

Disability Rights Education & Defense Fund

January 31, 2023
via electronic mail

The Honorable Cathy McMorris-Rodgers
Chair
Energy and Commerce Committee
US House of Representatives
Washington DC 20510

The Honorable Frank Pallone Jr.
Ranking Member
Energy and Commerce Committee
US House of Representatives
Washington, DC 20510

Re: Support for the Protecting Health Care for All Patients Act of 2023

Dear Chair McMorris-Rodgers and Ranking Member Pallone:

The Disability Rights Education & Defense Fund (“DREDF”) writes to support H.R.485, the Protecting Health Care for All Patients Act of 2023. The legislation prohibits the use of Quality-Adjusted-Life-Years (QALYs) and similar measures for determining coverage and payment decisions in federal health care programs, including Medicaid. Millions of people with disabilities and chronic conditions, across all ages and races/ethnicities in the US, are deeply impacted by how key federal programs such as Medicare, Medicaid, and CHIP make decisions on the effectiveness and value of health care treatments.

DREDF is a national cross-disability law and policy center that protects and advances the civil and human rights of people with disabilities through legal advocacy, training, education, and development of legislation and public policy. We are committed to increasing accessible and equally effective healthcare for people with disabilities and eliminating persistent health disparities that affect the length and quality of their lives. DREDF's work is based on the knowledge that people with disabilities of varying racial and ethnic backgrounds, ages, genders, and sexual orientations are fully capable of achieving self-sufficiency and contributing to their communities with access to needed services and supports and the reasonable accommodations and modifications enshrined in U.S. law.

At a time when federal and state governments face accelerating health care costs, DREDF appreciates the desire to have an “objective” means of evaluating the cost-effectiveness of current and new pharmaceutical treatments. Unfortunately, the QALY is **not** objective in how it purports to measure the value of a drug or therapy. This is because the QALY’s base value is rooted in how a treatment would extend the life of a person in perfect non-disabled health. QALY values are derived from the general public’s assignment of a score to living with such conditions as mobility limitations, self-care limitations, limits on engaging in usual activities, pain/discomfort, and anxiety/mental health. QALY values therefore doubly disadvantage individuals with disabilities and chronic conditions because the life years of disabled persons are automatically valued lower than the life years of non-disabled persons, and because most

members of the general public who are assigning value have negative stereotypes about the quality of life of people living with disabilities and chronic conditions.

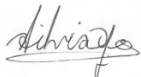
Moreover, QALY valuations have implications for racial/ethnic health equity as well given how disability is experienced among distinct population groups. For example, the Centers for Medicare and Medicaid Services states that American Indians and Alaskan Native (AI/AN) populations experience markedly higher rates of disability in the US, and are [50.3% more likely to have a disability compared to the national average](#). When Medicaid programs use QALYs to develop guidelines on the economic “worth” of a particular pharmaceutical or drug treatment, the impact of those guidelines cascade down to multiple public and private program payer decisions on whether to include the drug in formularies, and the terms of its coverage when it comes to cost sharing, prior authorization, and other utilization management techniques.

In 2021, DREDF issued a [legal memo](#) that detailed our opinion that the use of QALYs violates existing disability rights laws. We agree with the recommendations made by the National Council on Disability (NCD) in its 2019 report on [QALYs and the Devaluation of Life with Disability](#) that Congress should ban the use of QALYs in federal and state programs that receive federal financial assistance.

The Protecting Health Care for All Patients Act will turn the NCD recommendations into concrete action. DREDF recognizes that this act can be the latest example of Congress’ ability to achieve bi-partisan legislative victories on behalf of people with disabilities, from Section 504 of the Rehabilitation Act of 1973, through the Americans with Disabilities Act of 1990, to the Affordable Care Act of 2010 (ACA). The ACA stated that the Secretary of Health and Human Services could not deny coverage of items or services “solely on the basis of comparative effectiveness research” nor use such research in a manner that would attribute a lower value to extending the lives of older adults, people with disabilities or people with a terminal illness.

DREDF supports the Protecting Health Care for All Patients Act as an important step toward recognizing the rights of people with disabilities and chronic conditions to equally effective healthcare. We urge all members of Congress to join the decades-long bipartisan effort to advance the rights of people with disabilities. Please contact Silvia Yee at syee@dredf.org if you have any questions.

Sincerely,



Silvia Yee
Senior Staff Attorney