



June 30, 2020

Secretary Mary C. Mayhew  
Agency for Health Care Administration  
Bureau of Medicaid Policy  
2727 Mahan Drive, MS #8  
Tallahassee, FL 32308

Sent electronically to: [FLMedicaidWaivers@ahca.myflorida.com](mailto:FLMedicaidWaivers@ahca.myflorida.com)

RE: 1115 MMA Waiver Extension Request

Dear Secretary Mayhew,

Thank you for the opportunity to comment on Florida's Managed Medical Assistance (MMA) Program section 1115 demonstration waiver extension application. On behalf of people with cystic fibrosis (CF), we write to express our serious concerns with this waiver's request to extend the elimination of retroactive coverage for all non-pregnant adults through June 2024. Before requesting a two-year extension to this policy, the state should evaluate and provide data on the impact of eliminating retroactive coverage on beneficiaries. We ask Florida to remove this policy from the waiver extension application.

Cystic fibrosis is a life-threatening genetic disease that affects approximately 30,000 people in the United States, including over 1,600 in Florida. Over half 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. 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 Floridians, 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. 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 2,500 people living with CF, 45 percent of this patient population spent \$5,000 or more annually in out-of-pocket costs for copayments, coinsurance, and noncovered services.

We strongly urge Florida to rescind its requested extension of waived retroactive coverage for non-pregnant adults. Retroactive eligibility helps the 280 adults living with CF in Florida who rely on Medicaid avoid gaps in coverage and costly medical bills. The Cystic Fibrosis Foundation appreciates your attention to these important issues. 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 and Advocacy