CYSTIC FIBROSIS FOUNDATION®

April 15, 2020

Mr. Kevin Corbett
CEO, Oklahoma Health Care Authority
Federal Authorities Unit
4345 N. Lincoln Boulevard
Oklahoma City, OK 73105

Dear Mr. Corbett,

Thank you for the opportunity to comment on Oklahoma's SoonerCare 2.0 Healthy Adult Opportunity (HAO) section 1115 demonstration application. On behalf of people with cystic fibrosis (CF), we write to express our serious concerns about this waiver application — including the state's request to change SoonerCare's funding structure, implement work and community engagement requirements, and trim services from the benefits package, which are barriers to accessing the high-quality care that people with CF need. Pursuing these changes to SoonerCare during the COVID-19 global pandemic threatens to endanger access to Medicaid and exacerbate financial instability for Oklahomans when they can least afford it. The state acknowledges in this waiver that fewer people will be able to enroll in and maintain Medicaid coverage due to provisions of the Healthy Adult Opportunity plan. As such, we ask the state to rescind this application immediately.

Cystic fibrosis is a life-threatening genetic disease that affects approximately 30,000 people in the United States, including over 300 in Oklahoma. Of the 135 adults living with CF in the state, a quarter relies 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. As a complex, multi-system condition, CF requires targeted, specialized treatment and medications. Many patients follow an extensive daily treatment regimen, 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. If left untreated, infections and exacerbations caused by cystic fibrosis can result in irreversible lung damage and the associated symptoms of CF lead to early death, usually by respiratory failure.

Specifically, within the state's section 1115 demonstration application, we are concerned with the following provisions:

Block Grant Funding Model
We have serious concerns that imposing aggregate or per capita cap on Medicaid spending creates a framework for Oklahoma to restrict SoonerCare funding and this waiver application provides insufficient details on how much in capped funding the state would receive. Aggregate and per capita caps are not responsive to changes in program costs and incentivize the state to reduce program spending, which may result in access barriers for the CF population. Oklahoma would remain responsible for unexpected

increases in per-person SoonerCare costs, such as increased costs due to public health crises like COVID-19 or innovations in medical treatment like the approval of breakthrough medications. People with CF have benefited tremendously from new therapies in recent years and we have already seen states implementing clinically inappropriate criteria in an effort to constrain spending on these drugs. Under a capped funding arrangement, states will be under additional pressure to trim program costs and may look to alter eligibility, reduce provider rates, or cut benefits when public health crises or new treatments emerge.

For patients with serious chronic conditions like CF, these changes could mean that Medicaid no longer provides access to their care provider or covers the complex, specialized care they need. This waiver states that Oklahoma already plans to exclude nonemergency transportation and long-term care for SoonerCare 2.0 enrollees and is considering pursuing a limited formulary—and with ongoing budget pressure, the state could further look to cut services in the future. Such limits on care and the full range of CF prescription therapies are unacceptable and could severely compromise the health of a person with cystic fibrosis.

Beyond our above concerns, we also believe the block grant funding structure violates federal statute. Under Section 1115 of the Social Security Act, the Secretary of Health and Human Services has the authority to waive compliance with multiple sections of the Act when they are "likely to assist in promoting the objectives" of the Medicaid program.[1] However, the Medicaid payment model and match rates are outlined in Sections 1903 and 1905, sections notably absent from the list of waivable provisions under Section 1115.[2] As the Centers for Medicare and Medicaid Services (CMS) itself recently acknowledged to North Carolina, we do not believe the state's proposed funding structure is approvable under federal law.[3,4]

Work and Community Engagement Requirements

The Cystic Fibrosis Foundation opposes Oklahoma's proposed community engagement requirements, as they threaten access to high-quality, specialized CF care for people with cystic fibrosis. If SoonerCare enrollees are unable to satisfy the work requirements imposed by this waiver, they may only reapply for coverage only 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 SoonerCare enrollees with CF at risk of experiencing unacceptable gaps in care and jeopardize their access to vital care and treatments they need. At a time of unprecedented unemployment and requirements for social distancing due to the COVID-19 pandemic, work requirements are increasingly difficult to fulfill; now more than ever we need to ensure people have access to coverage for the good of everyone's health and wellbeing.

While the Cystic Fibrosis Foundation appreciates Oklahoma's decision to exempt from community engagement and work requirements individuals who are "physically or medically unfit for employment," we still have serious concerns about the administrative challenges someone with CF could face in

[1] Social Security Act § 1115(a)
[2] Hannah Katch, Judith Solomon, and Aviva Aron-Dine, "Tennessee Block Grant Proposal Threatens Care for Medicaid Beneficiaries," Center on Budget and Policy Priorities, September 25, 2019, https://www.cbpp.org/research/health/tennessee-block-grant-proposalthreatens-care-for-medicaid-beneficiaries
[3] Social Security Act § 1115(a)
[4] Centers for Medicare & Medicaid Services, North Carolina Medicaid Reform Demonstration Approval, October 19, 2018, https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/nc/Medicaid-Reform/nc-medicaid-reform-demo-demo-appvl-20181019.pdf

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.[5] In total, 18,000 people in Arkansas lost Medicaid coverage as a result of the state's work and community engagement requirements.[6]

Premiums and Co-payments

The CF Foundation also opposes the addition of premium payments for some enrollees, as it may put them at risk of losing coverage. Oklahoma's waiver specifies that nonexempt SoonerCare members must submit their premium payment before their coverage can begin and their applications will be denied if they do not make an initial payment within three months. This policy will 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 added premiums in its Medicaid program, with a maximum premium of $20 per month, almost half of enrollees lost coverage.[7] An analysis of Indiana's Medicaid program also 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.[8]

In addition to premiums, some members may be subject to copayments of up to five percent of their household income, which could 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. Although Oklahoma says that members cannot be denied services or disenrolled from coverage for failure to make copayments, the state does not specify what services will be subject to cost-sharing and what the copay amounts would be.

Elimination of Medicaid Retroactive Eligibility

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 residents of Oklahoma 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 a Medicaid application. Medicaid applications can be burdensome and confusing as well, and people may not realize their coverage has lapsed until they seek care.

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[5] https://humanservices.arkansas.gov/images/uploads/newsroom/181217_AWreport.pdf

[6] https://khn.org/news/study-arkansas-medicaid-work-requirements-hit-those-already-employed/

[7] Artiga, Samantha, 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 1, 2017. Accessed at: https://www.kff.org/medicaid/issue-brief/the-effects-of-premiums-and-cost-sharing-on-low-income-populations-updated-review-of-research-findings/

[8] 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

Without retroactive eligibility, people with CF may face significant out-of-pocket costs. Cystic fibrosis care and treatments are costly, even with coverage. For instance, according to the aforementioned George Washington University survey, 45 percent of this patient population spend $5,000 or more annually in out-of-pocket costs for copayments, coinsurance, and noncovered services.

Conclusion and Policy Recommendation

We strongly urge Oklahoma to rescind its waiver application and to instead focus on immediately expanding Medicaid eligibility without barriers to ensure as many Oklahomans as possible have coverage and access to care, especially in the midst of the current public health crisis caused by COVID-19. The Cystic Fibrosis Foundation appreciates your attention to these important issues. Please consider us a resource moving forward.

Sincerely,

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