



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

September 24, 2019

The Honorable Frank Pallone, Jr.
Chairman, Committee on Energy & Commerce
US House of Representatives
Washington, DC 20515

The Honorable Richard E. Neal
Chairman, Committee on Ways & Means
US House of Representatives
Washington, DC 20515

The Honorable Bobby Scott
Chairman, Committee on Education & Labor
US House of Representatives
Washington, DC 20515

Chairmen Pallone, Neal, and Scott:

Thank you for your leadership in addressing rising prescription drug costs. We appreciate the opportunity to weigh in on HR 3.

The Consortium for Citizens with Disabilities (CCD) is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society.

People with disabilities and chronic conditions are most likely to face the burdens of high prescription drug costs through cost-sharing and significant utilization management burdens. CCD supports several provisions of HR 3, including the out-of-pocket cap and simplification of the Part D benefit. We write to recommend improvements, specifically a ban on the use of Quality Adjusted Life Years (QALYs). We believe these improvements will ensure that prescription drug reform does not discriminate against people with disabilities and serves the people most in need of relief.

CCD Supports the Out of Pocket Cap and Simplification of the Part D Benefit

CCD strongly supports the creation of an out-of-pocket cap in Medicare. The creation of an out-of-pocket cap will help people with disabilities and chronic conditions on Medicare who face significant prescription drug costs. We support the lower \$2,000 cap in HR 3 over the \$3,100 cap recently passed by the Senate Finance Committee.

CCD also supports the simplification of the Part D benefit, especially the final elimination of the coverage gap. Simplification of the benefit, combined with the out-of-pocket cap, will make the Part D benefit easier to understand and more closely resemble other insurance designs.

CCD Supports the Application of Lower Prices to Cost-Sharing

Under current law, Medicare beneficiaries pay coinsurance based on the list price of medications rather than the lower price negotiated between Part D plans and manufacturers. HR 3 has several provisions that require cost-sharing in Medicare and commercial insurance to be based on the Maximum Fair Price (MFP) and/or the price after the inflationary rebate. CCD believes that lower prices paid by plans should translate to lower cost-sharing, including copays and coinsurance, and urges Congress to ensure cost-sharing is based off of these lower prices in both Part B and Part D. Congress should also take steps to eliminate cost-sharing for low-income Medicare beneficiaries.

CCD Supports Not Using Access to Care as Leverage in Negotiations

HR 3 does not rely on a national formulary in Medicare and does not otherwise use access to care as leverage to extract price concessions from manufacturers. CCD supports efforts by policymakers to reduce costs to beneficiaries and the system but opposes weakening consumer protections and coverage to extract further price concessions. We appreciate that HR 3 does not rely on creating a national formulary or otherwise restricting access in order to negotiate prices. However, HR 3 does provide exceptions to the non-interference clause, including the formulary provision. CCD is concerned this may open the door to future imposition of a formulary and will work with Congress to ensure that any current or future legislative efforts do not result in a national Medicare formulary.

CCD Strongly Encourages the Addition of Language Banning the use of QALYs

CCD has expressed concern with the use of value assessments and cost-effectiveness measures that rely on Quality Adjusted Life Years (QALY). The QALY is a discriminatory measure based on the idea that disabled lives are less valuable than non-disabled lives. CCD opposes the use of QALYs and related measures and supports an explicit ban on the use of QALYs in any health care legislation that considers value or effectiveness of health care.

CCD appreciates that HR 3 does not include language on “value” of medications or cost-effectiveness. However, the bill includes discussion of alternative treatments and comparative effectiveness in consideration of negotiated prices. Based on this, CCD still strongly supports including language banning the use of QALYs to ensure that negotiations do not discriminate against people with disabilities. QALY-ban language already exists in Medicare¹ and exists by precedent in Medicaid.² We believe that similar language is entirely appropriate in such a comprehensive package to address the prices of prescription drugs in Medicare and the system overall.

CCD Is Concerned about the Use of International Prices

HR 3 relies on international prices to set an upper limit in negotiations. Many of the nations used to create the average international market price rely on QALYs to determine their coverage and prices. CCD is very concerned that these provisions effectively import a QALY-based and

1 See, 42 U.S.C. § 1320e–1 (b)(1)-(c)(1) (2019), https://www.ssa.gov/OP_Home/ssact/title11/1182.htm

2 Louis W. Sullivan, M.D. Secy. of Health and Human Services. “Oregon Health Plan Is Unfair to Disabled.” *The New York Times*, 1 Sept. 1992, p. A16. Retrieved from: <https://www.nytimes.com/1992/09/01/opinion/l-oregon-health-plan-is-unfair-to-the-disabled-659492.html>

discriminatory system from abroad. These systems are discriminatory against people with disabilities and do not have a place in the United States health care system.

CCD Supports Preservation of the Medicaid Drug Rebate Program

Many people with disabilities rely on Medicaid to access the care they need, including prescription drugs. The Medicaid Drug Rebate Program is very effective in lowering Medicaid drug costs for states and the federal government. We appreciate that HR 3 protects the Medicaid Drug Rebate Program and maintains access to life-saving medication for people with disabilities.

CCD Supports Reinvesting the Savings to Improve Medicare

CCD is pleased that the summary of the future Title IV explicitly recognizes the importance of oral health and seeks to reinvest savings to improve Medicare by expanding Medicare to cover oral health, as well as vision and hearing benefits. We also support using these savings to ensure low-income people with disabilities and older adults can access all of their Medicare benefits, including prescription drugs, by expanding the reach of the Medicare Savings Programs and Part D Low-Income Subsidy.

We appreciate the opportunity to weigh in on this important legislation. Please do not hesitate to reach out with any question to Rachel Patterson, rpatterson@efa.org or 301-918-3791.

Sincerely,

CCD Health Task Force Co-Chairs:

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Epilepsy Foundation

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