

Positions on Access to Prescription Drugs June 2019

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.

Prescription drugs are an essential aspect of daily life for many people with disabilities and chronic conditions. As Congress and the administration consider policy proposals to reduce the cost of prescription drugs, we encourage policymakers to keep the needs of people with disabilities and chronic conditions at the forefront of all discussions. CCD believes that all people should have access to treatment that is affordable, accessible, easy to navigate, and based on a physician-directed and person-centered treatment plan determined by the individual and their health care providers.

Oppose the use of Quality Adjusted Life Years

Quality Adjusted Life Years (QALYs) is a discriminatory measure based on the idea that disabled lives are less valuable and less worth living 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 the value or effectiveness of treatments or health care.

Support Limits on Cost Sharing

Cost sharing is a blunt and largely ineffective tool for improving efficient use of health care dollars, as most health care decisions and costs, particularly those for people with disabilities, are driven by health care providers and plans. Cost sharing does not produce "smart" use of health care, instead it reduces use of needed care and creates substantial and often unexpected cost burdens on people and families. CCD supports efforts to limit cost sharing, and eliminate coinsurance, high deductibles, and other practices which place a more substantial burden on people with disabilities and chronic conditions.

Oppose Discriminatory Benefit Design

Formularies and other benefit designs can explicitly discriminate against people with disabilities, such as through placing higher prior authorization or cost sharing requirements on treatments for certain conditions or placing all drugs to treat a condition on the specialty tier. CCD supports the prohibitions on discriminatory benefit design, with robust monitoring and enforcement at the state and federal levels.

Don't Use Access to Care as Leverage in Negotiations

CCD supports efforts by policymakers to reduce costs in the system but opposes policies which use limitations in access to care as leverage to extract price concessions from providers and manufacturers. Insurance practices like step therapy, prior authorization, cost-sharing designs, and tiered formulary

design are used in negotiation with pharmaceutical manufacturers and other providers and manufacturers to extract discounts. CCD opposes weakening consumer protections to extract further price concessions including Medicaid's broad outpatient prescription drug requirements and Medicare's six protected classes. These efforts end up hurting the very people they are intended to help: people with disabilities and chronic conditions who have high health care costs.

Support and Strengthen Programs that Provide Access for People with Disabilities

The Medicaid Drug Rebate Program (MDRP) achieves substantial rebates for states, significantly reducing their prescription drug costs and allowing them to continue to provide all needed prescription drugs to Medicaid beneficiaries. Other programs, like the Part D Low-Income Subsidy, protect certain low-income Medicare beneficiaries with their out of pocket costs. We oppose any change that could undermine the MDRP or Part D and LIS programs. We do support changes that could strengthen the programs, such as lifting the cap on Medicaid rebates to states, expanding the LIS program, and putting a cap on Part D out of pocket costs.

Support Access to Generics, but not at Expense of Those who Need Brand Name Medications

CCD supports increased options for individuals to lower their out of pocket costs, including access to safe and effective generics. However, many people with disabilities may not be able to take a generic, due to drug interactions, side effects, ineffectiveness, or inability to obtain a list of all ingredients in the generic drug. For this reason, CCD opposes policies that reduce or unduly restrict coverage of brand name drugs to promote generics, such as mid-year formulary changes that remove brands to replace with generics, or excluding cost-sharing on brand name drugs from out-of-pocket maximums if a generic is available.

Endorsed by:

Allies for Independence

American Association of People with Disabilities

American Association on Health and Disability

American Association on Intellectual and Developmental Disabilities

American Medical Rehabilitation Providers Association

American Physical Therapy Association

American Therapeutic Recreation Association

Autism Society of America

Autistic Self Advocacy Network

Brain Injury Association of America

Center for Public Representation

Disability Rights Education & Defense Fund

Easterseals

Epilepsy Foundation

Justice in Aging

Lutheran Services in America-Disability Network

National Alliance on Mental Illness

National Association of Councils on Developmental Disabilities

National Council for Behavioral Health

National Down Syndrome Congress

National Health Law Program

The Arc of the United States

United Spinal Association