



October 11, 2019

Jim Jones  
Wisconsin Medicaid Director  
1 West Wilson Street  
Madison, WI 53703

Re: Section 1115 Demonstration Waiver – Wisconsin Medicaid

Dear Mr. Jones:

On behalf of people with cystic fibrosis (CF), the Cystic Fibrosis Foundation writes to express our concern about Wisconsin's recently approved community engagement and premium requirements and ask the state to specifically and automatically exempt people with cystic fibrosis.

Cystic fibrosis (CF) is a life-threatening genetic disease that affects 386 adults in Wisconsin, more than 20 percent of whom rely on Medicaid for all or some of their health care coverage. Cystic fibrosis is both serious and progressive, causing the body to produce thick, sticky mucus that clogs the lungs and digestive system, and often leading to life-threatening infections. As a complex, multi-system condition, CF requires intensive daily treatments, as well as regular visits to an accredited care center for multidisciplinary, specialized care. 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 individuals' health and well-being.

Making work a condition of Medicaid eligibility threatens access to care for people with CF, as their ability to work can vary with changes in health status or the amount of time they need to spend on their treatments. For instance, variations in health status due to pulmonary exacerbations, infections, and other events are common and can take someone out of the workforce temporarily or for long periods of time. Furthermore, many patients bear a significant treatment burden, 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, which can interfere with their ability to work. For these reasons, many people with CF experience periods when they are unable to work or attend school.

The Cystic Fibrosis Foundation appreciates Wisconsin's decision to exempt from community engagement and work requirements individuals who are medically frail and those physically or mentally unfit for employment; this reflects the important reality that health status can significantly affect an individual's ability to search for and sustain employment. Likewise, we are pleased to see the state plans to offer Medicaid enrollees opportunities to pursue good cause exemptions. However, we know from recent experience in Arkansas that people have serious administrative challenges understanding and navigating these requirements and the exemption process.

In addition, we worry the proposal to require premium payments and co-payments for non-emergency uses of the emergency department for some enrollees may impose unmanageable health care costs on

financially vulnerable and medically complex adults if they are unable to obtain an exemption. Our research shows that while 99 percent of people with CF have insurance, almost 60 percent delay or skip care due to cost concerns. Such actions seriously jeopardize the health of people with CF and lead to costly hospitalizations and fatal lung infections. As such, we strongly urge you to specifically and automatically exempt people with cystic fibrosis from both community engagement and new premium payment and co-pay requirements.

The Cystic Fibrosis Foundation is grateful for the opportunity to provide input on these important policy changes. As the health care landscape continues to evolve, we look forward to working with Wisconsin 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 Dwight  
Senior Vice President, Policy & Advocacy  
Cystic Fibrosis Foundation



Lisa Feng, DrPH  
Senior Director, Policy & Advocacy  
Cystic Fibrosis Foundation