at the end.

Myisha R. Rodrigues, PhD, LMHC

Executive Director, NAMI Massachusetts