



September 11, 2020

The Honorable Alex Azar
Secretary, U.S. Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

RE: FL 1115 MMA Waiver Extension Request

Dear Secretary Azar,

The Cystic Fibrosis Foundation appreciates the opportunity to submit comments on Florida's Managed Medical Assistance (MMA) Program section 1115 demonstration waiver extension application. We urge the Centers for Medicare and Medicaid Services (CMS) to reject Florida's proposal to extend the elimination of retroactive coverage for all non-pregnant adults through June 2024. Especially during this time when many are experiencing financial instability and health insurance changes due to job loss, retroactive eligibility is an important policy to ensure that people with CF are protected from gaps in coverage and high out-of-pocket health care costs.

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. 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. Additionally, individuals with CF may be at increased risk of developing serious illness if they become infected with COVID-19, according to the Centers for Disease Control and Prevention (CDC).¹

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. Retroactive eligibility 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.

¹ https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Fcoronavirus%2F2019-ncov%2Fneed-extra-precautions%2Fgroups-at-higher-risk.html

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. Retroactive eligibility helps adults living with CF in Florida who rely on Medicaid avoid gaps in coverage and costly medical bills.

We have serious concerns with this waiver's request to extend the elimination of retroactive coverage and believe the state should evaluate and provide data on the impact of eliminating such policy before requesting a two-year extension. Furthermore, we are disappointed with the state's decision to pursue this extension at a time when so many Floridians are experiencing financial hardship, job loss, and changes in insurance as a result of the current pandemic. Therefore, we urge CMS to deny the state's requested extension of waived retroactive coverage for non-pregnant adults.

Thank you for the opportunity to submit comments.

Sincerely,

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