



February 3, 2021

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

RE: Arizona 1115 Waiver Demonstration Renewal Proposal

Dear Acting Secretary Norris Cochran,

Thank you for the opportunity to comment on the proposed extension of the Arizona Health Care Cost Containment System's (AHCCCS) Section 1115 Demonstration Project. On behalf of people with cystic fibrosis (CF) living in Arizona, we write to express our serious concerns with this waiver application. While we support Arizona's request to discontinue the AHCCCS Choice, Accountability, Responsivity, and Engagement (CARE) program, we oppose the state's proposed work and community engagement requirements and continuation of the elimination of retroactive eligibility for most Medicaid beneficiaries. We fear these policies will jeopardize patient access to quality and affordable healthcare at a time when they can least afford it and therefore urge the Centers for Medicare and Medicaid Services (CMS) to reject the state's request for continued authority to implement these harmful policies.

Cystic fibrosis is a life-threatening genetic disease that affects more than 30,000 people in the United States, including over 550 in Arizona. Roughly a quarter of adults living with CF in the state rely on Medicaid for some or all 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. As a complex, multi-system condition, CF requires targeted, specialized treatment and medications. If left untreated, infections and exacerbations caused by CF can result in irreversible lung damage and the associated symptoms of CF lead to early death, usually by respiratory failure.

The Cystic Fibrosis Foundation offers the following comments on the demonstration extension request:

Work and Community Engagement Requirements

The Cystic Fibrosis Foundation opposes Arizona's proposed community engagement requirements, as they threaten access to high-quality, specialized CF care for people with cystic fibrosis. If Medicaid enrollees are unable to satisfy the work requirements imposed by this waiver, they will lose coverage for the next two months and may only reapply after fulfilling the requirements or meeting exemption criteria. The ability of people with CF to work can vary with changes in health status and such penalties for noncompliance put Arizona Medicaid enrollees with CF at risk of experiencing unacceptable gaps in care and jeopardize their access to the care and treatments they need to stay healthy. Declines in health status due to pulmonary exacerbations, infections, and other events are common and can take someone out of the workforce for significant periods of time. CF patients bear a significant treatment burden on a daily basis, amounting to hours of chest physiotherapy, delivery of nebulized treatments, administration of intravenous antibiotics,

and/or other activities required to maintain or improve their health. Maintaining sustained employment may not be possible due to the time required to undergo necessary treatment, which includes an intense and time-consuming daily regimen.

While the Cystic Fibrosis Foundation appreciates Arizona's decision to exempt from community engagement and work requirements individuals who are medically frail or have an acute medical condition, 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 or request an exemption failed to do so, putting these individuals at risk for loss of coverage.¹ In total, 18,000 people in Arkansas lost Medicaid coverage as a result of the state's work and community engagement requirements.²

Furthermore, while this proposal is concerning until normal conditions, the state's decision to move forward with this request during the current public health emergency further threatens access to care and financial stability for Arizonans when they can least afford it. We urge CMS to reject the state's request for continued authority to impose work and community engagement requirements on AHCCCS members.

Waiver of Retroactive Eligibility

We are concerned with this waiver's request to extend the elimination of retroactive coverage for all non-pregnant adults and believe the state should complete its evaluation of the impacts of eliminating this policy before requesting an extension. Retroactive eligibility helps ensure continuous coverage for people with CF who experience changes in insurance status and become Medicaid eligible. There are many reasons why Arizonans, including people with CF, may not be able to submit a timely Medicaid application when they become eligible. Someone with CF may be consumed by a complicated medical situation—such as an extended hospitalization—that can make it difficult to complete an application. Applications can be burdensome and confusing and people may not realize their coverage has lapsed until they seek care.

Retroactive eligibility helps adults living with CF in Arizona who rely on Medicaid avoid gaps in coverage and costly medical bills, and is an especially important safeguard for those who have lost their job or are experiencing changes in their insurance status as a result of the COVID-19 pandemic. Without it, people with CF may face significant out-of-pocket costs. Cystic fibrosis care and treatments are costly, even with coverage. According to a survey conducted by George Washington University of 1,800 people living with CF and their families, over 70 percent indicated that paying for health care has caused financial problems such as being contacted by a collection agency, having to file for bankruptcy, experiencing difficulty paying for basics like rent and utilities, or having to take a second job to make ends meet. And while 84 percent received some form of financial assistance in 2019 to pay for their care, almost half reported still having problems paying for at least one medication or service in that same year.

Cost-Sharing Requirements

The CF Foundation applauds Arizona's decision to discontinue its AHCCCS Choice, Accountability, Responsivity, and Engagement (CARE) program, which would have required individuals with incomes above 100 percent of the federal poverty level to pay monthly premiums and coinsurance for select services, including non-emergency use of the emergency department.

¹ https://humanservices.arkansas.gov/images/uploads/newsroom/181217_AWreport.pdf

² <https://khn.org/news/study-arkansas-medicaid-work-requirements-hit-those-already-employed/>

Under this program, an individual's failure to pay their monthly premiums would have resulted in disenrollment. This policy would likely increase the number of enrollees who lose Medicaid coverage, as nominal premiums are often unaffordable for low-income beneficiaries and 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 example, when Oregon implemented a premium in its Medicaid program, with a maximum premium of \$20 per month, almost half of enrollees lost coverage.³ An analysis of Indiana's Medicaid program also found that nearly 30 percent of enrollees either never enrolled in coverage or were disenrolled from coverage because they failed to make premium payments. 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.⁴

Research has also shown that even relatively low levels of cost-sharing for low-income populations limit the use of necessary healthcare services.⁵ The CARE program's coinsurance requirement for low-income beneficiaries would also have been a significant financial burden for patients. People with CF bear a significant cost burden and out-of-pocket costs can present a barrier to care. The aforementioned GW survey found that while 98 percent of people with CF have some type of health insurance coverage, 58 percent have postponed or skipped necessary medical care or treatments due to cost concerns. Such actions seriously jeopardize the health of people with CF and can lead to costly hospitalizations and fatal lung infections.

The Cystic Fibrosis Foundation appreciates the opportunity to comment on the proposed extension of the Arizona Health Care Cost Containment System's (AHCCCS) Section 1115 Demonstration Project. We encourage CMS to approve Arizona's proposed changes to its premium program and urge you to reject the state's request for continued authority to implement work and community engagement requirements and to limit retroactive eligibility for AHCCCS members.

Thank you for your consideration.

Sincerely,



Mary B. Dwight
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Senior Vice President of Policy & Advocacy

³ Id.

⁴ Lewin Group. Healthy Indiana Plan 2.0: POWER Account Contribution Assessment. March 31, 2017. Retrieved from <https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/in/Healthy-Indiana-Plan-2/in-healthy-indiana-plan-support-20-POWER-acct-cont-assesmnt-03312017.pdf>

⁵ Samantha Artiga, Petry Ubri, and Julia Zur, "The Effects of Premiums and Cost Sharing on Low-Income Populations: Updated Review of Research Findings," Kaiser Family Foundation, June 2017. Available at: <https://www.kff.org/medicaid/issue-brief/the-effects-of-premiums-and-cost-sharing-on-low-income-populations-updated-review-of-research-findings/>.