

Testimony before the  
United States House of Representatives Energy and Commerce Committee,  
Subcommittee on Health

Hearing Titled: *Lives Worth Living: Addressing the Fentanyl Crisis, Protecting Critical  
Lifelines, and Combatting Discrimination Against Those with Disabilities*

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Chairwoman Rodgers, Chair Guthrie, Ranking Member Eshoo, and Members of the Committee:

Thank you for inviting me to testify on Quality Adjusted Life Year (QALY) measures and combatting discrimination against people with disabilities. My name is Kandi Pickard and I proudly serve as the President and CEO of the National Down Syndrome Society (NDSS). NDSS is the leading human rights organization for all individuals with Down syndrome. We envision a world in which all people with Down syndrome have the opportunity to enhance their quality of life, realize their life aspirations, and become valued members of welcoming communities.

In my role at NDSS, I work closely with individuals with Down syndrome, their families, and members of the greater disability community. I have the privilege of seeing the Down syndrome community through many stages of life – from prenatal and birth diagnoses, many of which are delivered to new and expectant parents in a troubling manner, to adulthood and aging and the dignity that comes from living a full and meaningful life. I get the opportunity to see people with Down syndrome and other disabilities experience and accomplish life's greatest joys: attending school, getting their first paycheck, finding love, and more. I am also tasked with supporting our community through some of the most arduous circumstances: segregated workplaces and barriers to competitive integrated employment, heightened lifetime risk of developing Alzheimer's disease, and potentially the most life-threatening – being denied coverage or access to quality health care solely because they have a disability.

These experiences become even more real for me when I think of my ten-year-old son, Mason, who has Down syndrome. As a leader in the disability community, I advocate tirelessly against discrimination. As a mother, I fear that, one day, Mason's life will be devalued by an equation, and he will be denied needed health care because he has Down syndrome.

NDSS stands in strong support of a nationwide ban on the use of quality-adjusted life years (QALYs) and similar measures in coverage and payment determinations under federal health care programs, like the one proposed in the Protecting Health Care for All Patients Act of 2023. This bill is critical to preventing discrimination against individuals with disabilities and chronic conditions by prohibiting QALYs and similar metrics that fail to account for people who do not fit arbitrarily determined standards of health.

QALYs seek to measure the value of health outcomes by placing a numerical value on the quality of one's life before and after health care treatments and interventions. These indicators are often determined by individuals who do not understand the day-to-day life of a person with a disability and may consider them to be in a less valuable state of health than someone without a disability. Thus, people with disabilities are frequently assigned a lower QALY, opening the door for further discrimination.

These measurements are regularly used by federal programs, such as Medicaid, to determine the cost-effectiveness of treatments and services, and thus coverage for patients. Since a substantial number of individuals with disabilities receive their health care through Medicaid, this flawed and discriminatory metric directly impacts access to necessary, and at times critical, health care treatments when they are not deemed "cost-effective" enough to administer to individuals with disabilities.

NDSS is particularly concerned about the use of QALYs in response to Alzheimer's disease. People with Down syndrome are uniquely situated in the Alzheimer's landscape because they have an extra copy of chromosome 21. The 21<sup>st</sup> chromosome carries the amyloid precursor protein (APP) gene, which is strongly associated with the formation of amyloid peptides and plaques, a hallmark of Alzheimer's disease. As a result, individuals with Down syndrome have

an elevated lifetime risk – higher than 90 percent – for developing Alzheimer’s disease, with the onset of symptoms coming earlier and progressing faster than in the general population.<sup>1</sup> In fact, Alzheimer’s disease is the number one cause of death for individuals with Down syndrome.<sup>2</sup>

Access to and coverage of treatments for this life-altering disease is paramount for our community. Yet, in the Centers for Medicare & Medicaid Services (CMS) most recent National Coverage Decision (NCD) for Alzheimer’s treatments, a report from the Institute for Clinical and Economic Review (ICER) was used to inform coverage decisions that ultimately excluded the Down syndrome community from access and coverage of these drugs.<sup>3</sup> In ICER’s report, QALYs and similar one-size-fits-all approaches were used to determine the cost-effectiveness of such treatments. The lack of transparency around how people with disabilities were considered in these value assessments, and the lack of transparency from CMS on how this study affected their coverage decision, only reinforces the need for a QALY ban. Medicaid coverage decisions cannot be made based on flawed assessments that devalue the lives of people with disabilities. Especially when those lives are uniquely at risk.

Discriminatory metrics and value assessments are also experienced by individuals with disabilities in the organ transplant system, which is distinctly challenged by the fact that demand always far outweighs supply. Put simply, there are never enough organ donations to ensure that all patients who need organs can receive them. This in turn raises questions about which patients should receive organs and in what order. A 2019 report from the National Council on Disability (NCD), an independent federal agency advising Congress and the executive branch on disability

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<sup>1</sup> McCarron, M., et al. “A Prospective 20-Year Longitudinal Follow-up of Dementia in Persons with down Syndrome.” *Journal of Intellectual Disability Research*, vol. 61, no. 9, 2017, pp. 843–852., <https://doi.org/10.1111/jir.12390>.

<sup>2</sup> Hithersay, Rosalyn, et al. “Association of Dementia with Mortality among Adults with down Syndrome Older than 35 Years.” *JAMA Neurology*, vol. 76, no. 2, 2019, p. 152., <https://doi.org/10.1001/jamaneurol.2018.3616>.

<sup>3</sup> Synnott PG;Whittington MD;Lin GA;Rind DM;Pearson SD; “The Effectiveness and Value of Aducanumab for Alzheimer’s Disease.” *Journal of Managed Care & Specialty Pharmacy*, U.S. National Library of Medicine, <https://pubmed.ncbi.nlm.nih.gov/34714106/>.

policy issues, found that discrimination against people with disabilities persists in the organ transplant system rooted in biased attitudes about the value of the life of an individual with a disability.<sup>4</sup>

NDSS is proud to champion the bipartisan Charlotte Woodward Organ Transplant Discrimination Prevention Act, named after self-advocate and NDSS staff member Charlotte Woodward, which prohibits discrimination based solely on disability in the organ transplant system. While advocating for the passage of this bill, we remain vigilant in our response to other forms of value assessments, such as QALYs, that persist in many aspects of our healthcare system and threaten access to non-discriminatory health care for people with Down syndrome and other disabilities.

For decades, QALY prohibitions have been supported by a diverse group of stakeholders and a bipartisan group of lawmakers. In 1992, soon after the passage of the Americans with Disabilities Act, the Secretary of HHS publicly stated the discriminatory implications of QALYs.<sup>5</sup> In 2010, QALYs were barred from use in Medicare decisions related to coverage, reimbursement, and incentive programs.<sup>6</sup> In 2019, NCD released a report titled “Quality-Adjusted Life Years and the Devaluation of Life with Disability” as a part of their series on bioethics and disability.<sup>7</sup> In its report, NCD found sufficient evidence of the discriminatory effects of QALYs. Furthermore, as a part of their 2022 Health Equity Framework for People with Disabilities, NCD recommends that Congress “mandate a blanket prohibition on the use of Quality Adjusted Life Years by any federal agency, or recipients of federal financial assistance

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<sup>4</sup> “National Council on Disability First Report of Bioethics Series Examines Organ Transplant Discrimination, Calls on HHS OCR, DOJ to Issue Life-Saving Guidance.” NCD.gov, 25 Sept. 2019, <https://ncd.gov/newsroom/2019/NCD-bioethics-series-organ-transplant>.

<sup>5</sup> “Oregon Health Plan Is Unfair to the Disabled; Doesn't Single out Poor.” *The New York Times*, The New York Times, 1 Sept. 1992, <https://www.nytimes.com/1992/09/01/opinion/1-oregon-health-plan-is-unfair-to-the-disabled-doesn-t-single-out-poor-664092.html>.

<sup>6</sup> 111th Congress of the United States of America. (2010). H.R. 3590 The Patient Protection and Affordable Care Act. *Section 1182*. Washington, DC.

<sup>7</sup> National Council on Disability. Quality-adjusted life years and the devaluation of life with disability. (2019) at [https://ncd.gov/sites/default/files/NCD\\_Quality\\_Adjusted\\_Life\\_Report\\_508.pdf](https://ncd.gov/sites/default/files/NCD_Quality_Adjusted_Life_Report_508.pdf)

from the Department of Health and Human Services, both directly and through third-party assessments.”<sup>8</sup>

Patient and disability communities stand united in our advocacy to end the devaluation of the lives of people with disabilities through the use of QALYs and to remove barriers to accessing affordable and appropriate treatments and health care. As members of the Consortium for Constituents with Disabilities (CCD), NDSS presents a united voice with other organizations representing people with disabilities in affirming that a ban on QALYs is long overdue.

Every person is valuable. When I look at my son Mason, I see his value. I see value in his gummy smile when his favorite song is played. I see value in how hard he works at school to learn and keep up with his peers. I see value in the immense love his brothers and sister have for him. I see value in the joy he brings to the lives of our family and friends. Mason is no less valuable than my three children who do not have disabilities just because he has Down syndrome, and you would only need to meet him to know that for yourself.

It is outright discrimination to deny individuals with disabilities access to the treatment and care they deserve and need because a calculation determines their life is not worth the cost. Congress has the opportunity to take an important step toward ending this injustice with the passage of the Protecting Health Care for All Patients Act of 2023. I urge all members of this subcommittee to work in a bipartisan manner to pass this critical legislation. NDSS looks forward to working with the committee on common-sense health reforms that value patients and people with disabilities.

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<sup>8</sup> “National Council on Disability.” *Health Equity Framework*, <https://beta.ncd.gov/report/health-equity-framework/>.