

January 31, 2023

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

The Arc writes to show our support for prohibiting the use of Quality-Adjusted-Life-Years (QALYs) and similar measures in coverage and payment determinations under federal health care programs. This is an issue that impacts all levels of health care and prohibiting the use of these measures will positively impact the lives of millions of Americans.

The Arc is the largest national community-based organization advocating for and serving people with intellectual and developmental disabilities (I/DD) and their families. We have more than 140,000 members and more than 600 state and local chapters nationwide. The Arc has a longstanding history of opposing the use of QALYs due to the discriminatory impact on people with Intellectual and Developmental Disabilities.

QALYs design inherently relays a deeply troubling message, a year of life with a disability is of lower quality and lower value than life without a disability. The disability rights movement seeks to highlight that people with disabilities have a right to be included in society and that they can have high quality lives. QALY-based assessments do not accurately account for outcomes related to people with relevant health conditions. Applying QALYs to health care decision-making can alter access to care. In fact, some people with disabilities and chronic illnesses are not seen as worthy enough to treat. We agree with the conclusions of the National Council on Disability, that Congress should disallow QALYs in state and federal health care programs.

The Protecting All Health Care for Patients Act will solidify a decades-long bipartisan track record of supporting disability rights in federal programs. Section 504 of the Rehabilitation Act of 1973 ensures that people with disabilities will not be "excluded from participation in, be denied the benefits of, or otherwise be subjected to discrimination," under any program offered by any Executive Agency. Title II of the Americans with Disabilities Act of 1990 extended this protection to programs and services offered by state and local governments. In 2010, the Affordable Care Act, stated that the Secretary of Health and Human Services (HHS) has no authority to deny coverage of items or services "solely on the basis of comparative effectiveness research" nor to 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. Finally, the Inflation Reduction Act prohibits the use of measures that devalues the lives of people with disabilities and others in Medicare prescription drug negotiations. Under both the Trump and Biden administrations, the HHS Office for Civil Rights has taken action on discriminatory allocation of health care resources.



The Arc urges you to support this important legislation and join the decades-long bipartisan initiative to advance the rights of people with disabilities.

Please contact Brittany Owens at owens@thearc.org with any questions or follow-up.

Sincerely,

Julie Ward Senior Executive Officer, Public Policy The Arc