



February 21, 2020

NAME

Address 1

Address 2

City, State Zip

Dear Representative/Senator NAME,

On behalf of the approximately 740 people with cystic fibrosis (CF) in Missouri, we are writing to express our opposition to Senate Joint Resolution 32—which would create a ballot initiative to add work and community engagements as a condition of Medicaid eligibility. We urge you to oppose this bill and any other proposal that may create similar barriers to care for people with CF.

Uninterrupted access to high-quality, specialized CF care is essential to the health and well-being of people with cystic fibrosis. We are concerned that making work a condition of Medicaid eligibility would create eligibility barriers and administrative burdens for people with CF who rely on Medicaid for coverage.

We therefore urge you to protect access to care for people with CF and oppose SJR 32.

About Cystic Fibrosis

Cystic fibrosis is a life-threatening genetic disease that affects 30,000 children and adults in the United States. 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. Medicaid is a crucial source of coverage for patients with serious and chronic health care needs, often serving as a payer of last resort and filling important gaps in coverage left by private health plans. Medicaid helps people with CF afford the increasingly costly out-of-pocket costs for prescription medications and inpatient and outpatient care, ensuring access to life-saving services and allowing patients to maintain their health and well-being.

Barriers to Access

Work and community engagement requirements for Medicaid, such as those proposed in SJR 32, can create barriers to health care for people with chronic conditions like cystic fibrosis. While many people with CF are able to work full or part-time, others are unable to maintain employment due to their health condition. For instance, variations in health status due to pulmonary exacerbations, infections, and other events are common and can take someone out of the workforce temporarily or for long periods of time.

Patients also bear a significant daily treatment burden, 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. Denying coverage because an individual is unable to satisfy work requirements is excessively punitive for a person with a life-threatening condition like cystic fibrosis.

Administrative Burdens

Based on experiences in other states, the Cystic Fibrosis Foundation also has serious concerns about the administrative burdens someone with CF could face while navigating these requirements and the exemption process. Arkansas, one of only two states with experience implementing a work requirement, disenrolled more than 18,000 people from their Medicaid program within just 6 months of implementation for failing to report number of hours worked.¹ A study in *The New England Journal of Medicine* found that the program was associated with a significant loss of Medicaid coverage and not with a corresponding increase in employment, indicating that individuals did not find jobs that may have provided other healthcare coverage.²

Moreover, while an individual with CF may fall into an exemption category, we are concerned that the bureaucratic hurdles involved in obtaining an exemption will result in additional coverage losses for people with CF who rely on Medicaid. The Arkansas study found that miscommunication and confusion about the work requirement contributed to considerable coverage losses even though more than 95 percent of participants "appeared to meet the requirements or qualify for an exemption."³ People with CF, who rely on regular visits with an accredited CF care team and must follow intensive daily treatment regimens to manage their condition, cannot afford a sudden gap in care caused by administrative hurdles.

We urge you to help protect access to care for people with CF and oppose Senate Joint Resolution 32.

Ultimately, these requirements do not further the goals of the Medicaid program or help low-income individuals improve their circumstances. Implementing a Medicaid work requirement in Missouri would needlessly compromise access to care and force patients to navigate burdensome administrative requirements. The Cystic Fibrosis Foundation appreciates your attention to this important issue. As the health care landscape continues to evolve, we look forward to working with you and other Missouri legislators to improve the lives of all people with cystic fibrosis. Please consider us a resource moving forward.

Sincerely,



Mary B. Dwight
Chief Policy & Advocacy Officer
Senior VP of Policy & Advocacy
Cystic Fibrosis Foundation



Lisa Feng, DrPH
Senior Director of Policy & Advocacy
Cystic Fibrosis Foundation

¹ Arkansas Department of Health and Human Services, Arkansas Works Program, December 2018. Retrieved from http://d31hzlhk6di2h5.cloudfront.net/20190115/88/f6/04/2d/3480592f7fdb6c891d9bacb6/011519_AWReport.pdf

² Benjamin Sommers, et al. Medicaid Work Requirements—Results from the First Year in Arkansas. *New England Journal of Medicine*. 2019. Retrieved from https://cdf.nejm.org/register/reg_multistep.aspx?promo=ONFGMM02&cpc=FMAAALLV0818B

³ Ibid