



October 22, 2021

The Honorable Xavier Becerra
Secretary, U.S. Department of Health and Human Services
200 Independence Ave, SW
Washington, DC 20201

Re: ARHOME Section 1115 Demonstration Application

Dear Secretary Becerra,

Thank you for the opportunity to comment on Arkansas's ARHOME Section 1115 Demonstration. On behalf of people living with cystic fibrosis (CF) living in Arkansas, we write to express our serious concerns with this waiver application. While we support the state's request to extend Medicaid expansion, we oppose the state's proposal to limit retroactive coverage and increase cost-sharing requirements for some low-income enrollees. We fear these policies will jeopardize patient access to quality and affordable health care and therefore urge the Centers for Medicare and Medicaid Services (CMS) to reject the state's request 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 about 300 in Arkansas. Roughly a third 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 ARHOME waiver:

Retroactive Eligibility

We are concerned with this waiver's request to extend the limitation of retroactive coverage to 30 days for the Medicaid expansion population. There are no exemptions, including for medically frail individuals. Medicaid retroactive eligibility prevents gaps in coverage by reimbursing members health care services provided up to 90 days prior to the month of application, assuming the individual is eligible for Medicaid coverage during that time frame. It is common that enrollees are unaware they are eligible for Medicaid until a medical event or diagnosis occurs. Retroactive eligibility allows patients who have been diagnosed with a serious illness, such as cystic fibrosis, to begin treatment without being burdened by medical debt prior to their official eligibility determination.

Retroactive eligibility helps adults living with CF in Arkansas 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

Arkansas is proposing increasing monthly premiums from \$13 to a range of \$22 to \$27, based on income, for enrollees with incomes at or above the federal poverty line, which we fear will cause some members to lose coverage. Even 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.¹ Additional research on Michigan's Medicaid expansion program showed that modest increases of a few dollars in premiums resulted in disenrollment, especially among healthy individuals from the program.² 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 that nearly one in four individuals never enrolled because they did not make the first month's payment cited affordability concerns, and another 22 percent said they were confused about the payment process.³

We are also concerned that the state's proposal to increase copayments for some Medicaid members will impede access to vital care and treatments for people with CF. This waiver includes a request to impose copayments for Medicaid members with incomes at or above 21% of the federal poverty level (\$225 per month for an individual), ranging between \$5 to \$20 depending on the health care service. Research shows that even relatively low levels of cost-sharing for low-income enrollees limits the use of necessary healthcare services.⁴ People with CF bear a significant cost burden and out-of-pocket costs can present a barrier to care. According to the afore mentioned survey of people living with CF and their families, while virtually all people with CF have some type of health insurance coverage, nearly half postponed or skipped necessary medical care or treatments in 2019 due to cost concerns. We fear that increasing copayments may jeopardize the health of people with CF and lead to costly hospitalizations.

¹ Id.

² Cliff, B., et al. Adverse Selection in Medicaid: Evidence from Discontinuous Program Rules. NBER Working Paper No. 28762. National Bureau of Economic Research. May 2021. Accessed at: https://www.nber.org/system/files/working_papers/w28762/w28762.pdf.

³ Lewin Group. Healthy Indiana Plan 2.0: POWER Account Contribution Assessment. March 31, 2017. Retrieved from <https://www.medicaid.gov/Medicaid-CHIP-Program-Information/ByTopics/Waivers/1115/downloads/in/Healthy-Indiana-Plan-2/in-healthy-indiana-plan-support-20-POWER-acctcont-assesmnt-03312017.pdf>

⁴ 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/>.

The Cystic Fibrosis Foundation appreciates the opportunity to comment on the ARHOME Section 1115 Demonstration Application. We encourage CMS to approve Arkansas's proposal to extend Medicaid expansion and urge you to reject the state's request to limit Medicaid retroactive eligibility and increase cost-sharing requirements.

Sincerely,

A handwritten signature in black ink, appearing to read "Mary B. Dwight". The signature is fluid and cursive, with the first name "Mary" being the most prominent.

Mary B. Dwight
Chief Policy & Advocacy Officer
Senior Vice President, Policy & Advocacy
Cystic Fibrosis Foundation