



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

Dear Chair McMorris-Rodgers and Ranking Member Pallone:

The National Disability Rights Network (NDRN) writes to show our support for the Protecting All Health Care for Patients Act, to prohibit 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.

NDRN is the non-profit membership association of Protection and Advocacy (P&A) and Client Assistance Program (CAP) agencies located in all 50 States, the District of Columbia, and the United States Territories. In addition, there is a P&A and CAP affiliated with the Native American Consortium which includes the Hopi, Navajo, and San Juan Southern Paiute Nations in the Four Corners region of the Southwest.

P&A and CAP agencies are authorized under various federal statutes to provide legal representation and related advocacy services, and to investigate abuse and neglect of individuals with disabilities in a variety of settings. The P&A / CAP Network comprises the nation's largest provider of legally-based advocacy services for persons with disabilities. NDRN and the P&A / CAP Network have heard and write today to convey the concerns of people with disabilities, the P&A's and CAP's clients, on the use of QALYs.

The logic inherent in the QALY is concerning on its face: it is designed to measure the extent to which a year of life with a disability is of lower quality and lower value than life without a disability. The mission and vision of the P&A / CAP Network is to advocate that not only do people with disabilities have a right to participate in society, but that they can have high quality lives. QALY-based assessments also do not account for outcomes that matter to people living with the relevant health condition. When applied to health care decision-making, the results can mean that people with disabilities and chronic illnesses, including older adults, are deemed not worth the cost to treat. We agree with the conclusions of the National Council on Disability, an independent federal agency, 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, signed by President Nixon, 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, signed by President H.W. Bush, extended this protection to programs and services offered by state and local governments. In 2010, the Affordable Care Act, signed by President Obama, 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, signed by President Biden, prohibits the use of measures that devalue 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.

NDRN and the nationwide network of P&A and CAP agencies urges you to support this important legislation and join the decades-long bipartisan initiative to advance the rights of people with disabilities. Please contact Eric Buehlmann, Deputy Executive Director for Public Policy at [eric.buehlmann@ndrn.org](mailto:eric.buehlmann@ndrn.org) with any questions or follow-up.

Sincerely,

A handwritten signature in blue ink, appearing to read "Marlene Sells". The signature is fluid and cursive, with a long horizontal stroke extending to the right.

Executive Director  
National Disability Rights Network