



**CONSORTIUM FOR CITIZENS  
WITH DISABILITIES**

*Via email*

March 20, 2020

The Honorable Alex Azar, Secretary  
U.S. Department of Health and Human Services  
200 Independence Avenue SW  
Washington, DC 20020

Dear Secretary Azar:

The undersigned members of the Consortium for Citizens with Disabilities (CCD) strongly condemn the Centers for Medicare & Medicaid Services' (CMS's) new policy inviting states to apply for block grants and per capita caps, as announced in its January 30, 2019 Dear State Medicaid Director Letter.

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.

CMS's new policy will significantly harm adults and children with disabilities. Spending caps, such as block grants and per capita caps, are designed to produce huge federal funding cuts. Over time, caps do not cover states' actual costs of running their Medicaid program, forcing states to cut benefits or eligibility to make up the difference. For example, in 2017, the Administration supported legislative block grant proposals would have cut Medicaid by nearly a trillion dollars over 10 years.<sup>1</sup>

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<sup>1</sup> Congressional Budget Office, Cost Estimate of H.R. 1628, American Health Care Act of 2017 (May 24, 2017), <https://www.cbo.gov/system/files/115th-congress-2017-2018/costestimate/hr1628aspassed.pdf>.

We strongly oppose CMS issuing and implementing this guidance at any time. However, doing so when millions of low-income individuals and people with disabilities are facing high risks and likely serious disruptions to their lives and care would be even more unwise and unjustifiable.

All individuals on Medicaid would be impacted by cuts in funding and coverage of this magnitude. There is simply no way to “carve out” people with disabilities from these proposals, and no amount of administrative machinations will protect people with disabilities from the harm. For example, the 1115 block grant policy applies to “adults who qualify for Medicaid on a basis other than disability or need for long-term care services and supports and who are not covered under the state plan, including ... all individuals . . . described in the ‘adult group.’” This would include millions of people with disabilities who have become eligible through the Affordable Care Act’s Medicaid expansion. While specific numbers are difficult to pin down, available data shows that well over one in five Medicaid expansion adults report a disability or serious chronic condition, including behavioral health conditions.<sup>2</sup> In addition, millions of family caregivers who care for a child or older adult with a disability and hundreds of thousands of low wage direct care workers who serve people with disabilities gained coverage through the Medicaid expansion.<sup>3</sup> CMS’ spending caps would threaten or limit all these individuals’ coverage and services, potentially destabilizing our long-term services and support networks and access to these services.

Equally important, when states hit the budgetary shortfalls caused by caps and are forced to make cuts in services, there is nothing to prevent states from slashing Medicaid services for people with disabilities, especially

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<sup>2</sup> An Ohio survey of Medicaid expansion adults found that 39% reported at least one chronic condition. OHIO DEPT. OF MEDICAID, OHIO MEDICAID GROUP VIII ASSESSMENT: A REPORT TO THE OHIO GENERAL ASSEMBLY, 3 (2016). Over 21% had a claims history consistent with a serious disability. OHIO MEDICAID ASSESSMENT SURVEY, *The Changing Landscape of Healthcare Coverage Across Ohio: What Does It Mean for Our Health?*, 17 (Aug. 19, 2015), [http://grc.osu.edu/sites/default/files/inline-files/OMASSLIDEDECK\\_FINAL%281%29\\_0.pdf](http://grc.osu.edu/sites/default/files/inline-files/OMASSLIDEDECK_FINAL%281%29_0.pdf). In Pennsylvania, 18.8 percent of the expansion population reported a mental health condition, and 11.5 percent a substance use disorder. PENN. DEP’T HUMAN SERVS., *Medicaid Expansion Report*, 62 (Jan. 27, 2017), [www.dhs.pa.gov/cs/groups/webcontent/documents/document/c\\_257436.pdf](http://www.dhs.pa.gov/cs/groups/webcontent/documents/document/c_257436.pdf).

<sup>3</sup> Abby Marquand, PARAPROFESSIONAL HEALTHCARE INSTITUTE, *Too Sick to Care: Direct-Care Workers, Medicaid Expansion, and the Coverage Gap*, 5 (July 2015), <https://phinational.org/research-reports/too-sick-care-direct-care-workers-medicaid-expansion-and-coverage-gap>.

those covered through the Medicaid expansion. Medicaid has been a key driver of innovations in cost-effective community-based care. Older adults and people with disabilities rely on Medicaid for nursing and personal care services, specialized therapies, intensive mental health services, special education services, and other needed services that are unavailable through private insurance. If states lose significant federal funding, all of these services are at risk.

In exchange for agreeing to implement a restrictive block grant, HHS has offered states numerous other waivers of key Medicaid beneficiary protections. For example, CMS will allow states to disregard Medicaid enrollee prohibitions of charging premiums and excessive cost-sharing to people living in poverty. States could also ask to implement a restrictive closed formulary that excludes many medications currently covered by Medicaid, instead providing coverage of only one drug per therapeutic class, or implement work requirements that would cause tens of thousands to lose coverage. States could opt-out of federal protections and regulations regarding Medicaid managed care, including requirements for network adequacy and adequate capitation rates that are designed to ensure access to Medicaid services. States could choose not to provide non-emergency medical transportation, depriving people whose disabilities prevent them from driving from reaching medical appointments. States could seek to opt out of federal protections to provide early and periodic screening, diagnosis, and treatment services for enrollees ages nineteen and twenty, undermining the commitment Congress made to the healthy development of our nation's youth. States could end retroactive and presumptive eligibility, which ensure coverage for Medicaid-eligible individuals who are not yet enrolled. Such erosions of important Medicaid benefits and protections would restrict access to needed care and likely worsen health outcomes for millions of adults with Medicaid. And again, there is no way to effectively shield people with disabilities from these harmful waivers, because there is no way to effectively "carve out" this population.

All of these outcomes are inconsistent with the objectives of Medicaid. The primary objective of Medicaid is to furnish medical assistance to low-income individuals who otherwise can't afford the costs of health care and, in the context of rehabilitation or long term services, to provide services needed to help them attain or retain capability for independence or self-care.

For decades, the disability community and numerous administrations have worked together to ensure that people with disabilities of all ages have access to home- and community-based services that allow them to live, work, go to school, and participate in their communities instead of passing their days in institutions. We ask that CMS recommit itself to these shared goals of coverage and community inclusion by supporting Medicaid, not attacking it. We remain ready and willing to work with you to do so.

Sincerely,

American Association on Health and Disability  
American Association on Intellectual and Developmental Disabilities  
American Diabetes Association  
American Music Therapy Association  
American Network of Community Options & Resources (ANCOR)  
American Speech-Language-Hearing Association  
American Therapeutic Recreation Association  
AOTA  
Association of Assistive Technology Act Program  
Association of People Supporting Employment First (APSE)  
AUCD  
Autism Society of America  
Autistic Self Advocacy Network  
Bazelon Center for Mental Health Law  
Center for Medicare Advocacy  
Center for Public Representation  
Children and Adults with Attention-Deficit/Hyperactivity Disorder  
Christopher & Dana Reeve Foundation  
CommunicationFIRST  
Disability Rights Education & Defense Fund  
Easterseals  
Epilepsy Foundation  
Justice in Aging  
Lutheran Services in America-Disability Network  
National Academy of Elder Law Attorneys  
National Alliance on Mental Illness  
National Association of Councils on Developmental Disabilities  
National Association of State Head Injury Administrators

National Center for Parent Leadership, Advocacy, and Community  
Empowerment  
National Council on Independent Living  
National Disability Rights Network  
National Down Syndrome Congress  
National Health Law Program  
National Multiple Sclerosis Society  
National Respite Coalition  
Paralyzed Veterans of America  
RespectAbility  
Tash  
The Arc of the United States  
United Spinal Association