



October 10, 2019

The Honorable Alex Azar  
Secretary  
U.S. Department of Health and Human Services  
200 Independence Avenue, SW  
Washington, DC 20201

Re: Montana Section 1115 Waiver

Dear Secretary Azar:

Thank you for the opportunity to comment on the Montana Health and Economic Livelihood Partnership (HELP) Demonstration Program amendment and extension application. On behalf of people with cystic fibrosis (CF), we write to support Montana's request to extend Medicaid expansion and the twelve-month continuous eligibility period, but also to express our concern that work and community engagement requirements, as well as increased premiums, are barriers to accessing the high-quality care that people with CF need. As such, we ask you to direct the state to specifically and automatically exempt people with cystic fibrosis from these requirements.

Cystic fibrosis is a life-threatening genetic disease that affects 120 people in Montana. Almost 40 percent of the 70 adults living with CF in the state rely on Medicaid for all or some of their health care coverage. CF causes the body to produce thick, sticky mucus that clogs the lungs and digestive system, which can lead to life-threatening infections. For those with CF, health care coverage is a necessity and interruptions in coverage can lead to lapses in care, irreversible lung damage, and costly hospitalizations—compromising the health and well-being of those with the disease. Removing an individual from Medicaid coverage if they are unable to comply with work or premium requirements, or during the determination of whether an individual is eligible for an exemption, will leave these patients without coverage they depend upon to maintain their health. Explicitly exempting cystic fibrosis will minimize the number of individuals who are disenrolled from coverage due to these new requirements.

### ***Medicaid Expansion and Continuous Eligibility***

We strongly support the state's request to continue Medicaid expansion, which currently provides coverage to about 90,000 people, or 9 percent, of Montana's population.<sup>1</sup> Medicaid is a crucial source of coverage for patients with serious and chronic health care needs – often serving as a payer of last resort, filling important gaps in coverage left by private health plans. For people with CF, Medicaid helps them afford medications and inpatient and outpatient care, ensuring access to life-saving services and allowing people with CF to maintain their health and well-being. Extending Medicaid expansion will continue to increase access to affordable, high-quality health care and ensure a safety net for those who might otherwise be left without access to coverage.

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<sup>1</sup> <https://dphhs.mt.gov/helplan/medicaidexpansiondashboard> (as of August 2019)

We also appreciate the state's extension of its twelve-month continuous eligibility period, which helps enrollees maintain their coverage throughout the year, regardless of fluctuations in income that may otherwise impact eligibility and interrupt coverage. Continuous eligibility protects Medicaid enrollees, including those with CF and other complex medical needs, from gaps in coverage that can lead to decreased access to care and high out of pocket costs.

### ***Work and Community Engagement Requirements***

Continuous access to high-quality, specialized CF care is essential to the health and well-being of people with cystic fibrosis. Making work a condition of Medicaid eligibility threatens access to care for people with CF, as their ability to work can vary with changes in health status. The Cystic Fibrosis Foundation appreciates Montana's decision to exempt from community engagement and work requirements individuals who are medically frail; this reflects the important reality that health status can significantly affect an individual's ability to search for and sustain employment. Likewise, we are pleased to see the state plans to leverage existing resources to determine both standard and good cause exemptions.

Nonetheless, even considering exemptions listed above, we still have serious concerns about the administrative challenges someone with CF could face in understanding and navigating these requirements and the exemption process. Arkansas' program is a prime example of how administrative burdens can jeopardize coverage. The November 2018 Arkansas Works program report shows an overwhelming majority – nearly 80 percent – of those required to log-in and report compliance with the work requirements failed to do so, putting these individuals at risk for loss of coverage.<sup>2</sup>

Moreover, as this application notes, Arkansas' experience with work requirements shows that this policy causes people to lose Medicaid coverage and does not lead to significant gains in employment. Within six months of Arkansas implementing work requirements, more than 18,000 people lost Medicaid coverage in the state. If work requirements are implemented in Montana, the state estimates that between 4-12 percent of enrollees will lose coverage due to work requirements.

### ***Audit Trigger***

We support the state's proposal to initiate a third-party audit should suspensions due to Medicaid work requirements surpass 5 percent of program enrollees. If auditors find that more than 10 percent of enrollees in the sample were erroneously suspended, the Department will stop coverage suspensions until the end of the next general legislative session. This stopgap measure is a step in the right direction to prevent against massive coverage losses for Medicaid enrollees but in no way fully ameliorates the harmful effects of work requirements.

### ***Increased premiums***

In addition to above concerns, we worry the proposal to increase premium payments for some enrollees may impose unmanageable health care costs on financially vulnerable and medically complex adults if they are unable to obtain an exemption. A survey conducted by George Washington University of 2,500 people living with CF found that while 98 percent of people with CF have some type of health insurance coverage, 58 percent of CF patients postpone necessary medical care or forgo prescribed treatments due to cost concerns. Such actions seriously jeopardize the health of people with CF and lead to costly hospitalizations and fatal lung infections.

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<sup>2</sup>[https://humanservices.arkansas.gov/images/uploads/newsroom/181217\\_AWreport.pdf](https://humanservices.arkansas.gov/images/uploads/newsroom/181217_AWreport.pdf)

The state says that the goal of increasing premiums is to encourage enrollees to be discerning health care purchasers, to take personal responsibility for health care decisions, and to improve their health. However, increasing premiums will prevent Medicaid enrollees from achieving these goals, as this waiver acknowledges that Montanans have already begun to lose their coverage due to premium requirements. Montana's current premium requirements for enrollees with incomes above 100 percent of the federal poverty level (FPL) led to 2.9 percent of enrollees subject to the requirements losing coverage for non-payment in 2018.

Not only are nominal premiums often unaffordable for low-income beneficiaries, but the process of making a premium payment can create barriers to care for a population that may not have bank accounts or credit cards. For instance, an analysis of Indiana's Medicaid program found that nearly 30 percent of enrollees never enrolled in coverage or were disenrolled from coverage because they failed to make premium payments during the study period. The analysis found 22 percent of individuals who never enrolled because they did not make the first month's payment cited affordability concerns, and 22 percent said they were confused about the payment process.<sup>3</sup> Additionally, researchers found that many beneficiaries in Michigan used money orders to pay their premiums, as money orders are a common form of payment for individuals without a bank account or credit card, and beneficiary advocates and enrollment assisters noted that money order fees could sometimes equal or exceed the amount of premiums or copayments owed.<sup>4</sup>

We urge you to reject premium increases and community engagement requirements. However, if you approve this waiver, we ask you to direct the state to use its own data to identify people with CF for an automatic lifetime exemption. This would minimize the risk of inappropriate disenrollment and the administrative burden on enrollees.

The Cystic Fibrosis Foundation appreciates the opportunity to provide input on these important policy changes. As the health care landscape continues to evolve, we look forward to working with Montana and the Centers for Medicare and Medicaid Services to ensure access to high-quality, specialized CF care and improve the lives of all people with cystic fibrosis. Please consider us a resource moving forward.

Sincerely,

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<sup>3</sup> Lewin Group. Healthy Indiana Plan 2.0: POWER Account Contribution Assessment. March 31, 2017.

<sup>4</sup> Kaiser Family Foundation. An Early Look at Medicaid Expansion Waivers and Implementation in Michigan and Indiana. (Online). January 2017. Available: <http://kff.org/medicaid/issue-brief/an-early-look-at-medicaid-expansion-waiver-implementation-in-michigan-and-indiana/>