



July 13, 2023

The Honorable Kevin McCarthy
Speaker of the House
U.S. House of Representatives
Washington, D.C. 20515

The Honorable Hakeem Jeffries
Minority Leader
U.S. House of Representatives
Washington, D.C. 20515

Dear Speaker McCarthy and Minority Leader Jeffries,

The Consortium for Constituents with Disabilities (CCD) is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration, and inclusion of children and adults with disabilities in all aspects of society free from racism, ableism, sexism, and xenophobia, as well as LGBTQ+ based discrimination and religious intolerance. The undersigned members of CCD write to **urge you to support H.R. 485, the Protecting Healthcare for All Patients Act**, which would prohibit the use of Quality-Adjusted Life Years (QALYs) in federally funded healthcare programs.

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. QALYs devalue outcomes where a patient survives a health issue with a new disability or returns to a previous baseline state of health that includes disability. As an example, if a treatment results in a patient experiencing one additional year of life in perfect health, that is counted as 1 QALY. If, however, a treatment buys an additional year of life for a patient with less than perfect health due to a disability, the QALY is reduced by a fraction determined by a subjective assumption of how that disability would reduce "perfect health."

QALYs infuse treatment effectiveness decisions with an inherently ableist assumption about what constitutes a "good" quality of life because they discount the value of a year of life if it includes disability. This metric fails to consider other factors that influence quality of life, such as emotional well-being, the personal wishes and aspirations of the patient, will to live, the personal beliefs of the patient and more. Assessing "quality of life" through a subjective lens that places a higher value on people without disabilities 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 released a report entitled *Quality-Adjusted Life Years and the Devaluation of Life with Disability*, 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.

We recognize that many Members of Congress are concerned that the wording of H.R. 485 could jeopardize the authority granted to the Centers for Medicare and Medicaid Services by the Inflation Reduction Act to negotiate prescription drug prices. However, attorneys and policy experts at multiple disability rights organizations have reviewed the language and found such concerns to be unfounded. This bill is a great first step in recognizing the equal value of the lives of individuals with disabilities and will help address inequalities people with disabilities face in accessing healthcare.

We urge all Members of Congress to vote YES on H.R. 485. CCD looks forward to continuing to work with Congress to ensure that the bill is as strong and protective as possible for people with disabilities.

Sincerely,

Access Ready
ALS Association
American Association of People with Disabilities
American Association on Health and Disability
American Music Therapy Association
American Speech-Language-Hearing Association
American Therapeutic Recreation Association
Association of University Centers on Disabilities
Autism Society of America
Autism Speaks
Autistic People of Color Fund
Autistic Self Advocacy Network
Autistic Women and Nonbinary Network
CommunicationFIRST
Cure SMA
Disability Rights Education and Defense Fund
Epilepsy Foundation
Family Voices
Justice in Aging
Lakeshore Foundation
Muscular Dystrophy Association
National Alliance on Mental Illness
National Association of Councils on Developmental Disabilities
National Association of State Directors of Developmental Disabilities
National Center for Parent Leadership, Advocacy, and Community Empowerment
National Disability Rights Network
National Down Syndrome Congress
National Down Syndrome Society
RespectAbility

The Arc of the United States
The Partnership for Inclusive Disaster Strategies
United Spinal Association