

July 18, 2025

The Honorable Kat Cammack 2421 Rayburn House Office Building Washington, DC 20515 The Honorable Kevin Hern 171 Cannon House Office Building Washington, DC 20515

Dear Representatives Cammack and Hern:

The National Down Syndrome Society (NDSS) empowers individuals with Down syndrome and their families by driving policy change, providing resources, engaging with local communities, and shifting public perceptions. We write today in strong support of the passage of the *Protecting Health Care for All Patients Act of 2025* (H.R. 3864), which would protect patients in federal healthcare programs by ending the use of the Quality Adjusted Life Years (QALYs) and similar metrics that devalue the lives of people with disabilities.

QALYs attempt to measure the value of health outcomes by putting a numerical value on quality of life before and after health care treatments and interventions. Due to ill-conceived notions about the quality of life living with a disability, people with disabilities are frequently assigned a lower QALY value which invites further discrimination. Federal programs, such as Medicaid, frequently use these measurements to determine the cost-effectiveness of treatments and services, and thus coverage for patients. Because a substantial number of individuals with disabilities receive healthcare through Medicaid, this flawed metric denies access to necessary, and at times critical, healthcare treatments when they are not deemed "cost-effective" enough to administer to individuals with disabilities.

It is outright discrimination to deny individuals with disabilities access to treatment and care because a calculation determines their life is not worth the cost. NDSS stands in strong support of a nationwide ban on the discriminatory use of QALYs and similar measures in coverage and payment determinations under federal healthcare programs. Congress can take an important step toward ending this injustice by passing the Protecting Health Care for All Patients Act of 2025, which would prohibit QALYs and similar metrics that fail to account for those who do not fit arbitrarily determined standards of health.

NDSS envisions a world in which all individuals with Down syndrome are assured their human rights and valued by a more inclusive society. We urge Congress to pass this critical legislation for the disability community, and we thank you for your leadership regarding this important piece of legislation.

Sincerely,

Kandi Pickard President and CEO

National Down Syndrome Society

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