



July 8, 2021

Elizabeth Pitman
Director
Division of Medical Services
Donaghey Plaza
P.O. Box 1437
Little Rock, AR 72203

Re: ARHOME Section 1115 Demonstration Application

Dear Ms. Pitman,

Thank you for the opportunity to comment on Arkansas's Section 1115 Demonstration Application. On behalf of people with cystic fibrosis (CF) living in Arkansas, we write to express our serious concerns with this waiver application. We oppose the state's proposal to limit retroactive eligibility and increase premiums. We fear these policies will jeopardize patient access to quality and affordable healthcare and therefore urge that Arkansas revise its waiver application to remove these harmful provisions.

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.

Unfortunately, this proposal includes several provisions that do not meet the objective to provide accessible and affordable healthcare for people with CF. Therefore, the Cystic Fibrosis Foundation offers the following comments on the ARHOME waiver.

Retroactive Eligibility

This proposal would continue to limit retroactive coverage to 30 days for the Medicaid expansion population. There are no exemptions, including for medically frail individuals. Retroactive eligibility in Medicaid prevents gaps in coverage by typically covering individuals for 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 individuals 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 proposes to increase premiums for individuals with incomes at or above 100% of the federal poverty line. Premiums will likely discourage eligible people from enrolling in the program. 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 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

Research has also shown that even relatively low levels of cost-sharing for low-income populations limit the use of necessary healthcare services.⁹ The program's cost sharing 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. According to the afore mentioned survey of people living with CF and their families, 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 strongly recommends that Arkansas revise its waiver application as outlined to ensure that it meets the objectives of the Medicaid program. Thank you for the opportunity to provide comments.

Sincerely,



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

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.