



August 7, 2019

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

Dear Secretary Azar,

On behalf of people with cystic fibrosis, the Cystic Fibrosis Foundation appreciates the opportunity to support New Mexico's Section 1115 Demonstration Waiver amendment, which removes barriers to care for members of the state's Medicaid managed care program, Centennial Care 2.0, by eliminating co-payment requirements and monthly premiums, and restoring the three-month retroactive coverage period.

Cystic fibrosis (CF) is a life-threatening genetic disease that affects 150 people in New Mexico and 30,000 children and adults in the United States. 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.

Specifically, within the state's 1115 Demonstration Waiver, we support the following provisions:

**Removal of co-payment requirements for Centennial Care members and premium requirements for members in the Adult Expansion Group**

Even nominal co-payment and premium requirements have the potential to create barriers to care for people living with CF. The current waiver demonstration requires the state to implement \$10 monthly premiums for Centennial Care 2.0 members in the Adult Expansion Group whose incomes are above 100 percent of the Federal Poverty Level (FPL). It also authorizes the state to impose \$8 co-payments on non-emergency uses of the emergency department and non-preferred prescription drugs by all managed care enrollees. Premiums and co-payments may impose unmanageable health care costs on financially vulnerable and medically complex adults. A survey conducted by George Washington University of 2,500 people living with CF shows that while 99 percent of people with CF have insurance, one-quarter delay or skip care due to cost concerns. Such actions seriously jeopardize the health of people with CF and can lead to costly hospitalizations and fatal lung infections.

Lockout periods for failure to comply with premium requirements put people with CF at grave risk for gaps in coverage. The current demonstration waiver includes a three-month suspension period for Centennial Care 2.0 members who fail to pay premiums after a three-month grace period. For people with cystic fibrosis, consistent care and access to specialized therapies is a necessity and any loss or gap in coverage may put people with CF at risk of declining health by forcing them to forgo daily therapies—potentially leading to irreversible lung damage.

For these reasons, we support New Mexico’s request to remove co-payment requirements and monthly premiums for Centennial Care 2.0 members in the Adult Expansion Group category, including removal of the grace period and lock-out provisions for non-payment of premiums.

**Restoration of the three-month retroactive coverage period for non-pregnant adults covered under Centennial Care 2.0**

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 residents of New Mexico, 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. For instance, according to the aforementioned survey, 45 percent of this patient population spend \$5,000 or more annually in out-of-pocket costs for copayments, coinsurance, and noncovered services.

Eliminating retroactive eligibility also puts safety net hospitals and providers at risk for increased uncompensated care costs, driving up costs for all health care consumers. In Indiana, which eliminated its 90-day retroactive eligibility period for Medicaid expansion adults, data shows that individuals who incurred costs before enrolling in Medicaid averaged \$1561 in uncompensated care. With retroactive eligibility, Medicaid would have been able to reimburse providers for these medical bills.<sup>12</sup>We support New Mexico’s request to remove the requirement to phase-out and eliminate the three-month Medicaid retroactive eligibility period for non-pregnant adults. Restoring retroactive eligibility will help safeguard people with CF and other serious medical conditions against gaps in coverage and costly medical bills.

The Cystic Fibrosis Foundation appreciates the opportunity to provide input on these important policy changes. As the health care landscape continues to evolve, we look forward to working with the state of New Mexico to ensure access to high-quality, specialized CF care and improve the lives of all people with cystic fibrosis.

Sincerely,



Mary B. Dwight  
Senior Vice President of Policy & Advocacy



Lisa Feng, DrPH  
Senior Director of Policy & Advocacy

<sup>1</sup> [https://www.cbpp.org/research/health/uncompensated-care-costs-fell-in-nearly-every-state-as-acas-major-coverage#\\_ftn16](https://www.cbpp.org/research/health/uncompensated-care-costs-fell-in-nearly-every-state-as-acas-major-coverage#_ftn16)

<sup>2</sup> <https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/in/Healthy-Indiana-Plan-2/in-healthy-indiana-plan-support-20-lockouts-redetermination-07292016.pdf>