March 16, 2018

Re: Group VIII Work Requirements and Community Engagement 1115 Waiver

Dear Director Sears,

Thank you for the opportunity to comment on Ohio’s Group VIII Work Requirements and Community Engagement 1115 waiver. On behalf of people with cystic fibrosis (CF), we write to express our concern that work requirements and community engagement create an additional barrier to accessing the high-quality care that people with chronic conditions like CF need. We appreciate that the state is committed to ensuring a simplified exemptions process and that certain populations, such as people with CF, are exempt. However, we remain concerned with the lack of clarity in the definition of “physically or mentally unfit to work,” as it puts people with CF at risk of losing coverage.

Cystic fibrosis is a life-threatening genetic disease that affects 1,534 people in Ohio 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. Medicaid plays an important role in helping this patient population access the high-quality care and treatment necessary to maintain or improve health. Work and community engagement requirements introduce additional barriers to access, which may cause interruptions and delays in treatment and care. Continuous access to high-quality, specialized CF care is essential to the health and well-being of people with cystic fibrosis.

While many individuals with CF work full or part-time, the ability to work can vary with changes in health status. Declines in health status due to pulmonary exacerbations, infections, and other events are common and can take someone out of the workforce for significant periods of time. 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. As a result, sustained employment may not be possible due to the time required to undergo necessary treatment.

As you know from our recent conversation, although the waiver application exempts many individuals, including those who are “physically or mentally unfit to work” we are concerned that a lack of clarity around this exemption may cause individuals to lose coverage. We were pleased to hear that the state plans to make public a list of chronic conditions that will be exempt from work requirements and that the current Ohio Benefits system will be used to simplify the exemption process. The state’s efforts to clarify who will be eligible for an exemption reflects the important reality that health status can significantly affect an individual’s ability to search for and sustain employment.
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 Ohio 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,

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