

Empowered by hope

March 9, 2020

The Honorable Seema Verma Administrator Centers for Medicare & Medicaid Services Department of Health and Human Services P.O. Box 8016 Baltimore, MD 21244-1850

FOR CANCER SURVIVORSHIP

Dear Administrator Verma:

The undersigned organizations represent more than one hundred million Americans living with or at risk of chronic or serious health conditions, including many who rely on Medicaid as their primary source of healthcare coverage. Together and separately, our non-profit, non-partisan organizations are dedicated to working with the Administration, members of Congress and state governments on a bipartisan basis to ensure coverage is affordable, accessible and adequate for the patients we represent.

As many of our organizations shared in a letter to you in July, we strongly oppose the use of block grants and per capita caps in the Medicaid program. The policy that the Administration announced on January 30, 2020² represents a drastic change to the Medicaid program that would harm millions of patients with serious and chronic conditions, including low-income parents, older adults and people with disabilities. Per capita caps and block grants will result in reduced federal

funding for Medicaid and will force states to either make up the difference with their own funds or, more likely, make severe cuts to their programs that would reduce patients' access to care. The Administration's block grant policy also contains numerous policy changes affecting eligibility and enrollment, coverage of treatments and services, and financial and administrative barriers to care for patients and families, including multiple policies that many of our organizations have repeatedly opposed.³ The block grant policy, in any form, will jeopardize coverage for the patients we represent, and our organizations urge you to rescind this policy immediately.

Block Grant Structure

Under the block grant policy, states can change a significant portion of their Medicaid program to a block grant with an aggregate or per person cap. Neither financing structure will protect either the state or patients from enormous financial risk. As the gap between the capped allotment and actual costs of patient care increases over time, states will likely limit enrollment, reduce benefits, lower provider payments or increase cost-sharing, all of which would cause significant harm to the patients we represent.

The block grant amount would increase based on the lesser of the medical care component of the consumer price index (CPI-M) for all urban consumers plus 0.5 percent or the state's average Medicaid spending for the last five years, while the per capita caps would grow at CPI-M without an adjustment. CPI-M falls below the Congressional Budget Office's estimate of Medicaid spending growth through 2029.4 Many situations could lead states to exceed these caps. For example, a recession could increase Medicaid enrollment and the need for additional Medicaid funding at a time when other state resources are particularly strained. There are also many ground-breaking treatments in development for patients with serious and chronic illnesses; and if an expensive but highly effective treatment became available to treat or even cure one of these illnesses, states could be incentivized to impose additional barriers to access that treatment that delay or deny patients' access to care in order to keep spending below the caps. Additionally, a natural disaster such as a hurricane or wildfire would likely increase the need for medical care including costly services like emergency room visits and hospitalizations - again driving up state spending and putting treatments and services for patients at risk. For example, Texas hospitals reported \$460 million in losses after Hurricane Harvey hit the gulf coast in 2017, and a year later, one in six residents reported that they or someone in their household had a health condition that had developed or worsened as a result of the storm.^{5,6}

Similarly, a public health crisis like the opioid epidemic or an infectious disease outbreak like COVID-19 could greatly increase healthcare costs above negotiated caps. Allowing states to renegotiate their caps due to special circumstances like a public health emergency will not protect states and patients from the financial risks of block grants; there is no guarantee that CMS would authorize additional funding via a potentially lengthy re-negotiation process and, in the interim, states would face strong incentives to make cuts to the Medicaid program that would harm patients. Moreover, the federal government will likely be focused on responding to the emergency at hand – putting the renegotiation of complex budget neutrality agreements on the back burner.

Cuts to Medicaid will not only impact those enrolled, but the entire healthcare system. Many critical healthcare entities, such as children's hospitals, rely on Medicaid financing for their financial stability. The Affordable Care Act's Medicaid expansion has led to significant reductions in uncompensated care costs and reduced the likelihood of hospital closures, especially in rural

areas – progress that could be lost under block grant and per capita cap policies.^{7,8} Additionally, states may choose to cut payments to providers to help control spending under the new block grant. Our organizations are concerned that these cuts could affect provider participation in the program and make it harder for patients – who rely on prompt access to primary care providers as well as specialists – to get appointments with providers who can help them find the best treatments and manage their conditions.

There are many examples of states making cuts to Medicaid when their budgets were strained. For example, in 2005, Tennessee changed its eligibility rules to disenroll 170,000 individuals from its Medicaid program due to budgetary pressures. Subsequent research found that after this loss of coverage, individuals' self-reported health status and access to care declined, visits to doctors and dentists decreased and the use of public and free clinics increased.

Puerto Rico serves as a case study for the dangers of implementing a capped structure for a state's Medicaid financing. Medicaid and the Children's Health Insurance Program support health care for more than 1.5 million Puerto Ricans, about half of the territory's population. The block grant has jeopardized patients' access to care, creating longer wait times for healthcare and longer travel times to medical appointments. In Puerto Rico, the average emergency department wait time is 13 hours, far above the US national average of 4.5 hours. Puerto Rico is also experiencing an exodus of medical professionals to the U.S. mainland. In 2015 alone, approximately 500 physicians left the island. Options are few for adding funding to the block grant, as it requires an act of Congress.¹¹

Our organizations are particularly concerned about the changes states might make with the new authorities in the block grant policy given this troubling track record. While the policy contains some general guidance on monitoring and evaluation, no amount of oversight can adequately protect patients from the inherent risk of losing coverage and access to care due to block grant and per capita cap policies.

New Authorities & Harm to Patients

Our organizations also have serious concerns about many authorities that are given to states under the block grant policy. As we outline below, the evidence is clear that these authorities will decrease coverage and, for those who remain enrolled, will decrease access to treatments and services that patients need. Simply put, these authorities will not advance the Medicaid program's objective to provide coverage, but will instead reduce patients' access to care.

Eligibility & Enrollment

The block grant policy invites states to make a number of changes to eligibility and enrollment processes that will delay patients' access to Medicaid coverage. States can waive retroactive coverage or even establish a prospective effective date of coverage, meaning that individuals would have to wait to receive coverage even once they apply and demonstrate that they meet eligibility criteria. As a result, patients who have been diagnosed with a serious illness and are eligible to enroll in Medicaid might have to delay treatment or take on significant medical debt while waiting for their coverage to take effect. States can also waive hospital presumptive eligibility, which allows hospitals to provide temporary Medicaid coverage to individuals likely to qualify for Medicaid. This is an important entry point for individuals who qualify for Medicaid but are not yet enrolled to receive access to coverage promptly and again helps to protect patients from large medical bills. Our organizations are deeply concerned about the harm these changes will cause to patients' physical health and financial wellbeing.

States would also be permitted to use asset tests when determining Medicaid eligibility. Research has shown that removing asset tests improves the enrollment process, reduces administrative costs and increases access to healthcare coverage. Where asset tests currently apply in Medicaid, they limit enrollees' economic mobility and ability to save for the future. Furthermore, the block grant policy might permit states to create their own even more cumbersome asset tests, which could create additional administrative barriers to coverage for patients. Asset tests will not help improve enrollees' health or help low-income individuals obtain Medicaid coverage.

Benefit Package

The block grant policy allows states to make major changes to the benefit package for patients in the Medicaid program. The policy does not include clear information about the treatments and services that will be covered and our organizations are deeply concerned that these changes could reduce patients' access to care. For example, the policy notes that states will generally be expected to provide coverage of essential health benefits (EHBs), which are a critical standard for private insurance coverage but do not include all of the wraparound and other treatments and services that low-income patients in the Medicaid program need. Furthermore, the block grant policy permits states to weaken EHB standards by selecting another state's EHB benchmark for any category, selecting another state's EHB benchmark in its entirety or creating an entirely new EHB benchmark. Many of our organizations opposed similar changes in the Notice of Benefit and Payment Parameters for 2019, as this policy proposal could allow states to design benchmark plans that offer not just less generous coverage, but the least generous coverage available across the country. 13 Essential health benefits truly are critical to the patients we represent, helping them to access preventive services, emergency care and many other treatments and services necessary to maintain their health. Our organizations have serious concerns that low-income patients will lose access to services as a result of this policy change. In addition, our understanding of the policy is that a state could choose an entirely different EHB benchmark for the population subject to the block grant policy than they use for the marketplace population, which could result in significant confusion for beneficiaries who churn between Medicaid and marketplace eligibility.

The block grant policy also jeopardizes access to other vital services for low-income patients served by the Medicaid program, particularly those with serious and chronic diseases. States could waive Early and Periodic Screening, Diagnosis and Treatment (EPSDT) for individuals aged 19 and 20. EPSDT ensures that children and young adults can access services necessary to treat their health care conditions, and disruptions in medical treatment could have negative consequences for their long-term health and economic security. Additionally, states could waive Non-Emergency Transportation (NEMT) benefits. This benefit helps patients maintain key appointments with healthcare providers to manage their conditions and stay healthy. For example, one study found patients with asthma, hypertension or heart disease who needed multiple visits to a medical professional were more likely to keep their appointments if they had NEMT.¹⁴ Our organizations oppose policy changes that could reduce access to these benefits.

Prescription Drug Coverage

The block grant policy would allow states to significantly limit prescription drug coverage for patients by allowing them to create a closed formulary, covering as little as one drug per class. Diseases present differently in different patients and prescription drugs have different indications, different mechanisms of action and different side effects, depending on the person's

diagnosis and comorbidities. A closed formulary would limit the ability of providers to make the best medical decisions for the care of their patients. Our communities have already had experiences, some dire, in which Medicaid programs have delayed or denied patients access to needed therapies because of budget constraints. ^{15,16,17} While CMS says that it will expect states to comply with EHB requirements for prescription drug benefits, it also presents a pathway for states to dramatically limit the scope of their EHB coverage as outlined above. Our organizations are deeply concerned that patients will be unable to access needed medications as a result of this major change in policy.

Managed Care

More than two thirds of Medicaid enrollees currently receive their care through managed care organizations (MCOs) and it is critical that the federal and state governments ensure that these entities are providing adequate care to patients. Yet the block grant policy would greatly reduce federal oversight of MCOs and the care they provide to beneficiaries. For example, states would no longer need to have CMS review and certify that their managed care rates are actuarily sound or review and approve amendments to managed care contracts. Additionally, states would no longer have to comply with federal standards related to adequate networks. Without these federal requirements, an MCO could limit the number of specialists in its network or only contract with specialists in one part of the state, making it harder for patients to see the appropriate providers and receive the care they need. The difficulties patients face in accessing care through MCOs have been well documented in several states, including lowa, Kansas²⁰ and Texas. These problems would likely worsen under the sweeping changes in the block grant policy.

Premiums & Cost-Sharing

Under the block grant policy, states could charge premiums and cost-sharing up to five percent of household income. The link between increased cost-sharing and coverage losses is clear; this policy would likely both increase the number of enrollees who lose Medicaid coverage and discourage eligible people from enrolling in the program. For example, when Oregon implemented a premium in its Medicaid program, with a maximum premium of \$20 per month, almost half of enrollees lost coverage. The policy also eliminates beneficiary protections that exist in current law, such as the policy that providers cannot deny care to those who are unable to pay the copay. For individuals with chronic and acute conditions, maintaining access to comprehensive coverage is vital to accessing physicians, medications and other treatments and services needed to manage their health.

The block grant policy also allows states to charge copays for non-emergency use of the emergency department (ED), a policy change we strongly oppose. This would deter people from seeking necessary care during an emergency. Often one does not know if a health problem is an emergency until they are seen by a care provider, and people should not be financially penalized for seeking care for frightening situations like a breathing problem, symptoms of stroke, complications from a cancer treatment or any other critical health problem that could require immediate care. Furthermore, multiple studies demonstrate that this type of cost sharing may not result in the intended cost savings. ^{23,24} Again, our organizations are deeply concerned that these or other financial barriers would harm patients and compromise their access to care.

Work Requirements

As our organizations have repeatedly shared with CMS, requiring individuals to demonstrate that they work or meet exemptions increases the administrative burden on individuals in the Medicaid program and decreases the number of individuals with Medicaid coverage. For example, when

Arkansas implemented this policy, the state terminated coverage for over 18,000 individuals,²⁵ and in New Hampshire, nearly 17,000 individuals would have lost coverage if the state had not suspended implementation of its requirement.²⁶ The U.S. Court of Appeals for the District of Columbia recently reaffirmed that the purpose of the Medicaid program is to provide healthcare coverage and that Arkansas' restrictive waiver, including the work requirement policy, did not meet that objective.²⁷

Exemptions cannot capture all individuals with, or at risk of, serious and chronic health conditions that prevent them from working, and even for exempt enrollees there will be opportunities for administrative error that could jeopardize individuals' coverage. This loss of coverage could have serious – even life threatening – consequences for people with serious, acute and chronic diseases. Individuals who are in the middle of treatment for a life-threatening disease, rely on regular visits with healthcare providers or must take daily medications to manage their chronic conditions cannot afford a sudden gap in their care.

The evidence is clear that most people on Medicaid who can work already do so, and those who are unable to work often have physical or mental health conditions that interfere with their ability to work. ^{28,29} Evaluations of Arkansas's waiver demonstrate that it did not lead to increased employment among the Medicaid population. ³⁰ In contrast, continuous Medicaid coverage can actually help people find and sustain employment. For example, a report examining Medicaid expansion in Ohio found that the majority of enrollees reported that being enrolled in Medicaid made it easier to work or look for work (83.5 percent and 60 percent, respectively). ³¹ Terminating individuals' Medicaid coverage for non-compliance with work requirements will hurt rather than help people search for and obtain employment.

Loss of Transparency

Finally, our organizations are deeply concerned that states could make certain changes to their block grant programs without public comment and without review and approval by CMS. This would remove important opportunities for the public to provide feedback on how block grant programs impact key stakeholders before any policies are implemented or continued. While the block grant policy says that states will need to get prior approval for changes that have the potential to substantially impact enrollment, this standard is vague and may not incorporate numerous changes to benefits, access to providers and other policies that directly impact patients' access to care.

Conclusion

This policy was released and finalized without a public comment period. Our organizations are gravely disappointed that we were never afforded the opportunity to explain why we oppose such a sweeping new block grant policy, and that we can only write to explain the harm it will cause to millions of patients with serious and chronic health conditions after the fact. Block grants and per capita caps will reduce access to quality and affordable healthcare for patients with serious and chronic health conditions and are therefore unacceptable to our organizations. We urge you to rescind the block grant policy immediately.

Sincerely,

ALS Association
American Cancer Society Cancer Action Network
American Heart Association

American Kidney Fund American Lung Association **Arthritis Foundation** Chronic Disease Coalition **COPD** Foundation **Cystic Fibrosis Foundation Epilepsy Foundation Family Voices** Hemophilia Federation of America Leukemia & Lymphoma Society Lutheran Services in America Mended Hearts & Mended Little Hearts Muscular Dystrophy Association National Alliance on Mental Illness National Coalition for Cancer Survivorship National Health Council National Hemophilia Foundation National Multiple Sclerosis Society National Organization for Rare Disorders National Patient Advocate Foundation Pulmonary Hypertension Association Susan G. Komen United Way Worldwide

WomenHeart: The National Coalition for Women with Heart Disease

CC: The Honorable Alex Azar, Secretary

Department of Health and Human Services

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https://www.lung.org/assets/documents/advocacy-archive/partners-letter-to-cms-re-ky-1115-decision.pdf.

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https://www.medicaid.gov/sites/default/files/Federal-Policy-Guidance/Downloads/smd20001.pdf.

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