



October 26, 2018

Wendy Long, MD
Director
Division of TennCare
310 Great Circle Road
Nashville, TN 37243

Re: 1115 Waiver Amendment 38 to the TennCare II Demonstration

Dear Dr. Long:

The Cystic Fibrosis Foundation appreciates the opportunity to submit comments on Tennessee's 1115 Waiver Amendment, "Amendment 38 to the TennCare II Demonstration." On behalf of people with cystic fibrosis (CF), we write to express our concern that work and community engagement requirements are barriers to accessing the high-quality care that people with CF need. As such, we ask the state to specifically and automatically exempt people with cystic fibrosis from these requirements.

Cystic fibrosis (CF) is a life-threatening genetic disease that affects 340 adults in Tennessee, approximately 30 percent of whom 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. For those with CF, health care coverage is a necessity and interruptions in coverage can lead to lapses in care, irreversible lung damage, and costly hospitalizations—compromising the health and well-being of those with the disease. Removing an individual from Medicaid coverage if they are unable to comply with work and community engagement requirements will leave these patients without coverage they depend upon to maintain their health. Explicitly exempting Cystic Fibrosis will minimize the number of individuals who are disenrolled from coverage due to these new requirements.

Specifically, within the state's 1115 Waiver Amendment, we are concerned with the following provisions:

Work and Community Engagement Requirements

The Tennessee Amendment 38 seeks to add a work and community engagement requirement for most TennCare enrollees. This would increase the administrative burden on all TennCare patients. Individuals will need to either report that they meet certain exemptions or the number of hours they have worked. Increasing administrative requirements will likely decrease the number of individuals with TennCare coverage.

Arkansas is currently implementing a similar policy requiring Medicaid enrollees to report their hours worked or their exemption. As of October 2018, four months into implementation, the state has terminated coverage for 8,462 individuals and locked them out of coverage until January 2019.ⁱ An additional 12,589 individuals had one or two months of noncompliance and are at risk for losing coverage in the coming months.ⁱⁱ In another case, after Washington state changed its renewal process from every twelve months to every six months and instituted new documentation requirements in 2003, approximately 35,000 fewer children were enrolled in the program by the end of 2004.ⁱⁱⁱ Battling administrative red tape in order to keep coverage should not take away from patients' or caregivers' focus on maintaining their or their family's health.

Failing to navigate these burdensome administrative requirements could have serious – even life or death – consequences for people with cystic fibrosis. If the state finds that individuals have failed to comply with the new requirements for two months out of a six-month period, they will be locked out of coverage until they demonstrate their compliance. People with cystic fibrosis rely on daily treatments, regular visits with healthcare providers, and multiple medications to manage their conditions; they cannot afford a sudden gap in care.

Exemption Determination Process

We appreciate the state’s decision to exempt from community engagement requirements those determined to be medically frail, which reflects the important reality that health status can significantly affect an individual’s ability to search for and sustain employment. While an individual with CF may fall into this exemption category, we are unsatisfied with the specificity of this language and potential bureaucratic hurdles involved in obtaining an exemption for someone with CF.

We ask the state to specifically and automatically exempt people with CF from the work and community engagement requirements; to minimize the risk of inappropriate disenrollment and administrative burden on recipients, we also ask that you use your own data to identify people with CF for exemption.

As experts in cystic fibrosis care and research, please consider us a resource during the rulemaking and implementation process to minimize unintended errors and ensure our population is exempt. In particular, we can provide clinical expertise on service utilization, co-morbidities, and other factors that may help the state ensure people with CF are accurately captured by the state’s algorithm.

Estimate of Expected Change in Annual Enrollment

The Cystic Fibrosis Foundation also wishes to highlight that the federal rules at 431.408 pertaining to state public comment process require at (a)(1)(i)(C) that a state include an estimate of the expected increase or decrease in annual enrollment and expenditures if applicable. The intent of this section of the regulations is to allow the public to comment on a Section 1115 proposal with adequate information to assess its impact. However, on pages 5 of this proposal, the Department states that *“Some number of individuals may transition off of TennCare and into other coverage options as their earnings increase; however, it is not possible to reliably project the magnitude of this decrease in enrollment at this time.”* We urge the TennCare to update the waiver amendment with the estimated expenditure and estimate enrollment change and reopen the state comment period for an additional 30-days.

We believe healthcare should be affordable, accessible, and adequate. As proposed, Tennessee’s Amendment 38 does not meet that standard for people with CF.

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 Tennessee to ensure access to high-quality, specialized CF care and improve the lives of all people with cystic fibrosis. Please consider us a resource moving forward.

Sincerely,

Mary B. Dwight
Senior VP of Policy & Patient Assistance Programs
Cystic Fibrosis Foundation

Lisa Feng, DrPH
Senior Director of Access Policy & Innovation
Cystic Fibrosis Foundation

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- ⁱ Arkansas Department of Health and Human Services, Arkansas Works Program, August 2018. Accessed at: https://ccf.georgetown.edu/wp-content/uploads/2018/09/091218_AWReport_Final.pdf.; Arkansas Department of Health and Human Services, Arkansas Works Program, September 2018. Accessed at: [https://m.arktimes.com/media/pdf/9.18 -_aw work requirements report.pdf](https://m.arktimes.com/media/pdf/9.18_-_aw_work_requirements_report.pdf).
- ⁱⁱ Arkansas Department of Health and Human Services, Arkansas Works Program, August 2018. Accessed at: https://ccf.georgetown.edu/wp-content/uploads/2018/09/091218_AWReport_Final.pdf.; Arkansas Department of Health and Human Services, Arkansas Works Program, September 2018. Accessed at: [https://m.arktimes.com/media/pdf/9.18 -_aw work requirements report.pdf](https://m.arktimes.com/media/pdf/9.18_-_aw_work_requirements_report.pdf).
- ⁱⁱⁱ Tricia Brooks, "Data Reporting to Assess Enrollment and Retention in Medicaid and SCHIP," Georgetown University Health Policy Institute Center for Children and Families, January 2009.