



January 31, 2023

The Honorable Cathy McMorris Rodgers
Chairwoman
House Committee on Energy and Commerce
Washington, D.C. 20515

The Honorable Frank Pallone
Ranking Member
House Committee on Energy and Commerce
Washington, D.C. 20515

The Honorable Brett Guthrie
Chairman
House Committee on Energy and Commerce
Subcommittee on Health
Washington, DC 20515

The Honorable Anna Eshoo
Ranking Member
House Committee on Energy and Commerce
Subcommittee on Health
Washington, DC 20515

Dear Chairwoman Rodgers, Ranking Member Pallone, Chairman Guthrie, and Ranking Member Eshoo,

In service of the neuromuscular disease (NMD) patient community, the Muscular Dystrophy Association (MDA) is pleased to support the Protecting Healthcare for All Patients Act of 2023, which would prohibit the use of Quality-Adjusted Life Years (QALYs) in determining the benefit of medical interventions for patients with disabilities under Medicare and Medicaid. We appreciate the opportunity to provide the House Energy & Commerce Subcommittee on Health with information about how the use of QALYs adversely affects individuals living with neuromuscular diseases.

The Muscular Dystrophy Association (MDA) is the #1 voluntary health organization in the United States for people living with muscular dystrophy, ALS, and related neuromuscular diseases. For over 70 years, MDA has led the way in accelerating research, advancing care, and advocating for the support of our families. MDA's mission is to empower the people we serve to live longer, more independent lives.

Quality-Adjusted Life Years are used in health economic evaluations to quantify the health effect of a medical treatment and help payers allocate resources. QALYs evaluate how much a patient's life would improve from a given medical intervention, and for how long. However, the use of QALYs to determine the benefit of treatments for patients is flawed, as the "quality of life" metric relies on an inherently ableist and utilitarian concept of quality of life and assumes outcomes for able-bodied patients in perfect health. As an example, if a treatment results in one additional year of life in perfect health, that is counted as one QALY. If, however, a treatment buys an additional year of life for a patient with less than perfect health due to a neuromuscular disease, the QALY is reduced by a fraction determined by a subjective assumption of how that disease would reduce "perfect health." This can lead to the denial of treatments and interventions for patients with disabilities.

Such ableist assumptions about what constitutes a “good” quality of life in determining treatment effectiveness for patients with disabilities fail to consider other factors such as emotional well-being, the personal wishes, and aspirations of the patient, the will to live, the personal beliefs of the patient and more. Additionally, assessing “quality of life” through a subjective lens that places a higher value on people without disabilities only perpetuates prejudices within the medical profession and society writ large that see less worth and value in people with disabilities.

In 2019, the National Council on Disability (the Council) released a report entitled *Quality-Adjusted Life Years and the Devaluation of Life with Disability*¹, which found that continued devaluation of the lives of people with disabilities by society, the medical profession, and health economists leads to unequal access to medical care, poorer health outcomes, and reduced life expectancy for people with disabilities. As a result of these findings, the Council recommended Congress pass legislation to prohibit the use of QALYs in federally funded health programs.

The Protecting Healthcare Access for All Patients Act of 2023 reflects the recommendation made by the Council to prohibit the use of QALYs in Medicare and Medicaid. This bill is a great first step in recognizing that the lives of individuals with neuromuscular diseases and other disabilities are just as valuable as the lives of those without disabilities and will help address inequalities people with disabilities face in accessing healthcare.

MDA is proud to support this legislation, and we urge Members of the Energy and Commerce Health Subcommittee to support it. If you have any questions or desire additional information, please do not hesitate to contact me at mlewis@mdausa.org or (540) 447-9438.

Sincerely,

Michael Lewis

Michael Lewis
Director, Disability Policy
Muscular Dystrophy Association

¹ National Council on Disability (2019). *Quality-Adjusted Life Years and the Devaluation of Life with Disability*. Washington, DC: National Council on Disability.e