



February 3, 2021

Ms. Melody Anthony  
Medicaid Director  
Oklahoma Health Care Authority  
Federal Authorities Unit  
4345 N. Lincoln Blvd.  
Oklahoma City, OK 73105

Sent electronically to: [federal.authorities@okhca.org](mailto:federal.authorities@okhca.org)  
RE: Oklahoma 1115 Demonstration Waiver Amendment Request

Dear Director Anthony,

Thank you for the opportunity to comment on the 1115 demonstration waiver amendment regarding the Enrollment of Certain Medicaid Members under the Demonstration and Implementation of SoonerSelect Managed Care Model. On behalf of people with cystic fibrosis (CF) living in Oklahoma, we write to express our serious concerns with this waiver's request to eliminate retroactive coverage for all non-pregnant adults and ask that the state remove this proposal from its amendment application before submitting the request to the Centers for Medicare and Medicaid Services (CMS).

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 rely 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.

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 Oklahomans, 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.

Without retroactive eligibility, 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, 44 percent reported still having problems paying for at least one medication or service in that same year.

We strongly urge Oklahoma to remove the proposal to eliminate retroactive coverage from this waiver extension request. Retroactive eligibility helps adults living with CF in Oklahoma who rely on Medicaid avoid gaps in coverage and costly medical bills. The Cystic Fibrosis Foundation appreciates your attention to this important issue. Please consider us a resource moving forward.

Sincerely,

A handwritten signature in black ink, appearing to read "Mary B. Dwight". The signature is fluid and cursive, with a large initial "M" and "D".

Mary B. Dwight  
Chief Policy & Advocacy Officer  
Senior Vice President of Policy & Advocacy