



National Council on Disability

An independent federal agency making recommendations to the President and Congress to enhance the quality of life for all Americans with disabilities and their families.

April 29, 2021

The Honorable Frank Pallone
Chairman
Committee on Energy and Commerce
U.S. House of Representatives
2125 Rayburn House Office Building
Washington, DC 20515

The Honorable Bobby Scott
Chairman
Committee on Education and Labor
U.S. House of Representatives
2176 Rayburn House Office Building
Washington, DC 20515

The Honorable Richard Neal
Chairman
Committee on Ways and Means
U.S. House of Representatives
1102 Longworth House Office Building
Washington, DC 20515

The Honorable Cathy McMorris Rogers
Ranking Member
Committee on Energy and Commerce
U.S. House of Representatives
2322-A Rayburn House Office Building
Washington, DC 20515

The Honorable Virginia Foxx
Ranking Member
Committee on Education and Labor
U.S. House of Representatives
2101 Rayburn House Office Building
Washington, DC 20515

The Honorable Kevin Brady
Ranking Member
Committee on Ways and Means
U.S. House of Representatives
1139 Longworth House Office Building
Washington, DC 20515

Dear Chairmen Pallone, Scott, and Neal; and Ranking Members McMorris Rogers, Foxx, and Brady:

I write on behalf of the National Council on Disability (NCD), as your federal disability policy advisor, to urge policymakers not to rely on foreign drug prices set in reliance on the quality adjusted life year (QALY), a cost-effectiveness measure that devalues the lives of people with disabilities and chronic illnesses, when pursuing legislative solutions to high drug prices, as has been envisioned in the newly reintroduced H.R. 3, Elijah E. Cummings Lower Drug Costs Now Act. NCD first advised Congress of the same in November 2019 when we released our *Quality-Adjusted Life Years and the Devaluation of Life with a Disability* report. That report highlighted that countries that rely on the

QALY to set drug prices limit access to life-sustaining and lifesaving drugs and treatments for people with disabilities.¹

NCD recently expressed concern to the Congressional Budget Office (CBO) regarding their recent assessment of H.R. 3, which dismissed concerns about the discriminatory design and impact of the QALY.² NCD voiced concern to CBO that such dismissal makes light of the fact that the QALY assigns a lower value to the lives of people with disabilities and chronic illnesses. It also ignores the fact that countries that rely on the QALY have restricted or denied patients with disabilities access to effective drugs used to treat chronic conditions and to breakthrough medications.

In NCD's *Quality-Adjusted Life Years and the Devaluation of Life with a Disability* report, describing the QALY methodology and its ethical and legal implications, NCD documents sufficient evidence of the discriminatory effects of the QALY to warrant concern and recommend its prohibition. Our recommendation is based on issues raised by bioethicists, patient rights groups, and disability rights advocates; compelling arguments from prominent bioethicists condemning the use of the QALY; and the inability of patients with disabilities to access life-sustaining, lifesaving, and life-changing medications in countries where the QALY is used.³

In fact, the restricted access occurring in countries utilizing QALY-based cost effectiveness research raised concerns that its use in the U.S. would result in rationing care to seniors and people with disabilities, leading Congress in 2009 to prohibit its use under the Affordable Care Act of 2010 (ACA).⁴ The ACA prohibits the Patient-Centered

¹ National Council on Disability, "Quality-Adjusted Life Years and the Devaluation of Life with a Disability" (2019), available at https://ncd.gov/sites/default/files/NCD_Quality_Adjusted_Life_Report_508.pdf.

² CBO's Model of Drug Price Negotiations Under the Elijah E. Cummings Lower Drug Costs Now Act: Working Paper 2021-01, at 10 (February 4, 2021), available at <https://www.cbo.gov/publication/56905> (referencing QALY as, "the best available to CBO and is consistent with the approach taken by many countries to negotiate drug prices.")

³ See footnote 1, *supra*; also see, NCD's letter of January 15, 2021, to the Centers for Medicare and Medicaid Services regarding the Most Favored Nation Model Interim Final Rule, available at <https://ncd.gov/publications/2021/ncd-letter-cms-most-favored-nation-rule> (explaining the discriminatory nature and impact of the QALY and the danger of importing this metric through reliance on foreign drug prices).

⁴ See, e.g., statements made during House and Senate debates on health care reform bills in October and November of 2009, expressing concern that U.S. use of cost-effectiveness research, like that utilized in the United Kingdom and Canada, would result in rationing care similar to that experienced by patients in those countries: Senator Kyl (AZ). Congressional Record 155:142 (October 5, 2009) p. S10081; Senator McConnell (KY). Congressional Record 155:19 (October 28, 2009) p. S25860; Senator Kyl (AZ). Congressional Record 155:161 (November 2, 2009) p. S10970; Representative Broun (GA).

Outcomes Research Institute (PCORI) from using the QALY or similar measure “that discounts the value of a life because of an individual’s disability as a threshold to establish what type of health care is cost effective or recommended.”⁵ It also prohibits the Secretary of Health and Human Services from using the QALY, or similar measures, to determine coverage, reimbursement, or incentive programs under the Medicare program.⁶ NCD’s findings in its 2019 report underscores Congress’s findings a decade earlier.

Based on the discriminatory design and impact of the QALY, resulting in restricted access to life-sustaining and lifesaving drugs for persons with disabilities, and in recognition of the concerns that led to the prohibition of its use under the ACA, NCD recommends that Congress consider alternative ways to lower drug costs that do not rely on this discriminatory metric. In our 2019 report, NCD identifies a number of alternatives to the use of the QALY method, including multi-criteria decision analysis, which can be used in a nondiscriminatory manner.⁷

Drug prices need to be lowered. They should not be permitted to be lowered based on the use of a pricing methodology that has unarguably been proven to be discriminatory in its use against persons with disabilities. Acceptance of foreign drug prices set in reliance on the QALY method effectively endorses the use of this discriminatory pricing methodology.

NCD welcomes further opportunity to discuss our concerns and brief you and your staff on our 2019 report. NCD Council Member Mary Vought is set to testify before the House Energy and Commerce Committee regarding our report on the QALY on May 4 at the hearing titled, "Negotiating a Better Deal: Legislation to Lower the Cost of Prescription Drugs." Given the pace of consideration of drug pricing legislation, we

Congressional Record 155:162 (November 3, 2009) p. H12274; Representative Pitts (PA). Congressional Record 155:163 (November 4, 2009) p. H12293; Senator Roberts (KS). Congressional Record 155:173 (November 20, 2009) p. S11888.

⁵ Patient Protection and Affordable Care Act, Pub. L. 111–148, title VI, § 6301(c), Mar. 23, 2010 (codified at 42 U.S.C. 1320e-1(e))(The Patient-Centered Outcomes Research Institute...shall not develop or employ a dollars-per-quality adjusted life year (or similar measure that discounts the value of a life because of an individual’s disability) as a threshold to establish what type of health care is cost effective or recommended. The Secretary shall not utilize such an adjusted life year (or such a similar measure) as a threshold to determine coverage, reimbursement, or incentive programs under subchapter XVIII.

⁶ *Id.*

⁷ Grosse, Teutsch, and Haddix, “Lessons from Cost Effectiveness Research,” 366; Joe Craven McGinty, “Why the Government Puts a Dollar Value on Life,” Wall Street Journal, March 25, 2016, <https://www.wsj.com/articles/why-the-government-puts-a-dollar-value-on-life-1458911310>.

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request to arrange a briefing for your staff by no later than May 10. NCD's Executive Director, Anne Sommers McIntosh (amcintosh@ncd.gov) and NCD's General Counsel and Director of Policy, Joan Durocher (jdurocher@ncd.gov) will contact your staff to offer to arrange such a briefing, and I encourage you to communicate this as a priority for your staff to attend.

Respectfully,



Andrés J. Gallegos
Chairman

cc: The Honorable Nancy Pelosi, Speaker, U.S. House of Representatives
The Honorable Steny Hoyer, Majority Leader, U.S. House of Representatives
The Honorable James Clyburn, Majority Whip, U.S. House of Representatives
The Honorable Kevin McCarthy, Minority Leader, U.S. House of Representatives
The Honorable Steve Scalise, Minority Whip, U.S. House of Representatives
The Honorable Carolyn Maloney, Chairwoman, U.S. House Committee on Oversight and Reform
The Honorable Mark Takano, Chairman, U.S. House Committee on Veterans' Affairs
The Honorable James Comer, Ranking Member, U.S. House Committee on Oversight and Reform
The Honorable Mike Bost, Ranking Member, U.S. House Committee on Veterans' Affairs
The Honorable Kim Knackstedt, Director of Disability Policy, Domestic Policy Council at The White House